

Essential thrombocythaemia (ET)



Your guide to diagnosis,
treatment and living
well with ET

**Blood
cancer
UK**

Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.



Call free on **0808 2080 888**

Email **support@bloodcancer.org.uk**

Visit **bloodcancer.org.uk**

Talk to others at **bloodcancer.org.uk/our-forum**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

My diagnosis is:

.....

My hospital number is:

My NHS number is:

My main point of contact (key worker) is:

Name:

Role:

Phone no:

Email:

You should be given a key worker. Ask if you're not sure who this is, or call us.

My consultant's name is:

.....

Haematology ward/clinic:

Phone no:

If I need medical help outside normal hours, I can call:

Name of service:

Phone no:

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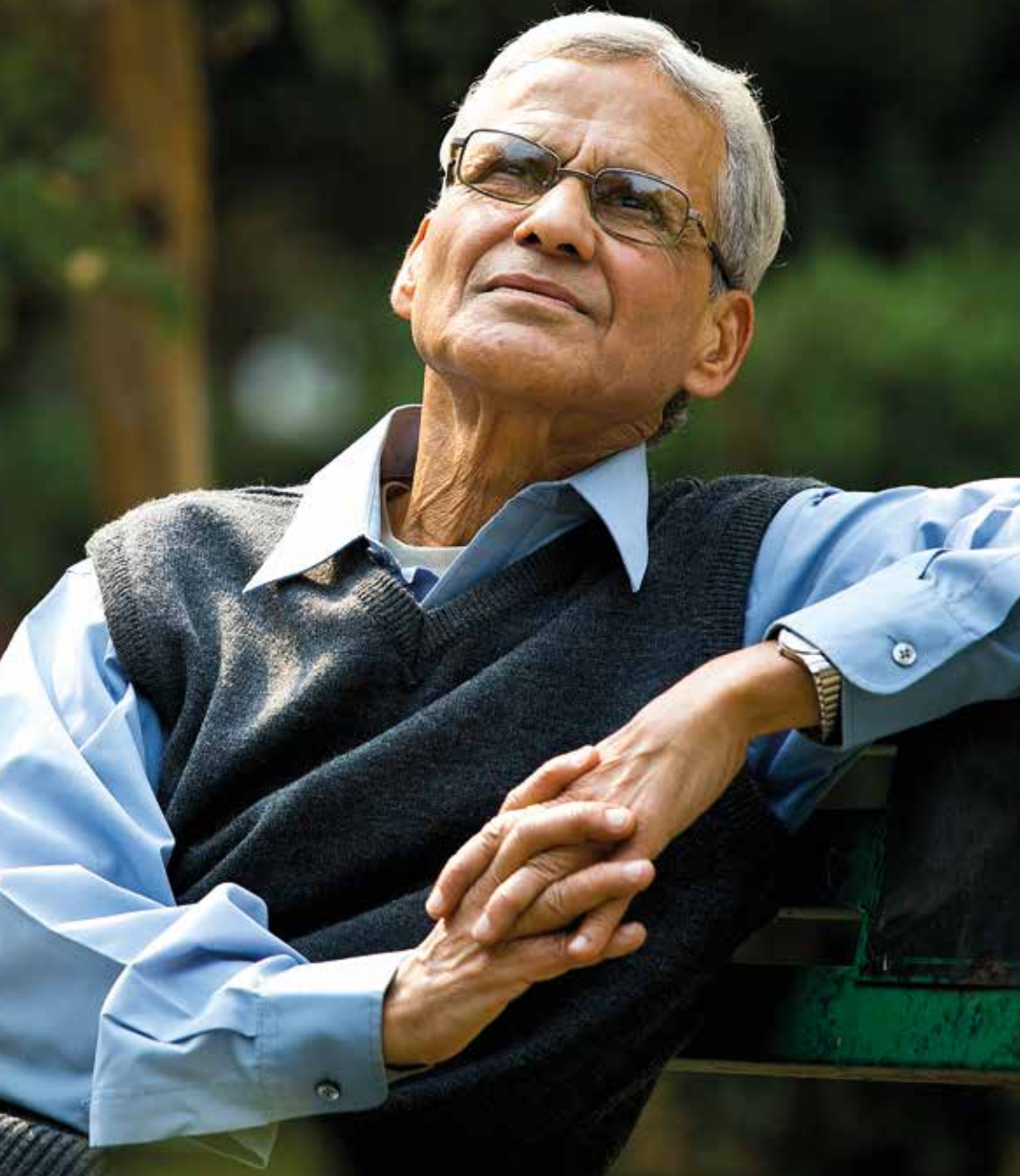
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Finding out you have ET



If you've just been told you have ET, you may find there's a lot to take in.

This booklet aims to give you the basics, so you understand a bit more about what having ET might mean for you.

We have written it with people who know what it's like to live with ET. So as well as including medical information, it includes stories and advice about how people get used to their new situation.

Don't feel you have to read this booklet all at once. Keep it handy so you can come back to it when you're ready or show others to help them understand. You can order more free copies for your family and friends from bloodcancer.org.uk/our-booklets

The worst thing you can do is google. Use Blood Cancer UK. Phone the support line and join the online community forum, because it's reassuring to talk to people who've had ET a long time.

Gail, living with ET since 1991



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Is ET blood cancer?

The word cancer describes diseases where cells start to grow out of control.

In ET, your body starts to make too many blood cells called platelets. That's why it's classed as a blood cancer. It's one of a group of blood cancers called MPNs (myeloproliferative neoplasms).

It's really important to know from the start:

- ET is a slow-growing blood cancer.
- ET can be treated.
- The main risk to your health is not from the cancer, but from blood clots.
- You'll take medicine to lower your risk of blood clots.

The next chapter will tell you more about what ET is. See "Understanding ET" starting on page 15.

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I couldn't get the words 'blood cancer' out of my head. I felt really shocked and upset. It was more psychological than physical because I didn't have many symptoms at the time.

Anna, living with ET since 2021



Is it normal to feel how I'm feeling?

It's completely understandable to feel shocked, upset, frightened or worried when you're told you have ET.

Many people say that when a doctor or nurse explained the diagnosis, the word "cancer" was the one thing they heard. It can be a lonely moment, and one that affects your mental health as well as your physical health.

Others have a different view. They felt relieved that doctors had found out what's wrong. Some say they were just happy it wasn't something worse.

However you feel, it's OK. You won't be alone in feeling that way. There are about 20,000 people living with ET in the UK, so there are people who will understand. You can connect with some of them on our online community forum at **bloodcancer.org.uk/our-forum**

The next steps

It's good to know what will happen next, but it can be hard to take in what your doctor or nurse has told you. Don't be afraid to ask them to go over things again. Here are some useful things to know:

- **You should be given a key worker**, your main point of contact in the hospital team. This may be a clinical nurse specialist (CNS). Ask who is responsible for your care and who to contact if you have questions. If you don't have a key worker, it's OK to ask for one.
- **You may have more tests** to find out more about the ET and whether you need treatment straight away. Ask your team what the tests are for and if you'll have them again. We have information about tests at bloodcancer.org.uk/et-tests
- **Your hospital team will explain your treatment plan** and how you will be monitored. Ask any questions you like – you'll find some suggestions in this booklet. You can also ask for another appointment. Most people need more than one visit to take it all in.

ET is a type of blood cancer called an MPN. A haematologist (a doctor who specialises in blood conditions) will be responsible for your care but you can ask for a referral to an MPN specialist if you wish. Call our Support Service if you would like support to speak to your hospital team about this or anything else.

Checklist of things you can do

Here are some practical things you can do to make life a bit easier in the early days:

- Contact our Support Service to talk through your diagnosis and what comes next.
- Try not to google – the information can be out of date, misleading or might not be relevant to you personally.
- Put all your appointments in a diary or calendar so you know what's coming up.
- If you have face-to-face appointments, decide how you will get to them and consider taking someone with you.
- Get a folder so you can keep medical letters and health information in one place.
- Keep a list of questions to ask at your next appointment or to email your hospital team (for some ideas, see page 12).
- Choose books, magazines, podcasts or videos to give you something to do if you have to wait around for medical appointments.
- Think about whether you need extra help such as childcare or help caring for a relative while you're at appointments, or just to give yourself a break.

If you need to talk

If you'd like to talk about what your diagnosis means, how you're feeling or what to do next, contact our Support Service.

Call free on **0808 2080 888** or email **support@bloodcancer.org.uk** and tell us that you've just been diagnosed with ET.

Telling people about your diagnosis

It's your choice whether you tell people about your ET diagnosis. Some people are open about it and others prefer to tell only a few people, or no one at all. For most people, treatment happens at home and doesn't change the way they look. So not telling people can be an option when you have ET.

If you decide to tell friends and family, you may get a range of reactions. Most people will be supportive, but they may get upset or not know what to say. They will probably have never heard of ET, so this booklet may help you explain what ET means for you, and for them. You can order more copies from [bloodcancer.org.uk/our-booklets](https://www.bloodcancer.org.uk/our-booklets)

Once you've told someone, don't be afraid to let them know when you want to talk about your health, and when you want to talk about other things.

If you're employed, consider telling your workplace. ET is classed as a blood cancer, so you have rights under disability laws. Your employer can't tell anyone else without your permission. See page 54 for more information about working with ET.

Questions to ask after your diagnosis

It can be hard to know what questions to ask your hospital team, so here are some suggestions. There's also space to write your own on page 63.

- Who is my main point of contact?
- What support is available to me?
- Will I need more tests?
- What kind of tests will I need?
- What are the tests for?
- When will I get the results?
- Who will explain the results to me?
- What treatment will I have?
- Will it help with my symptoms?
- How will having ET affect my life?
- You mentioned [any medical term]. What does that mean?



Gail

How do you feel about living with ET?

"I feel I've been very lucky. I've been very well looked after...I'm also hopeful about the research that's going on into ET and other MPNs. It's bound to be there in the back of your mind if you have ET. But I would say go ahead and live your life. Enjoy everything."

Read Gail's story at bloodcancer.org.uk/gail or call us and we'll post you a copy.

Understanding ET



Many people find it helps them feel more in control to learn more about what ET is and how it can affect them.

People often talk about having to learn a new language when they're diagnosed with blood cancer. Different people have different feelings about how much they want to read up on their condition, and that's a personal choice. But most would agree there are some things that it's good to know from the start.

Knowing more about ET can also make you feel more confident about asking questions so you can get more out of your appointments.

This chapter will give you a brief summary of what ET is and the effect it has on your health. You'll find more information at [bloodcancer.org.uk/et](https://www.bloodcancer.org.uk/et)

If you don't use the internet, call our Support Service and we will send you a printed copy.

My way of dealing with things is to read a lot and feel like I've got the information. And I ask a lot of questions too.

Esther, living with ET since 2018



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How does having ET affect me?

When you have ET, your body makes too many blood cells called platelets.

Platelets are blood cells that help your blood to clot. They stick together to stop you bleeding if you have a cut or a bruise. If you have too many platelets, it can make your blood too thick. This can cause blood clots (thrombosis).

Risk of blood clots

Blood clots can lead to a range of problems, depending on where they are in the body:

- In the brain, clots can cause stroke or mini stroke (known as a TIA).
- In the eyes, clots can cause blurred vision or loss of sight.
- In the heart, they can cause a heart attack.
- In the stomach area (abdomen), they can cause damage to organs such as your liver.
- In the legs, they can cause deep vein thrombosis (DVT), which can lead to a clot travelling to the lungs (a pulmonary embolism).

These clots can cause serious problems and some are life-threatening. So it's important to be aware of the symptoms. But once you're diagnosed with ET, you can start taking medicine that will lower your risk of blood clots.

What to look out for

The symptoms of a blood clot will vary depending on where it is, but they include:

- slurred speech
- weakness on one side of the body
- drooping on one side of your face
- sudden chest pain, dizziness and feeling short of breath
- one leg or arm becoming painful, swollen and warm
- coughing up blood
- sudden blurred vision or loss of sight
- sudden pain in the stomach area, possibly with swelling
- a yellowing of the eyes, and yellowish skin in people with lighter skin tones (jaundice).

If you have one or more of these symptoms, it's a medical emergency. Call 999 and get medical help straight away.

Risk of bleeding

ET can also cause a higher risk of unusual bleeding (haemorrhage).

It may seem odd that having too many platelets can cause bleeding as well as clotting. But bleeding can happen when the number of platelets is very high and they don't work normally. If you are diagnosed with ET, your hospital team will monitor you for unusual bleeding as well as blood clots.

Your risk of blood clots or bleeding

Doctors will assess your chance of having blood clots or bleeding based on:

- your age
- whether you have had problems with blood clots or bleeding before
- other medical conditions you may have
- the number of platelets in your blood.

If you have any other conditions that can also increase your risk of blood clots or bleeding (such as high blood pressure or high cholesterol), these will need to be managed effectively. This might mean reviewing the medicines you're already taking.

Your doctor may also advise you to follow general advice on healthy eating and exercise (see pages 52 to 53).

Symptoms you may have

Some people have no symptoms when they're diagnosed with ET, but typical symptoms include headaches, dizziness, extreme tiredness (fatigue), bruising easily and unusual bleeding such as nose bleeds or heavy periods. You may have pain in your stomach area if your spleen is swollen.

Your doctor will ask you about your symptoms, so you may want to keep a note of them and how they change. Treatment for ET should help to control your symptoms so they have less impact on your day-to-day life.

Your risk of infection

Having ET can affect how well your immune system works. This varies from person to person, but it's important to know that you may be more likely to get infections like flu and covid, and may be at higher risk of serious illness. That's why it's important to get the vaccinations you're entitled to.

People with blood cancer shouldn't have live vaccines, but most vaccines aren't live, including the seasonal flu and covid vaccinations.

If you need a shingles vaccination, you should have the one called Shingrix, which is not live. Shingles is an infection of the nerve and cells around it which you can get if you have had chicken pox in the past.

Check with your GP which vaccinations you should have if you're not sure. We have information about vaccinations at **[bloodcancer.org.uk/staying-safe](https://www.bloodcancer.org.uk/staying-safe)**

It's also a good idea to follow standard advice on hygiene and food safety.

We have general guidance about managing your risk of infection at **[bloodcancer.org.uk/managing-infection](https://www.bloodcancer.org.uk/managing-infection)**

Genetic changes in ET

We know that ET starts with a genetic change (a mutation) that causes your body to make too many platelets.

Genes are like a set of instructions that tell your cells how to behave, but sometimes the instructions go wrong and cause a mutation.

We don't know why genetic mutations happen, but we know that most people with ET have a mutation in one of three specific genes:

- **JAK2** – over half have the JAK2 gene mutation
- **CALR** – over a quarter have the CALR mutation
- **MPL** – about a tenth have the MPL mutation.

Doctors will test for these mutations because it gives them useful information. For example, people with a CALR mutation tend to have a lower risk of blood clots than those with a JAK2 mutation.

Some people have triple negative ET, which means they do not have the JAK2, CALR or MPL mutation. They may have another mutation which researchers haven't identified yet.

Whether or not tests show a specific mutation, you will get the best treatment for you, based on your age and fitness, your symptoms, your medical history and the number of platelets in your blood.

Can ET be inherited?

It's rare to have a family history of ET, but talk to your specialist doctor if you are worried about this. In most cases, the genetic mutations that cause ET happen during your lifetime, and can't be passed on.

What does the future look like?

ET is a lifelong (chronic) condition and people with ET are expected to live a normal lifespan.

Treatment can't cure ET, but it aims to protect you from the problems it can cause, like heart attack and stroke. It also aims to control any symptoms you may have.

Everyone is different, and your personal experience of ET will depend on a lot of things – your age, your life stage, your symptoms, your treatment and other health conditions you're living with.

Talk to your hospital team about what's likely to happen in the future (your prognosis). They can help you decide how best to adapt to your new situation, depending on your individual circumstances and what's most important to you.

You'll find some ideas on things you can do to look after yourself from page 43.

The risk of developing another blood cancer

In a few cases, ET can develop into another MPN called myelofibrosis (MF), or a type of leukaemia called acute myeloid leukaemia (AML). The risk of this happening is low, although there is some evidence that it increases over time.

This isn't easy to hear and you might feel anxious about it. It may help to talk it through with your hospital team, because they are best placed to explain your individual prognosis.

If you think you would benefit from counselling or other psychological support, your doctor or nurse can refer you. Or you may be able to refer yourself – see page 60.

If you want to know more about MF or AML, search “MF” or “AML” at **bloodcancer.org.uk**

Research and clinical trials

Scientists are researching better and kinder treatments for all types of blood cancer, including ET.

If you need treatment for ET, you may be interested in joining a clinical trial. This offers the chance of having either the best current treatment or a new one that may be even better. Ask your doctor about clinical trials or speak to our clinical trials support service on **0808 2080 888**.

You can find out more about research developments at **bloodcancer.org.uk/researching**. Read about our clinical trials support service at **bloodcancer.org.uk/clinical-trials**

Talk to people who know

It can help to talk to people who are living with
ET and other chronic blood cancers.

Visit our online community forum where you can
meet other people who've had similar experiences,
and find emotional support and understanding.

Join the conversation at
bloodcancer.org.uk/our-forum

Questions to ask about your prognosis

You may have questions about your prognosis – what will happen in the future.

Here are some suggestions for questions to ask. Or you can note your own questions on page 63.

- What's my risk of blood clots or bleeding?
- Which genetic mutation do I have?
- What does having this genetic mutation mean for me?
- What does it mean if I have triple negative ET?
- Does my age affect my prognosis?
- Who can I talk to about my feelings?
- How will having ET affect how I live my life?



Ed

What were you told when you were first diagnosed?

“They said I needed to get my platelet level under control and that it would help to keep fit, eat well, never smoke, and reduce my stress levels. With a bit of luck along the way they were confident I will live more than long enough to see my grandkids.”

Read Ed’s story at bloodcancer.org.uk/ed or call us and we’ll post you a copy.

Treatment and monitoring for ET



Treatment can't cure the ET, but it can manage the symptoms and improve your quality of life.

Treatment for ET aims to protect you from the effects of blood clots, such as heart attack and stroke. Your treatment will depend on your personal circumstances and may be different from other people you meet with ET. If you're not sure why you're being given a particular treatment, it's perfectly OK to ask your doctor to explain.

Treatment usually happens at home and can be fitted into your daily routine. You will have regular tests to monitor how the treatment is working and adjust the dose if needed.

This chapter covers treatments that were available for ET at the time the booklet was published. For the most up-to-date information about ET treatments, go to bloodcancer.org.uk/et-treatment or call us.

I've had different treatments over the years and they've kept the ET under control. If one option doesn't work for you, there are others to try.

Gail, living with ET since 1991



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Decisions about your treatment

Your doctor will recommend a treatment based on:

- your age
- your level of risk for blood clots (see page 18)
- the number of platelets in your blood.

Your age is relevant because some treatments are better than others for people at certain life stages. For example, if you're younger, you may wish to take a drug that doesn't affect your ability to have a child (your fertility). Some drugs are more suitable for older people because they may increase the risk of developing another blood cancer if they are taken for many years.

It's common to stay on the same treatment for many years, although your dose may change. Your hospital team will discuss the treatment plan with you and take your wishes into account. They may also suggest you take part in a clinical trial, which is an opportunity to try a new drug or combination of drugs that may not be available otherwise. Go to **bloodcancer.org.uk/clinical-trials** to find out more.

You may need to change treatment if it stops working, causes too many side effects, or your circumstances change, such as wanting to start a family.

Try not to worry if your blood counts go up and down a bit – this is expected with ET. You'll have regular check-ups so your doctor can monitor your blood and adjust your treatment as needed.

Taking aspirin

Most people will start taking a low daily dose of aspirin when they're first diagnosed with ET. If your overall risk of blood clots is low, this may be the only treatment you need for the time being.

Aspirin works by making platelets less sticky. Lots of people who are at risk of heart attack and stroke take it, and it can be effective for people with ET. Some people can't take aspirin but there is an alternative called clopidogrel, which works in a similar way. For more information, go to bloodcancer.org.uk/et-treatment

It can be confusing to be told you have blood cancer but only need to take aspirin. Although aspirin is a type of treatment, you may find you have feelings in common with people who have other types of slow-growing blood cancer and are on "watch and wait". This means they have regular check-ups but no treatment. Read our information at bloodcancer.org.uk/watch-and-wait

People are so surprised I'm just on aspirin. In fact someone asked if there was a trial I could go on. But I will have another treatment if my platelets go up significantly.

Ed, living with ET since 2022



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Drugs that lower your platelet count

Depending on your risk of blood clots, your doctor may prescribe medicine to lower the number of platelets in your blood.

Any drug that interferes with cell growth is classed as a chemotherapy drug. So there may be standard warnings on the drug packaging, which may seem alarming. If you are worried about any drugs you are taking, talk to your doctor or nurse.

On the next pages, you'll find key facts about the main drug treatments that were approved for ET when this booklet was published. For more up-to-date information, go to our website bloodcancer.org.uk/et-treatment

If you don't use the internet, call us free on **0808 2080 888** and we'll print the information for you.

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The first time you put the pill on your tongue, you think, am I going to turn green or yellow? It's weird knowing that you're taking something toxic, but trust your doctor and try not to worry.

Gail, living with ET since 1991



Hydroxycarbamide

- Hydroxycarbamide is a capsule you can take at home.
- Most people with ET take a very low dose of hydroxycarbamide and have few side effects.
- It may increase the chance of developing acute myeloid leukaemia (AML) if it is taken over a long period of time.
- It may increase the risk of skin cancer, so follow standard sun safety advice.
- Taking hydroxycarbamide can affect your ability to have children.

Interferon

- Interferon is injected under the skin. You or someone who supports you at home can be shown how to do this. Or it can be given by your GP practice nurse or district nurse if you have difficulty.
- Some people become depressed while taking interferon. Tell your doctor if you notice any changes in your mood.
- Interferon shouldn't affect your ability to have a child and you can carry on taking it during pregnancy.

Anagrelide

- Anagrelide is taken as a capsule.
- It is usually recommended after you have tried at least one other treatment.
- Anagrelide may increase the chance of developing another MPN called myelofibrosis (MF).
- It may affect how babies develop in the womb so it is not safe to take during pregnancy.

Busulfan

- Busulfan is taken as a tablet.
- It is usually only used when other drugs have stopped working or aren't suitable for you and is mainly given to older people.
- Busulfan may increase the chance of developing acute myeloid leukaemia (AML) if it is taken over a long period of time.

Find out more online

For more detailed information about current treatments for ET, see our online information at **bloodcancer.org.uk/et-treatment**

If you don't use the internet, call us free on **0808 2080 888** and we'll print the information you need.

Treatment side effects

As with most drugs, there's a chance that treatment for ET can cause unwanted side effects. Some side effects are more common than others, but everyone reacts differently, even if they are taking the same drugs.

The important thing is to tell your doctor or nurse if you notice any changes in how you feel. There are medicines and self-help tips that can make a difference. Remember that side effects can be mental as well as physical so do tell your team if your mood changes, especially if you're taking interferon.

You'll find general information about some of the most common side effects of blood cancer treatment at **bloodcancer.org.uk/side-effects** but remember that you won't have all the side effects listed and may have none.

If you would like information about the side effects of a specific drug, MPN Voice has leaflets you can download or print from **mpnvoice.org.uk**

There's more information about taking care of yourself in the next chapter. You may also want to head to our online community forum at **bloodcancer.org.uk/our-forum**

People often find it helps just to talk about how you're feeling to someone else who's living with blood cancer. Though their experience may be different from yours, they will understand.

Sex and fertility

You must use a barrier method of contraception if you or a sexual partner are taking chemotherapy drugs. This is because they can be passed on to a partner through sex.

Eggs and sperm can also be affected by chemotherapy drugs so you must avoid getting pregnant.

If you take the combined contraceptive pill, it may add to your risk of blood clots if you have ET. So ask your GP about other options.

If you think you may want to start a family or have more children at some stage, you may be offered treatment with interferon as it's less likely to affect your fertility. Or you may have the option of fertility treatment such as freezing your eggs or sperm before you start treatment.

We have more information at [bloodcancer.org.uk/fertility](https://www.bloodcancer.org.uk/fertility)

Managing the menopause

Many women take hormone replacement therapy (HRT) to help with symptoms of the menopause.

HRT tablets may raise your risk of blood clots, so if this applies to you, talk to your hospital team or GP. There are other types of HRT you can use, such as patches or gels.

Regular tests and check-ups

You will have tests to monitor the ET and how your treatment is working. Your GP or specialist doctor (haematologist) will discuss the results with you at a regular check-up appointment. Some appointments are likely to be by phone or video call.

Your doctor will tell you how often you need check-ups. If your blood counts are stable over time, you may need them less often.

Full blood count (FBC)

This is a simple blood test which measures how many of each type of cell there is in your blood. This test will show whether your blood cell counts are within the normal range and in particular, whether your platelet count is higher or lower than before.

Checking your spleen

You may have a physical examination where your doctor feels (palpates) your spleen. The spleen is an organ where some of your blood cells are made, and it can sometimes become swollen and painful when you have ET.

If there are concerns about your spleen, you may have an ultrasound scan to check it, but you won't need this routinely. We have more information about ultrasound scans at [bloodcancer.org.uk/et-tests](https://www.bloodcancer.org.uk/et-tests)

Bone marrow biopsy

You won't have a bone marrow biopsy every time you have a check-up. You may need one from time to time to monitor your treatment.

A bone marrow biopsy is a minor surgical procedure done in hospital as a day patient, so you won't need to stay in overnight. It takes about half an hour in total, but removing the samples takes just a few minutes.

Bone marrow is the soft spongy tissues inside some of your bones where most of your blood cells are made. In a biopsy, samples are taken from the back of your pelvis (the ring of bones at the base of your spine). You'll be asked to curl up on your side to make this easier. You might need to change into a hospital gown.

You will have a local anaesthetic to numb the area where the needle goes in. The doctor will use one needle to draw some cells out of the bone marrow and a second needle to take a sample of bone marrow tissue (a core).

These samples will be examined under a microscope. The results usually take about one to two weeks to come through, although they can take longer, so check with your hospital team.

Does a bone marrow biopsy hurt?

People's experiences of having a bone marrow biopsy vary. Some find it painful, others just feel a pulling or pushing sensation which may be a bit uncomfortable.

There are things that can make having a bone marrow biopsy more comfortable:

- Take paracetamol before and after the biopsy.
- Ask your hospital team what other pain relief you can have – they may offer you gas and air or a sedative to make you sleepy.
- Make sure you wear comfortable, loose clothes as your back might be sore afterwards.
- If you can, ask someone to take you home afterwards.

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The thought was definitely worse than the actual procedure! I felt a little discomfort, some pressure and a tugging sensation but it was over quickly. I was back to my usual activities by the next day.

Anna, living with ET since 2021



Waiting for your test results

It's natural to think or worry about test results before you get them. Here are some tips for managing this:

- **Distract yourself** – Get engrossed in an activity you enjoy, something that's achievable but needs a bit of mental or physical effort, or both. This might be a DIY or craft project, an exercise programme, gardening or reading.
- **Unwind and relax** – If you find it difficult to concentrate, something that needs less effort might work better, like watching TV shows or films, reading magazines or chatting to friends about other things. Anything that will take your mind off your worries for a period of time will help.
- **Say your worries out loud** – You might prefer the more direct approach of talking through the possible outcomes of your test results and your feelings about them. Expressing your worries out loud can often help you manage them.
- **Try techniques for managing anxiety** – If you've experienced anxiety in the past, you may already know some self-help techniques you can use. If not, or you need a reminder about different things to try, you'll find a range of ideas at [bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)

Anxiety around waiting for test results is a common topic of conversation with our Support Service. Contact us if you want to talk things through.

Questions to ask about treatment and monitoring

- Why am I having this particular treatment?
- What are the common side effects?
- How will I know the treatment is working?
- How often will I need a check-up?
- Who will I see for my check-ups?
- Will I see someone face-to-face?
- What tests will I have and what are they for?
- Who do I contact if I'm worried in between check-ups?

For more information

Go to our website for more information about tests for ET: **bloodcancer.org.uk/et-tests**

We also have information about side effects at **bloodcancer.org.uk/side-effects** and fertility matters at **bloodcancer.org.uk/fertility**

Or call us free on **0808 2080 888**.

Looking after yourself with ET



Some people say that a slow-growing blood cancer like ET is as much a mental cancer as a physical one.

Getting any cancer diagnosis is likely to affect your mood. It's important to look after yourself mentally and physically and there are things you can do that will help.

Alongside general advice on healthier living, you'll find suggestions in this chapter about looking after your mental health. These are all things that people with blood cancer have found effective.

Of course, different things will work for different people, but you may find something here that you would like to try.

Exercise helps a lot. Until you get an injury you don't realise how important it is and what you miss. Just getting out in the morning. If I don't, I don't feel set up for the day.

Ed, living with ET since 2022



”

Looking after your mental health

There are small, simple things that you can do that that might make a big difference to your mental wellbeing.

Focus on the here and now

Focusing on the present can help if you feel overwhelmed. Try focusing on your breathing for a minute, or engaging your senses (listen to the sounds around you, feel the texture of something in your hands, or simply look at the objects around you and notice their shapes and colours).

Mindfulness exercises like this can help calm you, and you can do them anywhere. There are lots of mindfulness resources online, including some you will find at **[bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)**

Keep up your hobbies, or start a new one

Anything you enjoy and which keeps your mind occupied can give you a break and lift your mood. A hobby can be something you find relaxing, or something that motivates you. Getting engrossed in something that requires some mental or physical effort can help. Gardening, DIY, drawing or crafting can take you out of your head.

Have goals or a focus

Goals can keep you going, provide motivation, and help you feel positive. Setting goals can give you a sense of control over your life. So if you're having a bad day, focus on mini goals like going for a walk, calling a friend or planning a day out.

Practise balanced thinking

Sometimes, when we're under stress, our thoughts become unbalanced. We see things as all good or all bad. Or we focus on worst case scenarios.

This is understandable after a blood cancer diagnosis, and no one should put pressure on themselves to feel fine all the time. But balanced thinking can improve your mood.

If you have a negative thought, try to give it a more positive slant. For example:

- "If I feel there are things I can't control, I will concentrate on what I can control, like taking a walk every day."
- "I do get tired easily now, but if I pace myself I can still do the things I enjoy."

Talk to someone

Trying to keep things to yourself can add extra pressure and make things harder. Talking about worries can make them feel more normal and less scary.

If you prefer not to talk to friends and family, contact our Support Service and talk to us. Or visit our online community forum and find other people who will understand how you feel. You can be anonymous and don't even have to share your thoughts – it often helps just to read other people's. Go to **[bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum)**

Keep connecting with other people

While it's OK to say no when you don't feel like seeing people, it's also important not to withdraw too much. Seeing or talking to other people about things that are not related to blood cancer can really help to lift your mood.

Keep a diary or log

Record your goals, things you've achieved since you were diagnosed, things that have helped you, and how you're feeling each day. It can be helpful and motivating to look back at how far you've come.

Keep doing things that make you smile

Carry on as much as you can with the things you enjoy. If you have fatigue or side effects from your treatment you may need to make adjustments, but life doesn't have to stop because of ET.

“

I started writing a journal when I was first diagnosed, and I read it the other day, and I thought oh my gosh, I've really moved on. It was actually really interesting to see how far I've come.

Esther, living with ET since 2018



Living well with blood cancer

We have more information about how to make the most of life after a blood cancer diagnosis at [bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well), including personal stories from people who have learned what works for them.

Call us free on **0808 2080 888** if you don't use the internet.

Helping your family and friends

If you decide to tell family and friends about your diagnosis, you may find they are very worried about you. They will want to help, but may not know how.

If you're worried about how someone you know is taking your news, contact our Support Service team. We often talk to people about the impact their diagnosis is having on their family and friends. Or if you haven't told anyone yet but are planning to, we can help you prepare.

Here are some suggestions for ways to make sure your loved ones are OK, and life goes on as normally as possible.

Give them trustworthy information

Googling can cause unnecessary worry as things on the internet aren't necessarily true, balanced or up to date. So if people want to know more about ET, order free copies of this booklet from **bloodcancer.org.uk/our-booklets**

We also have information for family and friends about how they can support you, and look after themselves, at **bloodcancer.org.uk/friends-family**

Tell them where to find a listening ear

If your loved ones are finding it hard to understand or cope with your diagnosis, they are very welcome to call our Support Service to ask questions or just talk about how they feel.

Think of ways they can help

Family and friends often feel better if they have a role to play. So think about specific things people can do for you, so you're ready when people offer.

It's common to feel embarrassed about accepting help, but it's a positive thing to do for them, and for you – especially in the first weeks and months when you may be getting used to a new routine.

Suggest they support research

Some people won't be in a position to help you directly, perhaps because they live far away or have other commitments. But they can always help you and others by supporting research into better treatments. There are lots of ways to do this at [bloodcancer.org.uk/involved](https://www.bloodcancer.org.uk/involved)

It's a tricky time going through any kind of diagnosis. When I was waiting for my results, I don't think I slept. I wasn't eating properly. So you might need a bit of help and support.

Anna, living with ET since 2021



Looking after your physical health

Following general advice on healthier living will certainly improve your overall health and often your mood too.

Staying hydrated

Everyone should make sure they drink plenty of fluids, but it's particularly important if you have a high level of platelets.

The NHS recommends drinking 6 to 8 glasses of water, or other low fat and low sugar drinks, every day. This includes tea and coffee (as long as the milk is low fat and you don't add sugar).

Ask your hospital team how much fluid you should aim to drink each day.

Stopping smoking

ET increases your risk of blood clots, and so does smoking. So if you smoke, it's very important to stop, or at least cut down.

This may not be easy, but you can get help. Go to **[nhs.uk/better-health/quit-smoking](https://www.nhs.uk/better-health/quit-smoking)** for a range of ideas to help you stop smoking, or speak to your GP.

Managing fatigue (tiredness)

Fatigue is a feeling of extreme tiredness that can come on suddenly and leave you feeling completely drained. It's common in people with all types of blood cancer and can be a side effect of some treatments.

There are things that can help you manage fatigue:

- **Exercise can help** – It may seem like the last thing you want to do when you feel tired, but there's evidence that exercising can improve fatigue. Ask your doctor or nurse for advice and see our guidance on keeping active on the next page.
- **Balance activity and rest** – Plan time to rest in between activities or days out and learn what's doable for you. If you are working, think about adjusting your hours or building in breaks (see page 54).
- **Go easy on yourself** – If you need a rest day, make sure you have one. Fatigue isn't like normal tiredness, so don't think you're being lazy.

We have more information at [bloodcancer.org.uk/fatigue](https://www.bloodcancer.org.uk/fatigue)

Keeping active

Research suggests that being physically active can improve your fitness and strength, reduce fatigue and improve your mood. Many people with blood cancer agree.

- **Walking is good exercise** – If you haven't done much exercise recently, start with what you can easily manage and slowly build up.
- **Goals are motivating** – Set yourself goals and tick them off when they're done. Order a free activity planner from bloodcancer.org.uk/our-booklets or use an app like Habit Tracker or Done.
- **Do something you enjoy** – If you choose an activity you like, you're more likely to keep it up. If you want to try something new, check with your GP first.
- **Make it social** – This usually helps people stick to their plans. Find an exercise buddy (your partner, a friend, a neighbour) and follow a plan together.
- **Get tips from other people with blood cancer** – Join our online community forum and find out how other people with blood cancer are staying active.
- **Don't push yourself too hard** – Just do a little more each time to build up your stamina.

Go to bloodcancer.org.uk/keeping-active for more ideas.

Eating well

Eating well is important, as it will give you the nutrients and energy you need to stay healthy. Here are some general tips to bear in mind:

- **No diet, supplement or “super food” can cure cancer** – in fact, cutting out too many foods could mean you’re not getting everything you need.
- **It’s best to follow a healthy, balanced diet** – Ask your hospital team or GP if there’s anything specific you need to eat more or less of.
- **You need carbohydrates** – Wholewheat pasta, wholegrain bread or potatoes with skin on will release energy through the day. Carbs should make up around a third of a meal.
- **Eat lots of fruit and veg** – They’re packed with vitamins, minerals, and are a good source of fibre. Boost your intake by adding extra vegetables into sauces.
- **Protein helps your body grow and repair** – Try beans, peas, lentils, fish, meat, dairy, eggs and vegetarian and vegan alternatives such as Quorn or tofu.
- **Iron is vital for energy** – You can get iron from beans, nuts, dried fruit, wholegrains and dark-green leafy vegetables as well as meat.

We have tips for making cooking and eating easier if you’re tired at [bloodcancer.org.uk/eating-well](https://www.bloodcancer.org.uk/eating-well)

Managing your daily life

Working with ET

If you are working or studying when you are diagnosed with any type of blood cancer, you should know:

- **You're protected** – Everyone with a cancer diagnosis is entitled to support, whatever treatment they're on.
- **You have rights** – Cancer is classed as a disability in UK law, so you are protected against discrimination.

If you're worried about going to work because of the risk of infection, or you are finding it hard to do your job, your employer has to consider "reasonable adjustments" to help you stay in work. Examples include:

- having time off for medical appointments
- taking more breaks
- changing your duties or hours to help you manage fatigue
- changing your hours so you can travel when it's quieter
- supporting you to work from home.

Contact our Support Service for help talking to your employer about managing at work. We also have a fact sheet about blood cancer you can share with your employer. You can order or download it for free from bloodcancer.org.uk/our-booklets or give us a call.



Esther

What's it like working with ET?

"I've found that adding breaks, recognising when is not a great time for meetings, making sure I'm not wall-to-wall with meetings or events can all go some way to helping me manage fatigue. If I'm facing deadlines or big projects, I'll automatically build in some leave after them."

Read Esther's story at bloodcancer.org.uk/esther or call us and we'll post you a copy.

Help with money

If you're worried about money, make sure you get the financial support you're entitled to:

- **Benefits** – Whether you're in or out of work, if you're on a low income, you may be able to claim benefits like Universal Credit, Employment and Support Allowance (ESA), or Personal Independence Payment (PIP) – or Attendance Allowance if you're state pension age.
- **Sick pay** – If your GP or hospital team believe you're not able to work because of ET or any other illness, they can give you a fit note (previously called a sick note) which gives you access to your company's sick leave policy and pay, or Statutory Sick Pay (SSP).

Ways to save money on health costs

- **Parking** – At all hospitals in Wales and most hospitals in Scotland parking is free. In England and Northern Ireland, some hospitals offer free parking to people with cancer in certain circumstances – check with your hospital.
- **Prescriptions** – These are free in Scotland, Wales and Northern Ireland. In England, they are free if you have cancer. If you live in England, ask your GP for an exemption certificate.
- **Travel to hospital** – If you have a low income, or get certain benefits, you may be able to get refunds for your travel to hospital. Speak to your doctor or nurse to find out more.

Help paying bills

Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer. Get help from Citizens Advice at **citizensadvice.org.uk**

Do you have insurance?

Could you make a claim on income protection insurance or critical illness cover? Contact your insurance provider to find out.

Financial help from charities

Some charities offer grants that you don't have to pay back. Call us on **0808 2080 888** to find out which organisations might be able to help you.

Who else can help?

Ask your GP, doctor or nurse about financial help or ask a family member or friend to research it online.

The government website MoneyHelper offers free webchat, WhatsApp and phone advice on all money matters at **moneyhelper.org.uk**

You could also call Macmillan Cancer Support on **0808 808 00 00**.

You can read our online information about work and money matters at **bloodcancer.org.uk/money-work**

Places to get support

Blood Cancer UK Support Service

We can talk to you about anything that's on your mind, or even if you just fancy a chat with someone.

People contact us about:

- understanding their condition
- treatment
- living with blood cancer
- impact on family and friends
- work issues
- mental health
- how they're feeling.

Call our confidential support line free on **0808 2080 888** or email **support@bloodcancer.org.uk**

Blood Cancer UK website

Our website has more information about ET and blood cancer in general, plus regular news articles and stories from people affected by blood cancer. Explore **bloodcancer.org.uk**

Blood Cancer UK publications

If you prefer your information in printed form, browse our booklets about conditions, watch and wait, treatment and side effects and living with blood cancer. Go to **bloodcancer.org.uk/our-booklets**

Blood Cancer UK online community forum

Talking to other people with blood cancer helps. They understand and will have tips from their own experience. You can ask questions, or just read other people's posts. You don't have to create an account and you can remain anonymous. Visit bloodcancer.org.uk/our-forum

Other support groups

- Ask your hospital or GP what support groups are available in your area.
- Enter your postcode on the NHS website and find support groups near you: www.nhs.uk/service-search/other-services/cancer-information-and-support/LocationSearch/320
- Contact Blood Cancer UK on **0808 2080 888** to see if we have a branch in your area. Our branches are for fundraising and volunteering, but you might find that it helps to do things with other people affected by blood cancer.
- MPN Voice runs a buddy programme where you can ask questions and get support from someone else with an MPN by email or phone. To find out more, visit mpnvoice.org.uk/get-involved/buddy-programme

Counselling services

Many people find talking to a trained counsellor helps them come to terms with difficult emotions or life changes.

NHS counselling

- Ask your hospital team how you can access counselling. Some hospitals offer this themselves.
- Tell your GP you want counselling.
- Refer yourself online. In England, go to **nhs.uk/service-search/find-a-psychological-therapies-service** and in Scotland **breathingspace.scot/living-life**. In Wales and Northern Ireland, you will need to go through your GP.

Private counselling

Find a qualified counsellor anywhere in the UK at **BACP.co.uk** or call them on **01455 883300**.

Local cancer support centres

Cancer support centres such as Maggie's offer different types of emotional and psychological support for people diagnosed with any type of cancer and their families.

Visit **maggies.org** or ask your hospital team about cancer support centres in your area.

Social media

Some people find support in Facebook groups or other social media platforms.

- Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter (X).
- Search online or on Facebook for ET or MPN support groups.

Travel advice

People often wonder if they can still travel and get travel insurance once they're diagnosed with ET.

- You can call our Support Service on **0808 2080 888** to talk through your plans and where to get more information about travel insurance.
- We've partnered with Staysure to make travel insurance easier to access for people with blood cancer:
bloodcancer.org.uk/get-involved/travel-insurance-with-staysure
- MoneyHelper has information on travel insurance for people with cancer and other health conditions:
moneyhelper.org.uk/en/everyday-money/insurance/travel-insurance-if-you-have-a-medical-condition

Useful publications

Printed resources

- **Your blood cancer diagnosis: what happens now?**
- **Watch and wait fact sheets**
- **If your employee or colleague has blood cancer**
- **Eating well with neutropenia**
- **Acute myeloid leukaemia (AML)**

Order free copies at bloodcancer.org.uk/our-booklets or call us free on **0808 2080 888**.

Online resources

- further information about ET:
bloodcancer.org.uk/et
- key things to know after your diagnosis:
bloodcancer.org.uk/newly-diagnosed
- living well with blood cancer:
bloodcancer.org.uk/living-well
- blood cancer and infection risk:
bloodcancer.org.uk/infection
- current blood cancer research:
bloodcancer.org.uk/researching
- support and advice for friends and family:
bloodcancer.org.uk/friends-family
- ways to get involved with Blood Cancer UK:
bloodcancer.org.uk/involved

If you don't have internet access, call our Support Service free on **0808 2080 888**.

Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



bloodcancer.org.uk



0808 2080 888 (calls are free and confidential)



support@bloodcancer.org.uk



bloodcancer.org.uk/our-forum



Blood Cancer UK



@bloodcancer_uk



@bloodcancer_uk



Blood Cancer UK

Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Anna, Ed, Esther, Gail and everyone who gave their insights into what it's like to live with ET. To Dr Mallika Sekhar and Dr Clare Kane for checking the medical content and to Clinical Nurse Specialist Jodie Nightingill and Advanced Clinical Practitioner Maddie Ward for their invaluable advice and support.

A list of references used in this booklet is available on request. Please email information@bloodcancer.org.uk

Disclaimer

We make every effort to ensure that the information in this booklet is accurate, but you should always seek advice from your doctor if you have any concerns or questions about your health. As far as applicable by law, Blood Cancer UK cannot accept responsibility for any loss or damage resulting from any inaccuracy in this information, or in external information that we link to.

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Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at bloodcancer.org.uk

Or call us free on **0808 2080 888**



The information in this booklet was correct at the time it was printed (September 2023). Date of next full review: September 2026.

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