Newly diagnosed with essential thrombocythaemia (ET)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. We are here for you and your loved ones every step of the way. Here are some of the ways we can help.

Helpline

Contact us for advice, support or someone to talk to.

- Call our freephone helpline on **08088 010 444** (weekdays 9am to 4.30pm)
- Send a WhatsApp message to **07500 068065** (weekdays 9am to 5pm)
- Email support@leukaemiacare.org.uk

Support groups

Connect, share experiences and find comfort from other people who've been affected by ET.

Buddy support

Chat to someone who's had a similar experience to you and understands what you're going through.

Facebook groups

Connect online with other people with leukaemia or their carers in our closed Facebook groups.

Leukaemia counselling service

Access up to six sessions of counselling to help you cope with the emotional impact of ET.

Advocacy and welfare team

Get advice on financial support, housing, employment issues and more.

Cost of living service

Apply for a one-off grant to help with essential living costs.

Will service

Write a free, simple Will so you know what happens to your money, property and belongings when you die.

Information

Find trustworthy, easy-to-understand information online and in print.

Leukaemia Care magazine

Subscribe to our free magazine for inspirational stories, articles and updates.

To access our services or find out more:

- Scan the QR code
- Call **08088 010 444**
- Search 'support' at www.leukaemiacare.org.uk

In this booklet

There is a lot of information about cancer on the internet. Some of it may not be reliable or up to date. A lot of it may not apply to you. Your haematology team are your best source of information because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Check for a quality mark, such as the Patient Information Forum (PIF) tick.

Abbvie provided arm's length partial funding for this project. Abbvie has had no influence in the project, or the development of any associated materials.

Introduction

There is a lot of information in this booklet. Each chapter has a summary at the beginning if you'd prefer a short overview.

Essential thrombocythaemia (ET) is a slow-growing type of blood cancer that makes your body produce too many platelets. This booklet covers what ET is, including how it is diagnosed and what treatments you might be offered. We also include practical information about living with ET.

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice or guidance from your health professional.

We'd like to thank the expert reviewers and patient contributors who helped us with this information:

- Claire Woodley, Advanced Nurse Practitioner in Haematology, Guy's Hospital, London
- Kirsty Crozier, Haematology Advanced Clinical Practitioner, Great Western Hospital NHS Foundation Trust, Swindon
- Professor Mary Frances McMullin, Emeritus Professor of Haematology, Queen's University, Belfast
- Patient reviewers: Lisa, Robert and Sue
- Quote contributors: Andrea, Claire, Josie, Linda, Lisa, Lucy, and Margaret

This booklet includes addresses and QR codes that link to webpages for further support. If you cannot access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

About essential thrombocythaemia (ET)

Summary

- Essential thrombocythaemia (ET) is a rare blood cancer. It is usually slow growing.
- It happens when cells in your bone marrow grow out of control and make too many platelets.
- Platelets help your blood to clot. Having too many platelets can cause problems.
- ET mainly affects people aged 60 or over, although you can get it at any age.
- We do not know the exact cause of ET. It is not due to something you did or did not do.
- ET belongs to a group of blood cancers called myeloproliferative neoplasms (MPNs).

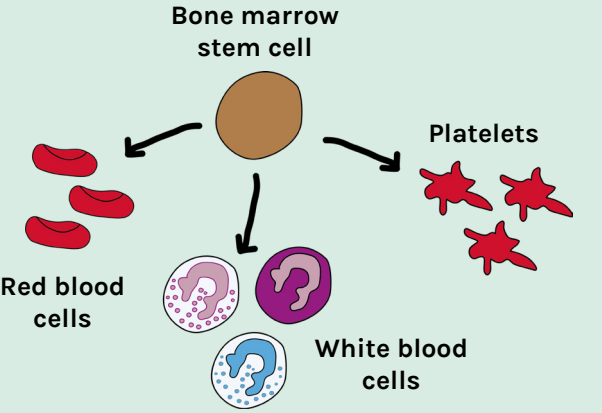
What is essential thrombocythaemia?

Essential thrombocythaemia (ET) is a type of blood cancer. It causes high numbers of platelets – the blood cells that help your blood to clot. You need platelets to stop bleeding if you have an injury, but having too many of them can cause problems.

ET belongs to a group of conditions called **myeloproliferative neoplasms** (MPNs). These are chronic blood cancers, which means they usually progress slowly.

Bone marrow and types of blood cells

Bone marrow is the soft, spongy substance found in the middle of some large bones in your body. Your bone marrow makes most of your blood cells. They develop from immature cells called stem cells. Stem cells can turn into any of the following types of blood cells:



- Red blood cells – these carry oxygen around your body
- White blood cells – these help you fight infection
- Platelets – these help to stop bleeding by causing blood clots to form

What is a myeloproliferative neoplasm (MPN)?

MPNs are blood cancers that develop when cells in your bone marrow make too many blood cells. There are different types of MPN depending on the type of blood cell your body is overproducing:

- In ET, your bone marrow makes too many platelets.
- In myelofibrosis (MF), your body makes too many immature blood cells. They cause your bone marrow to become inflamed and scarred. This stops your bone marrow from making enough healthy blood cells.
- In polycythaemia vera (PV), your bone marrow makes too many red blood cells. Sometimes, other blood cells, such as white blood cells and platelets, are also affected.

We have separate information about myelofibrosis and polycythaemia vera. Follow the links, scan the QR code or search for 'myelofibrosis (MF)' or 'polycythaemia vera' at leukaemiacare.org.uk

Who gets ET?

ET is rare. About 2,720 people are diagnosed with it each year in the UK. This is why you might not have heard of ET or met anyone with it before.

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

What causes ET?

We do not know exactly what causes ET. It does not happen because of something you did or did not do. But some things might increase your chance of getting it. These include:

- Genetic changes. These usually happen by chance as you get older (see page 10).
- Family history. ET is **not** passed on from parent to child. But if you have a close relative (parent, brother, sister or child) with ET, you may have a slightly higher chance of developing it too. The risk is still low. Most people who have a close family member with ET do **not** develop ET.

"The C word feels like a bombshell. Try to remember that there are many, many people living with cancer, and living well with it. It's not necessarily an immediate disaster."

Lucy, living with an MPN since 2017

Genetic changes

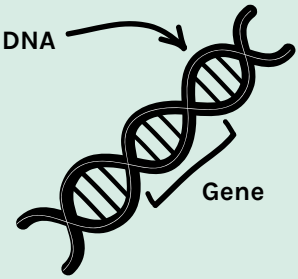
ET happens when genetic changes in some bone marrow cells stop the cells from working as they should. These changes usually happen by chance during your lifetime.

You do not usually get these genetic changes from your parents, and you cannot usually pass them on to any children you may have. Although there are cases of ET where siblings or other close relatives also have ET, this is rare.

There are several different genetic changes linked to ET. The most common ones affect genes called *JAK2*, *CALR* or *MPL*. They affect how your bone marrow makes proteins needed for blood cell development. Most people have only one of these genetic changes linked to their ET.

Your doctor will look for genetic changes in your blood or bone marrow cells. If they know which genetic change you have, it can help them look after you (see page 24).

Understanding genes and proteins



- DNA is like a thread of code in each cell of your body. Your DNA contains lots of different genes.
- Genes contain instructions for your cells on how to make proteins needed by your body. Proteins are important in the normal growth, development, and function of your cells.
- Sometimes changes called variants occur within a gene. These variants can cause your body to make different proteins.

Symptoms and complications of ET

Summary

- You might not have any symptoms of ET when you are diagnosed. You might start to get symptoms over time.
- Symptoms vary from person to person. They can depend on the genetics of your ET, how it affects your platelets and whether you have complications.
- Common symptoms of ET include:
  - Extreme tiredness
  - Numbness or pins and needles
  - Headaches or migraines
  - Problems with your vision
  - Bruising
  - Bleeding
- You may have other symptoms if you develop blood clots, which is the main complication of ET. Your symptoms will depend on where the blood clot occurs.
- In some cases, ET can transform into a different type of blood cancer. Your team will monitor you for this.
- If your ET transforms into another condition, your symptoms may change.

Symptoms of ET

Many people don't have any symptoms of ET when they're first diagnosed – that's because it often develops slowly. You might be diagnosed from a blood test done for another reason. You may start to get symptoms as your ET progresses.

Symptoms vary widely from person to person. They can depend on the genetics of your ET, how it affects your platelets, and whether you have complications or not.

Common symptoms of ET

You may have some symptoms due to ET affecting blood flow in your small blood vessels. ET can slow your blood flow down because you have more platelets than you need. It can make your blood more 'sticky'.

Symptoms of poor blood flow in your small blood vessels include:

- Numbness or pins and needles in your hands or feet
- Headaches or migraines
- Blurred vision or partial loss of vision, like a blind spot
- Dizziness or light-headedness
- Irregular, fast or fluttering heartbeat (palpitations)
- Chest pain
- High-pitched ringing in your ears (tinnitus)
- Burning, painful and red skin (this can be harder to see on brown or black skin), usually in your feet

You might be asked to fill out a symptom assessment form as part of your first appointment and during check-ups. This is a good way to check how ET is affecting your everyday life. It's also useful for monitoring whether your ET is stable or is progressing and whether any treatments you have are working (see page 34).

Blood clots

Blood clots are the most common complication of ET. Up to 35 in 100 people have one when they are diagnosed. It may be the first sign that you have ET.

About 14 in 100 people get a blood clot in their first 10 years of having ET. About 86 in 100 do not.

You may develop 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 develop 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, clots may damage your internal organs

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

Always trust your instincts and seek medical help if you think you have a blood clot. Go to 111.nhs.uk, call **111** or speak to your haematology team.

Call 999 if you develop symptoms of serious blood clots, including:

- Throbbing or cramping pain, swelling, warmth or redness of your leg or arm (redness may be harder to see on black or brown skin)
- Sudden breathlessness, sharp chest pain, or coughing up blood
- Drooping on one side of your face, inability to hold both your arms up, or problems speaking, such as slurred or garbled speech

Bleeding

It may seem strange that a condition in which you have too many platelets can cause bleeding. But it can happen if your platelet levels become very high and affect clotting factors in your blood.

You may have unexpected or unusual bleeding, like nosebleeds, bleeding gums or heavy periods. Tell your team if you notice these.

General symptoms of MPNs

You may also develop general symptoms that can happen in all MPNs. They 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

"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

You might have a swollen spleen large enough for your doctor to feel during a check-up. If your spleen is swollen, you may have symptoms like:

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

Transformation of ET

ET is usually a slow-growing, long-term type of blood cancer. But sometimes, it can progress into another type of MPN or into a faster-growing type of blood cancer. You may hear this called transformation.

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. About 1 in 100 people with ET develop PV. This means it does not happen in 99 in 100 people.
- 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. Fewer than 10 in 100 people with ET develop MF. This means it does not happen in more than 90 in 100 people.
- Acute myeloid leukaemia (AML) – this is a faster-growing blood cancer where immature white blood cells in your bone marrow multiply. Fewer than 5 in 100 people with ET develop AML. This means that it does not happen in more than 95 in 100 people.

Transformation is unusual, particularly in the first 10 years of having ET.

If your ET transforms into PV, MF or AML, you may notice that your symptoms change or become more intense. Symptoms can include blood clots and heavy bleeding, and general symptoms like night sweats, weight loss or itching.

Your haematology team monitor your blood test results to check if your ET has transformed so they can treat you promptly.

We have separate information about myelofibrosis and polycythaemia vera. Follow the links, scan the QR code or search for 'myelofibrosis (MF)' or 'polycythaemia vera' at leukaemiacare.org.uk

For more information on acute myeloid leukaemia (AML), follow the link, scan the QR code or search for 'AML' at leukaemiacare.org.uk

Diagnosis of ET

Summary

- Your haematology team will use a variety of tests to diagnose ET. These may include:
  - Blood tests
  - Genetic tests
  - Bone marrow tests
- Your test results and other factors are used to work out how much of a risk ET poses to your health.
- It can be difficult waiting for and coming to terms with test results. We are here for you if you need support. You can:
  - Email us at support@leukaemiacare.org.uk
  - Message us on WhatsApp at **07500 068065**
  - Or call our freephone helpline at **08088 010 444**

Diagnosis of ET

Your doctor may suspect you have ET based on a blood test for something else or your symptoms. You'll need further tests to make sure their diagnosis is right.

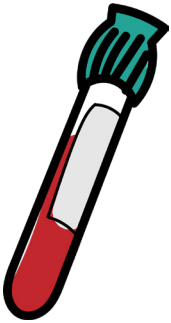
You'll be referred to a blood specialist (a haematologist) in the hospital. You usually have tests done as an outpatient and go home the same day. You'll be asked about your symptoms, if you have any. You'll also have an examination of your tummy to check the size of your spleen.

Some tests may be repeated throughout your care to check how your ET is progressing or how you are responding to treatment.

It can be hard to understand your diagnosis. Bringing someone with you to your appointments can be helpful.

Blood tests

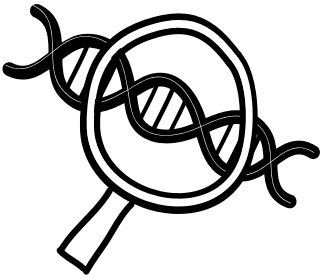
You will have blood tests to measure your numbers of red blood cells, white blood cells and platelets.



If you have ET, you usually have high numbers of platelets. You may also have low red blood cell numbers and high white blood cell numbers.

Your blood will be looked at under a microscope. This is to check for abnormal blood cells. If you have ET, your platelets may be of irregular size.

Genetic tests



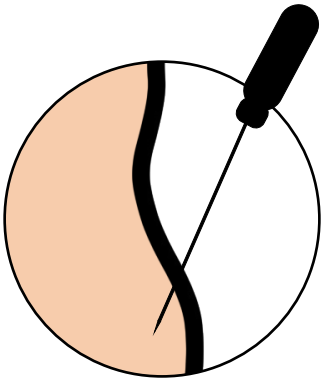
Your blood samples will go to the lab for specialised tests to look for genetic changes in your cells. They will test for changes in *JAK2*, *CALR* or *MPL* genes common in people with ET:

- Up to 60 in 100 people have a change to the *JAK2* gene
- Up to 30 in 100 people have a change to the *CALR* gene
- Around 5 in 100 people have a change to the *MPL* gene

Identifying one of these genetic changes helps your team diagnose ET.

Up to 15 in 100 people with ET don't have any of these genetic changes. This is called triple-negative ET. In this case, your team may use other genetic tests, such as a gene panel test, and your signs and symptoms to make an accurate diagnosis. A gene panel test looks for changes in more than one gene.

Bone marrow test



You may have a bone marrow test to confirm the diagnosis. This involves taking a sample of bone marrow, usually from your hip bone, with a local anaesthetic. The sample goes to the lab for testing.

You don't always need a bone marrow test to diagnose ET. Sometimes, blood tests and genetic tests on your blood are enough.

Risk groups

Your haematology team will use your test results to work out how much of a risk ET is to your health. They might call this your risk group. There are different scoring systems, but they usually take account of:

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

Your risk group reflects how likely you are to have a blood clot. Your risk group will be low or very low, intermediate (medium) or high.

Your haematology team will use your risk group to work out the best treatment plan for you.

"A cancer diagnosis can make you feel incredibly lonely. Leukaemia Care run support groups online and in person. These can be so helpful, whether you just need to sound off about your day or ask advice about symptoms and treatments."

Lucy, living with an MPN since 2017

Your test results may take a few weeks, which can be a worrying time for you. Your haematology team need all the results to make an accurate diagnosis. They need to be sure you've got ET and not another condition or other type of MPN. This will help them decide the most suitable options for you if you need treatment.

We are here for you if you need support. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Risk groups and outcomes

Outcomes for people with ET vary from person to person, depending on their risk group and other factors. Most people with ET live a long life.

Some people develop complications that pose a risk to their lives, such as serious blood clots and transformation to AML (see page 16). If this happens your expected outcomes may also change.

In ET, your risk group may give your doctors some idea of what you might have to come. But it cannot tell you how and when your ET will affect you, or how your ET may respond to treatment.

As a general guide:

- If you have low-risk ET, your outlook is usually better than if you have high-risk ET. This is because low-risk ET is less likely to pose a risk to your health due to blood clots.
- People with ET who do not develop MF or AML usually have good outcomes and often live almost as long as people in the general population.

If you want to know as much as possible about your outlook, it's best to talk to your doctor or haematology team. They can take into consideration everything they know about you, your ET and the care they can offer you.

We have separate information on general survival rates for people with ET. Follow the link, scan the QR code or contact the information team at information@leukaemiacare.org.uk or on 08088 010 444.

Treatment of ET

Summary

- You might not need treatment straight away. Instead, you might be offered regular check-ups (active monitoring).
- If you need treatment, your haematology team will recommend the best options for your individual circumstances.
- Treatment aims 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
- The main treatment options are:
  - Medicines to prevent blood clots
  - Medicines to lower your platelet count
- You may also have supportive treatments to prevent or manage other problems that may develop from ET or from treatment for it.

Treatment of ET

Not everyone with ET needs treatment straight away. If you have very low or low-risk ET, you may be offered active monitoring instead (see page 25). Your doctor will regularly monitor your ET and offer treatment if you need it.

If you need to start treatment, your haematology team will discuss your options with you. They will recommend treatments based on:

- Your preferences
- Your ET risk group
- Your symptoms
- Your blood cell counts
- Any genetic changes in your blood cells
- Your age, general health, and any other health conditions you may have

Most treatments aim to control your ET rather than cure it. You may have treatment 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 will talk to you about your treatment options. They will also discuss the side effects of treatments with you (see page 28).

Your loved ones or carers can also be involved in these discussions if you'd like them to be. This can help you reach an informed decision that is right for you.

Active monitoring

If you don't have any symptoms and ET is not causing you any problems, you are unlikely to need treatment straight away. Instead, you may be offered regular monitoring. 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. If you're symptom-free and have very low or low-risk ET, it's often better to wait to start treatment if and when you need it. That way, you avoid treatment side effects for as long as possible.

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

We have separate information on active monitoring. Follow the link, scan the QR code or visit leukaemiacare.org.uk and search 'active monitoring'.

Treatment options for ET

If you need treatment, your team might recommend:

- Medicines to prevent blood clots
- Medicines to lower your platelet count

Your haematology team may recommend a single treatment or a combination of treatments.

Medicines to prevent blood clots

Most people with ET have treatment to reduce their risk of blood clots. If your blood is 'sticky' and you're at risk of blood clots (see page 13), your team might recommend an antiplatelet medicine. These medicines stop your platelets from sticking together. You may be recommended:

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

Many people diagnosed 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, your team might recommend treatment to lower your platelets. Options include:

- A chemotherapy medicine called hydroxycarbamide. This comes as capsules you take by mouth at home.
- Injections of a medicine called peginterferon. Your team might suggest 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 might suggest:

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

Clinical trials

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is a research study that aims to find out what treatments work best for a particular condition.

Taking part in a clinical trial may give you access to treatments that are not routinely available. There are risks and benefits to taking part, which your haematology team should explain to you.

It is your decision whether to join a clinical trial. You can withdraw from a trial at any time.

"Consider taking part in medical trials. My consultant found a research trial for me, and now my care is shared between my local hospital team and the research doctors."

Lucy, living with an MPN since 2017

Cancer Research UK have more information about clinical trials. Follow the link, scan the QR code or visit www.cancerresearchuk.org and search 'what are clinical trials'.

Side effects of ET

Most medicines have side effects, including treatments for ET. Some side effects can be temporary while your body gets used to a medicine. They vary depending on what treatment you're having. They can also vary from person to person, even with the same treatment.

Some of the more common side effects of ET treatments include changes to your blood counts and immune system. Some medicines might increase your risk of skin cancer, so you need to protect your skin from the sun and regularly check for skin changes (see page 43).

"I take pride in knowing my own body. I might look okay on paper, but how I actually feel might be a completely different story. I know what my body needs and what it's asking for. I know this better than anyone; the same way you know your own body and health."

Andrea, living with an MPN since 2011

Side effects can make a big difference to your quality of life and not just while you're being treated. Some may cause health problems months or years after treatment.

"We are all individuals, despite having the same diagnosis. Our symptoms differ depending on the medication we have and how our condition affects us from day to day."

Lisa, living with ET since 2012

When to call your doctor about side effects

Call 999 if you develop:

- Difficulty breathing
- Chest pain or irregular heartbeat
- Sudden swelling of your face, lips or tongue

Go to 111.nhs.uk, call 111 or speak to your haematology team if you develop:

- Bleeding that is heavier than usual or takes longer to stop than usual, like nose bleeds, bleeding gums or heavy periods
- Unusual bruising like tiny red or purple spots under your skin - these may look purple or darker brown on black or brown skin
- Feeling weak or very tired
- Dizziness or fainting
- Itching or skin rashes
- Depression, confusion or hallucinations
- Peeling of your skin or nails
- Tummy upset such as feeling sick, being sick or diarrhoea
- Sore throat, body aches or other flu-like symptoms
- Problems going for a pee
- Changes to a mole, or any new or unusual marks on your skin that don't go away on their own

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. It is important to consider possible side effects when deciding which treatments are right for you.

If you are pregnant or breastfeeding, this is particularly important. Many medicines used to treat ET are not safe to use during pregnancy or while breastfeeding. You may be advised to avoid pregnancy if you are taking one.

Tips about side effects

- When you start treatment, you'll be given a consent form that lists all its side effects. You may want to keep this somewhere handy to refer to.
- If you need surgery or to have a tooth out, it's important to tell your surgeon or dentist that you have ET and any treatments you're on. Your haematology team can advise you on what steps to take to reduce your risk of bleeding or blood clots while you're being treated.

The electronic medicines compendium has more information about the side effects of treatments for ET. Follow the link, scan the QR code or visit www.medicines.org.uk/emc and search for the name of your medicine.

Supportive treatments

Your haematology team may offer you other support and treatments. They help prevent or manage complications of ET or side effects of treatment. Supportive treatments help you have a better quality of life.

Support for your heart health

It's important to look after your heart health as this can reduce your risk of blood clots. You can help yourself by maintaining a healthy weight, eating healthily and exercising (see page 41). Your haematology team should also support you to make other changes to help reduce your risk. These include:

- Not smoking
- Getting your blood pressure checked regularly
- Having regular tests to check your cholesterol and blood sugar levels

If you have risk factors for heart disease, you should be offered treatment for them.

Treatment for blood clots

If you have a blood clot, you may need to take a blood thinner. This can treat your clot and prevent future blood clots. You might have:

- An injected anti-clotting medicine like heparin or low molecular weight heparin, at first
- Longer-term treatment with anti-clotting medicines that you take by mouth, like warfarin or apixaban

For more serious blood clots, you may also have:

- Injections to help break down the clot and restore blood flow
- A procedure to remove the clot or allow the blood to flow around the clot

Your doctor will tell you what they recommend and what to expect from treatment. For some treatments, you need regular blood tests to check how easily your blood clots.

If you're not already on it, you may start taking medicine to reduce your risk of further blood clots, like hydroxycarbamide (see page 26).

Treatment for bleeding

Bleeding is a possible complication of ET. If you have heavy bleeding, you may need:

- Replacement fluids and a blood transfusion to bring your blood circulation back to normal
- An injection of tranexamic acid to help your body stop the bleeding

Your haematology team will review any medicines you're on for ET. They may adjust them to help improve your blood counts and reduce your risk of bleeding. This can include any antiplatelet medication you're on, like aspirin.

You may also have blood tests to check your risk of future clots and for other blood-clotting problems.

Treatment to help with other symptoms

You might have treatment to help you manage symptoms of ET like headaches or itching. These can impact your quality of life. The following medicines can help provide some relief:

- Aspirin. This is a common treatment for ET (see page 26). It can also help with symptoms like headache and burning, painful skin.
- Antihistamines like cetirizine and diphenhydramine. These medicines may help with itching.
- Antihistamines like loratadine and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen. These medicines may help with bone pain caused by ET. But check with your doctor before taking ibuprofen if you're already taking aspirin.

Tell your haematology team if ET symptoms are affecting your quality of life. They may be able to suggest medicines or lifestyle changes to help you.

"I would recommend Leukaemia Care's buddy scheme to anybody who needs someone to talk to. You need someone who understands what you're going through and all of the silly little things that go along with it. Just to say to somebody, 'Yes, I know what you mean.'"

Margaret, living with ET since 2002

Monitoring ET

Whether you are having treatment or not, you will have regular check-ups. These usually include blood tests, and an examination of your tummy to check how swollen your spleen is. You may need other tests depending on your symptoms.

Your team will ask if you've noticed any new symptoms or changes to your symptoms. Your team may ask you to share information from your app or your symptom diary if you've been keeping one, or to fill out a symptom assessment form.

You may also need regular check-ups with your GP to monitor your heart health. This may apply if you're at risk of blood clots or bleeding. Or if you have other conditions, such as heart disease or diabetes.

"Get on board with your healthcare team, both at your GP surgery and your hospital. If you feel they're not the right fit for you, find an MPN specialist and request a referral from your GP. This is your MPN journey, and it's too important for you to accept any unsupportive treatment."

Lucy, living with an MPN since 2017

You can use the free My MPN Voice app to track your symptoms for your records or as part of a patient-led research study, too. The study aims to find out whether a smartphone app could improve symptoms and quality of life for people with an MPN. For more information, follow the link, scan the QR code or visit www.mpnvoice.org.uk and search 'my MPN Voice app'.

Living with ET

Summary

- Having ET can affect your day-to-day life and impact you emotionally and physically.
- You may experience a variety of emotions. There is no right or wrong way to feel. But, if you think you may be depressed, contact your GP.
- You might want to talk to your friends and family about your condition. Remember, if or when you tell people is your choice.
- You might experience fatigue. Pacing yourself and saving energy for things that are important to you can help.
- Keep active and eat a healthy, balanced diet, if you can, to help your general fitness.
- Having ET can affect your work and finances. You may need adjustments or support to help you continue to work or study.
- If you like going away on holiday, talk to your GP or haematology team about managing your ET while you're travelling.
- You probably have lots of questions. Make a list of them for when you see your haematology team.
- If you are struggling, ask for help from friends, family, your haematology team or Leukaemia Care.

Living with ET

Being diagnosed with ET can be overwhelming. It can affect you both physically and emotionally. Your symptoms, side effects of treatment, and hospital appointments may all impact your day-to-day life. Here, we cover some practical information about living with ET and where to get support.

Managing your emotions

Being diagnosed with cancer can be very upsetting. You may experience a range of complex thoughts and emotions, which may be strange and unfamiliar to you.

You may feel:

- Shock or disbelief
- Uncertainty, anxiety or fear about the future
- Sadness or depression
- A sense of loss of the person you used to be, and how safe you felt
- Worry about other people's reactions
- Isolation, or a feeling that other people don't understand what you're going through
- Guilt, anger, frustration or irritability
- A loss of self-confidence

Everybody reacts differently. You may experience some of these emotions but not others. You might have different feelings at different times. There is no right or wrong way to feel.

Sadness and depression

You might be feeling low, which is a natural effect of your diagnosis and can be caused by some treatments for ET. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, it is important to contact your GP. They can help you access the support and treatment that you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Scan the QR code for details or go to the 'mental health' section at www.nhs.uk

"Reach out to support groups like those run by Leukaemia Care. I felt anxious, vulnerable, a fraud, and alone until I joined a support group and was with people who understood exactly how I felt."

Linda, living with ET since 2025

Telling other people

When you are first diagnosed with ET, there is a lot to take in. You may need time to adjust before you decide when and how you tell others. There will be people you want to tell and others you prefer not to. It's up to you who you tell and how much you tell them.

People may be anxious to know what's happening, which can make you feel under pressure to tell them. Let them know you need time to process things before you're ready to talk about it.

In conversation with your loved ones, you might want to:

- Explain that you have a condition that means your bone marrow does not work properly, and this affects the blood cells it produces.
- Tell them what symptoms you get and how they affect you.
- Explain what treatment you might be offered. You might want to talk about your possible outcomes.
- Explain your needs. Your family and friends may be happy to know they can support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. People who care about you will want to help you as best as they can.
- Have a print-out or factsheet handy so you don't have to remember everything your friends and family might want to know. Or you could give them a copy of this booklet.

"It can be exhausting explaining to others what we have, as it's not visible. That's why it's so important to talk to others who have experienced similar feelings and emotions. Do not underestimate what you have."

Linda, living with ET since 2025

Coping with fatigue

One of the most common symptoms of ET is fatigue. This feeling of extreme tiredness or lack of energy can interfere with your usual activities. Fatigue can be very frustrating as it doesn't get better with rest and cannot be treated with medicines.

Tips for coping with fatigue

Plan activities and pace yourself:

- Prioritise things that are important to you and save energy for these
- Accept help where you can

Balance rest and exercise:

- Take regular, gentle exercise
- Rest when you need to
- Try yoga or meditation, as these can help

Keep to a regular sleep schedule:

- Try to go to bed and wake up at around the same time each day
- Keep your bedroom quiet and at a comfortable temperature
- Avoid eating or drinking alcohol, coffee, tea, or chocolate before bedtime
- Avoid using laptops, tablets, or smartphones before going to bed

If you are having treatment for ET, you might find your fatigue gets better over time as the treatment starts to work.

Your experience of fatigue is likely to be different to another person with ET. It varies from person to person. Tell your haematology team if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

"Try to avoid 'activity cycling'. This is when you feel good and do a lot, but then end up having to rest, or even stay in bed, for a day or two. If you feel you can do a lot, do half!"

Josie, living with ET since 2015

We have more resources to help you cope with fatigue on our website. Scan the QR code to find out more, or search for 'fatigue' at leukaemiacare.org.uk

Healthy living

It is important to look after yourself well. Making small changes to your lifestyle can help you stay as well as possible after diagnosis and during treatment.

Living healthily has many benefits. Besides improving the quality of your life, it can help you cope with fatigue and other effects of ET and reduce your risk of blood clots.

> **"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

Having a healthier lifestyle

Adopting a healthier way of living is about making small, manageable changes to your lifestyle. If your current lifestyle is less than ideal, it's best to pace yourself and avoid changing too much at once.

Diet

If you can, try to eat a healthy, well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with treatment if you need it
- Improve your heart health

Side effects from some treatments, such as sickness and diarrhoea, can make it difficult to eat a healthy diet. If you are struggling, ask your haematology team for advice.

The NHS website has information and guidance on eating a healthy, balanced diet. Scan the QR code, or go to the 'live well' section at www.nhs.uk

Exercise

Exercise can improve your heart health, quality of life and wellbeing. It can also help to reduce some of the side effects and symptoms you may have, such as fatigue.

You may not feel like being active, especially if you are experiencing fatigue. Remember, even a gentle walk can help. Choose a level of exercise that works for you and how you're feeling. Try not to compare yourself to others with ET – everyone's experience of ET is individual.

"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

Sun safety

Skin cancer has become much more common in the UK. Some medicines for ET, such as hydroxycarbamide, can also increase your chance of getting skin cancer. You need to protect yourself from the sun and be particularly mindful of any skin changes.

Tips for preventing skin cancer

- Keep to the shade between 11am and 3pm on sunny days.
- Cover your skin with clothes, including a hat, shirt and sunglasses.
- Use a high-protection sunscreen of at least SPF 30 with UVA protection too. Apply it generously and often.
- Get to know what's normal for your skin by checking it regularly.
- Tell your doctor about any changes to a mole or any new or unusual marks on your skin that haven't gone away within 2 months.
- Go for annual skin checks if you're referred for them.

Work and education

Being diagnosed with ET and having to juggle work or education with hospital or GP appointments can be challenging. Your diagnosis, managing symptoms or side effects, or going to appointments may mean you need time off from work.

You are entitled to reasonable adjustments to help you cope at work.

Your haematologist or GP can write letters to your employer to confirm your diagnosis and how this may affect your work life. This can help your employer have arrangements in place for when you need time off and to discuss how else they can support you.

If you are diagnosed with ET while you're attending school, college or university, you should contact them. They might be able to offer you extra support, pause your studies, or defer your attendance for a while if you need it.

"Pacing yourself is important. On my bad days, I work for 30 minutes, then rest for 1 or 2 hours. It's amazing what you can get done in short periods throughout the day."

Josie, living with ET since 2015

Money and financial help

Your ET diagnosis may also affect your finances, whether or not you are working. Being diagnosed with ET can come with extra costs, such as travel to and from hospital, childcare costs or parking charges.

You should be able to get free NHS prescriptions as a person with cancer. Your haematology team or GP can tell you how to apply.

Charities and financial support

We have a range of **services that can help you**, including a welfare service and cost of living hub. Follow the link, scan the QR code or search for 'support for you' at **leukaemiacare.org.uk**

Macmillan have **information on benefits and financial support**. Follow the link, scan the QR code or search for 'benefits and financial support' on **www.macmillan.org.uk** for more information. Or contact them on **0808 808 0000** to discuss your eligibility for benefits, grants and support available.

Travelling with ET

Having ET shouldn't stop you living a fulfilling life. But, if you're planning to travel, there are a few things to think about. It's a good idea to plan ahead.

Tips for planning long-distance journeys

- Have a chat with your GP, haematologist or haematology team about your plans.
    - They can tell you if it's safe and discuss how to manage your ET while you are away.
    - They might assess your aspirin dose and discuss other medicines to help prevent clots.
    - You could also ask them for a letter explaining your condition and the medicines you take, in case you need it for any security checks.
- It's important to consider getting travel insurance, especially if you are travelling to a country with high medical costs.
    - You will need to declare you have ET when buying your insurance policy. Otherwise, it won't cover any costs relating to your illness.

- Take all your ET medicines with you, and some extra in case you lose any or need to stay away longer than planned.
    - Check the medicine information leaflet to see how you need to store your medicine while you are travelling.
    - Make a list of all the medicines you take, when you take them, and the dose you take.
- Be prepared for emergencies.
    - Check for a doctor or health centre near your destination, so you know where to go if you need medical help.
    - Take contact numbers of your healthcare professionals.
- Make sure your vaccinations are up to date and check if you need any extra vaccinations for your destination.
- Take water, snacks, pillows and anything else that helps you be comfortable and manage any fatigue.

"ET does not control your life. You control it with a positive outlook on your future."

Lisa, living with ET since 2012

Preventing blood clots when you travel

Travelling long distance increases your risk of getting a blood clot in your leg. This is called a deep vein thrombosis (DVT). Your risk is higher however you travel – by car, coach, bus, train – but especially if you travel by air.

It's important to try and reduce this risk as much as possible by:

- Walking around or standing up fairly often.
    - If you can, try and walk around the cabin or carriage every 2 to 3 hours. It helps if you're able to get an aisle seat.
    - If you are travelling by car, plan rest stops so you have time to stretch your legs and walk around.
- Exercising your leg muscles and stretching during your journey, such as:
    - Raising and lowering your heels while keeping your toes on the floor.
    - Raising and lowering your toes while keeping your heels on the floor.
    - Squeezing and relaxing your leg muscles.
- Asking your doctor or medical team about compression stockings. These are tight-fitting socks that help prevent blood clots. You can buy them from high street chemists, airports or online.

If you get symptoms of a blood clot (see page 14) whilst travelling, seek urgent medical help.

Going to appointments

Hospital and GP appointments often involve a lot of waiting around. You could download a podcast or TV programme to keep you occupied while you wait. Or take something physical like a book or travel game.

Once you're in your appointment, it can be hard to take in everything your doctor or nurse is telling you. Here are some tips to help you get the most from your appointment:

- Take a family member or friend with you for support.
- Ask any questions you may have. If you don't understand something, ask your haematology team to explain. They will be used to this.
- Take notes on your phone or paper to help you remember. You can always ask your doctor or nurse to make notes for you or ask if they are happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping. You and your haematology team are working together to keep you well.
- If you see a different doctor or clinical nurse specialist (CNS) every time, and it's causing you problems, ask if you can have continuity of care. This means seeing the same doctor or nurse for your appointments. This can help if you have a complicated history with your ET or treatments.

Questions for appointments

Sometimes it can be overwhelming to know what to ask in your appointments. Some questions you might want to ask include:

- What tests will I need?
- What might the tests show?
- How long will it take to get the results back?
- What treatment will I need?
- How long will my treatment last?
- How will I know if my treatment has worked?
- What might the side effects be?
- Are there any foods or medicines that I need to avoid?
- Will I be able to go back to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

"The confidence to push back or ask questions doesn't always come naturally or quickly; it takes time to build. But when you do, you know you're advocating for your best care, and it is empowering to be able to do that."

Andrea, living with an MPN since 2011

Our advocacy officer can help if you feel you need a second opinion or if you're struggling to get continuity of care. Email advocacy@leukaemiacare.org.uk or call **08088 010 444**.

Words you might see or hear

Active monitoring: a way of monitoring your health when you have a blood cancer that doesn't need immediate treatment. You have regular check-ups and you also monitor your own symptoms.

Acute myeloid leukaemia (AML): a fast-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Anaemia: a low red blood cell count.

Anagrelide: a medicine to reduce the number of platelets in your blood.

Bone marrow: the spongy centre of some of your larger bones where blood cells are made.

Busulfan: a type of chemotherapy medicine that stops cancer cells in your bone marrow multiplying.

***CALR* gene:** the gene that codes for a protein called calreticulin (CALR). CALR helps your cells to function normally.

Cancer: an illness that happens when abnormal cells grow and divide uncontrollably.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Clinical nurse specialist (CNS): an experienced nurse who has specialised in a particular area of nursing. They can offer you advanced care, support, advice and guidance.

Clotting factors: proteins that help your blood clot.

Diabetes: a common lifelong condition that causes your blood sugar level to become too high.

DNA: the genetic code that tells your cells how to grow and behave.

Essential thrombocythaemia (ET): a type of myeloproliferative neoplasm where your body makes too many platelets.

Gene: a section of DNA that tells your cells how to make a particular protein.

Genetic changes: changes to genes that can affect the proteins a cell makes. This may change how a cell behaves and grows. They are also known as genetic variants.

Haematologist: a doctor who specialises in diseases of the blood.

Haematology: the branch of medicine that deals with diseases of the blood.

Hydroxycarbamide: a chemotherapy medicine that helps lower your blood cell counts.

***JAK2* gene:** the gene that codes for the JAK2 protein, which helps regulate blood cell production.

Local anaesthetic: a medicine to numb part of your body so you don't feel any pain during medical procedures.

Mini-stroke: a temporary disruption in the blood supply to your brain. Also called a transient ischaemic attack (TIA).

***MPL* gene:** the gene that codes for a protein that helps control the number of blood cells in your bone marrow, particularly your platelets.

Myelofibrosis (MF): a type of cancer where your bone marrow becomes filled with scar tissue, which stops it making enough healthy blood cells.

Myeloproliferative neoplasms (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Palpitations: an unusual or uncomfortable heartbeat, like an irregular, fast, pounding or fluttering beat.

Peginterferon: medicine that alters the way your immune system works and helps stop cancer cells growing and multiplying.

Platelet: a type of blood cell that helps your blood clot and stops bleeding.

Polycythaemia vera (PV): a type of cancer where your bone marrow makes too many red blood cells.

Proteins: the building blocks of every cell, tissue and organ in your body. Your body needs proteins for growth, repair, and to fight infections.

Red blood cell: a type of cell in your blood that carries oxygen around your body.

Spleen: a fist-sized organ that sits under your ribs on the left side. It filters and stores blood and makes some blood cells.

Stem cells: immature cells in your bone marrow that can develop into all the different blood cells your body needs.

Stroke: a serious medical condition that happens when the blood supply to a part of your brain is suddenly cut off.

Tinnitus: hearing noises that do not come from an outside source, like a buzzing, ringing or whooshing sound in your ears.

Transformation: when one type of blood cancer develops into another type, usually a faster-growing one.

Transfusion: having blood or blood products through a drip into a vein.

White blood cells: cells in your blood that help your body fight infections.

Useful contacts and further support

Coping with ET can be difficult. You may need support from:

- Your healthcare team
- Family and friends
- Leukaemia Care
- Other charities

Here are some organisations you might find helpful.

Leukaemia Care

Helpline: **08088 010 444** (Monday to Friday, 9am to 4:30pm)

WhatsApp: **07500 068065** (Monday to Friday, 9am to 5pm)

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

MPN voice

Provides information, community and advocacy for MPN patients, their families and carers.

07934 689 354

www.mpnvoice.org.uk

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888

bloodcancer.org.uk

Cancer Research UK

Leading charity dedicated to cancer research.

0808 800 4040

www.cancerresearchuk.org

Macmillan

Provide free practical, medical and financial support for people facing cancer.

0808 808 00 00

www.macmillan.org.uk

Maggie's

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggies.org

Carers UK

Offer advice, information and support for carers.

0808 808 7777

www.carersuk.org

Citizens Advice

Offer advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

The Citizens Advice service does not cover Northern Ireland but their website lists contact details for local community advice agencies, depending on where you live.

How you can help us

Share your story

If you've been affected by ET, sharing your story can help others in a similar situation. It can also help people understand ET better.

To share your story:

- Go to www.leukaemiacare.org.uk/share-your-story
- Scan the QR code
- Email communications@leukaemiacare.org.uk

Volunteer with us

Volunteering with us can help you develop life skills, find a sense of purpose, and make a difference to other people. There are lots of ways to get involved, depending on how much time you have to give – and we'll be there to provide support. You could:

- Become a Buddy to help someone going through a similar experience
- Join our patient panel to help us shape what we offer

To find out more, email volunteering@leukaemiacare.org.uk

Tell us what you think of this booklet

Please follow the link or scan the QR code to complete a short survey to let us know how we can improve our information. Or get in touch by email, phone or post.

- Email information@leukaemiacare.org.uk
- Call our Head Office on **08088 010 444**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG

You can also contact us if you'd like a list of the sources we used for this booklet.

If we've helped you - here's how you can give back

We are here for people with leukaemia and their families, purely because of public support and generosity – kind people like you.

You can help

- Fancy the chance to win £25,000? Join our weekly lottery from as little as £1 a week.
- Organise your own event. You could host a quiz night or bake sale with friends, at work or school.
- Does your employer make charitable grants or donations to good causes?
- Ask your society, group or sports club about their charity of the year partner.
- Prefer to get outdoors? Take on one of our challenges of varying levels. Walk, run or for the more adventurous, a skydive?

No fuss options

- Make a one-off donation.
- Sign up for monthly donations.
- Or simply spread the word. Raising awareness of Leukaemia Care with your family and contacts is invaluable.

Contact our fundraising team

- Scan the QR code
- Email fundraising@leukaemiacare.org.uk
- Call **08088 010 444**

Plenty of ways to give

There are so many ways you can give to help support people affected by leukaemia. Find one that fits you!

By bank transfer

You can transfer your donation straight from your account to ours:

- Account name: **Leukaemia Care**
- Sort code: **20-98-61**
- Account number: **80823805**

By cheque

Please make your cheque payable to **Leukaemia Care** and pop it in the post to: Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG.

Online

Simply visit www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us on **08088 010 444** to donate by debit or credit card over the phone.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

- Call our freephone Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Send us a WhatsApp message: **07500 068065** (weekdays 9am to 5pm)
- **www.leukaemiacare.org.uk**
- **support@leukaemiacare.org.uk**

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no. 1183890) and Scotland (no. SC049802). Company number: 11911752 (England and Wales). Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

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Patient Information Forum

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