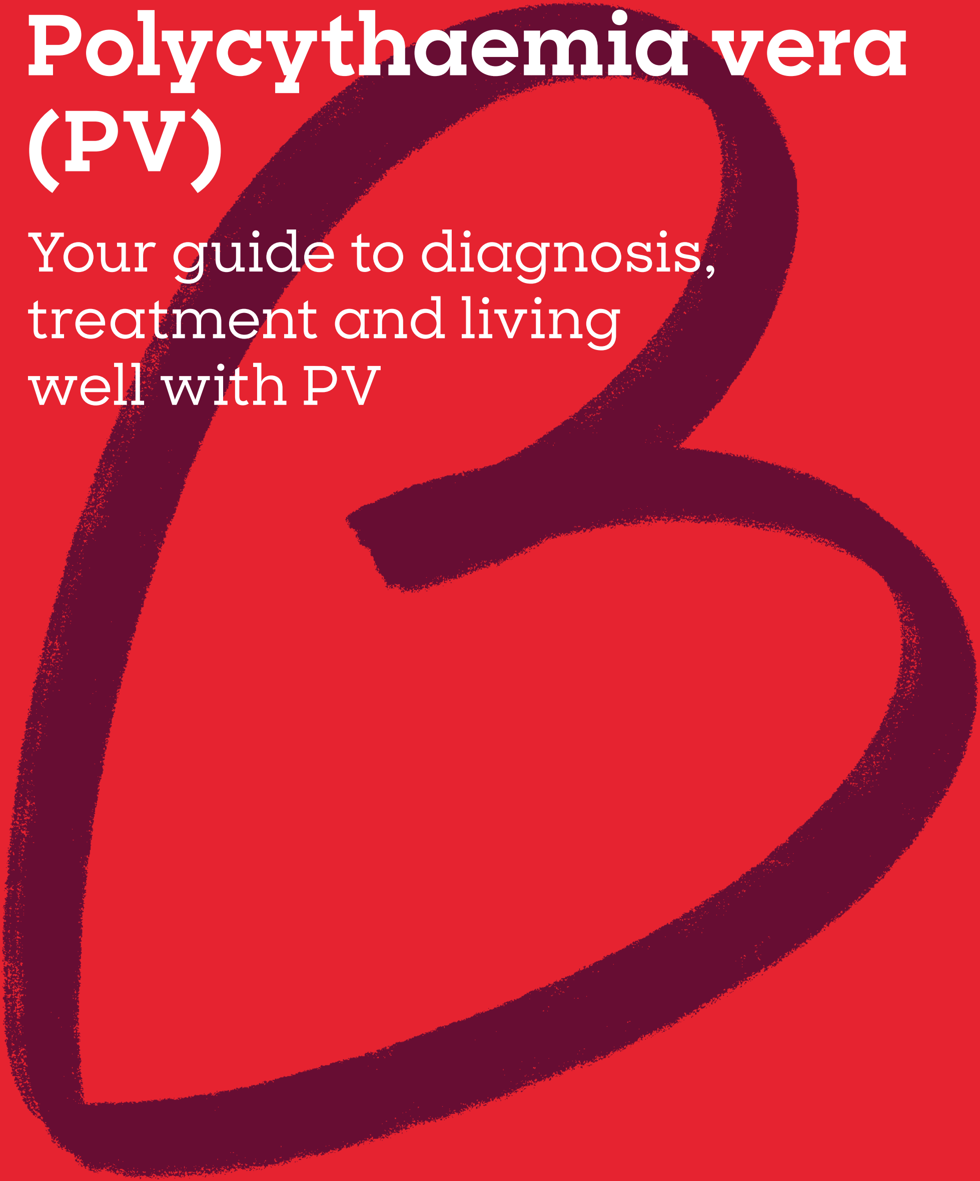
Polycythaemia vera (PV)

Your guide to diagnosis, treatment and living well with PV



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 **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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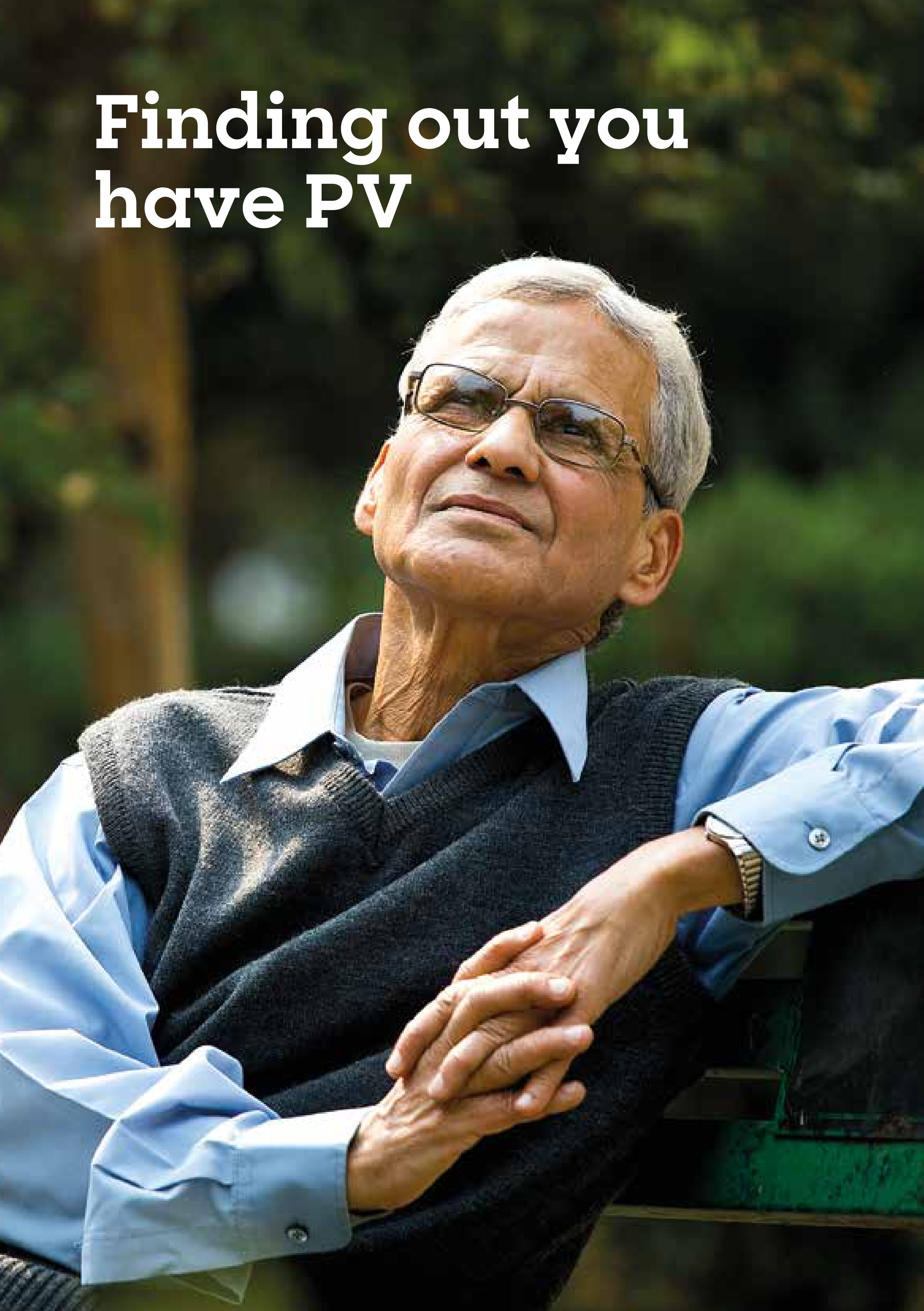


If you've just been told you have PV, you may be finding there's a lot to take in.

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

We have written it with people who know what it's like to live with PV. So as well as including medical information, it includes stories and advice about how people get used to their new situation. PV can be treated and most people find that with a few adjustments, they can get on with their lives.

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**

> **It's not a death sentence. There is treatment. And for me, the treatment has not been a problem at all. It doesn't affect my life very much. I just have to take the tablets every day.**
> Jacqui, living with PV since 2021

Is PV blood cancer?

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

In PV, your body starts to make too many red blood cells. 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:

- PV is a slow-growing blood cancer.
- PV 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 PV is. See "Understanding PV" starting on page 15.

> **Most people think cancer is about lumps and tumours. I thought, where's my lump? Where's my thing that needs to get removed? That's what probably scared me most.**
>
> Vij, living with PV
> since 2020

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 PV. 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 as well as your physical health.

Others have a different view. They felt relieved that doctors have 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 around 250,000 people living with blood cancer in the UK and over 8,000 have PV. 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 PV 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/pv-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.

PV 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 on **0808 2080 888** 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 want to talk about what your diagnosis means, how you're feeling or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you've just been diagnosed with PV.

Or talk to people who've been where you are now on our online community forum: **bloodcancer.org.uk/our-forum**

Telling people about your diagnosis

It's your choice whether you tell people about your PV diagnosis. Some people are open about it and others prefer to tell only a few people, or no one at all. Most people continue to look quite well and don't need to spend time in hospital. So not telling people can be an option when you have PV.

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 PV so this booklet may help you explain what PV means for you, and for them.

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. PV 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 56 for more information about working with PV.

Questions to ask after your diagnosis

It can be hard to know what questions to ask your hospital team, so here are some suggestions.

- 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 PV affect my life?
- You mentioned [any medical term]. What does that mean?

Jacqui

How do people react when you tell them about your diagnosis?

“They’re a bit shocked when I tell them I have blood cancer, but then they very quickly get over it because I seem to be perfectly normal. So I don’t get any special treatment from anyone!“

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

Understanding PV

Many people say that learning about what PV is, and how it can affect them, helps them feel more in control.

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 PV 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 PV is and the effect it has on your health. You'll find more information at **bloodcancer.org.uk/pv**, or If you don't use the internet, call us and we will send you a printed copy.

> **By the time I heard about PV being cancer, it was clear that it isn't life threatening. Yes, it's blood cancer, but only technically, because cells are not doing what they should be doing.**
> Jeremy, living with PV since 2018

How does PV affect me?

There are three main types of blood cell:

- **Red blood cells** carry oxygen around your body.
- **White blood cells** help your body fight infection.
- **Platelets** stick together to stop you bleeding.

When you have PV, your body makes too many red blood cells. You may also have higher numbers of white blood cells and platelets. This makes your blood thicker than normal and means you have a higher risk of developing blood clots.

Risk of blood clots

Blood clots can lead to a range of problems, which may be life-threatening:

- In the brain, clots can cause stroke or mini stroke (a TIA).

- In the eyes, clots can cause blurred vision or loss of sight.

- In the heart, they can cause chest pain (angina) or a heart attack.

- In the stomach area (abdomen), they can cause damage to organs such as your liver or gut.

- In the legs, they can cause deep vein thrombosis (DVT).

- In the lungs they can cause chest pain and difficulty breathing. Clots in the lungs can be related to DVT.

What to look out for

The symptoms of a blood clot will vary depending on where it is. 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

PV can also cause a higher risk of unusual bleeding (haemorrhage). This can happen if you have too many platelets in your blood, as well as too many red blood cells.

Keeping your blood cell counts in the normal range will lower your risk of bleeding. Your hospital team will monitor your blood test results and adjust your treatment if needed.

It's important to be aware of the risk of blood clots and bleeding, and what the signs are. But your hospital team and GP will do everything they can to help lower these risks.

Your risk of blood clots or bleeding

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

- your age
- whether you have had problems with blood clots or bleeding before
- other medical conditions you may have
- your blood counts – the number of red cells, white cells and 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, high cholesterol or diabetes), these will need to be managed effectively. This might mean reviewing the medicines you're already taking. Your GP will play an important role checking your general health regularly.

Your doctors might also advise you to follow general advice on healthy eating and exercise. See pages 52 to 53 for more information.

> **My blood gets too thick and that can cause a stroke or heart attack. So I feel like it saved my life really, being diagnosed with this.**
> Alex, living with PV
> since 2019

Your risk of infection

Having PV 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. Check with your GP which vaccinations you should have if you're not sure.

It's also a good idea to follow standard hygiene and food safety advice. See **bloodcancer.org.uk/managing-infection** for general guidance about managing your risk of infection or contact us.

Genetic changes in PV

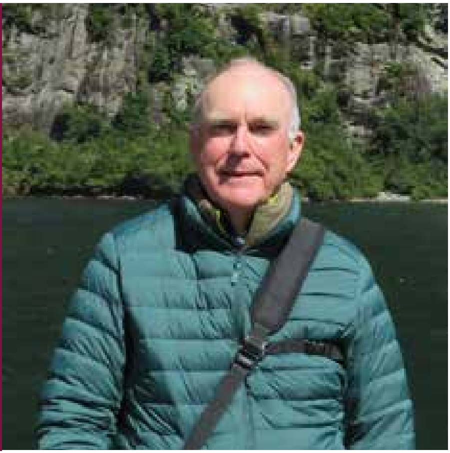
PV starts with a genetic change (a mutation) that causes over-production of red blood cells.

Genes are like a set of instructions that tell your cells how to behave, including how to divide to make new cells. Sometimes there's a copying mistake as the cell divides and that causes a mutation.

We don't know why genetic mutations happen, but we know over 95% of people (95 out of a hundred) have a gene mutation known as JAK2 V617F. Most other people have a mutation called JAK2 exon 12.

A few people with PV have no JAK2 mutation. 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 your blood test results.

> **So I immediately thought, are other members of my family going to be affected by it? They said no, it's not an inherited thing. It's something that happens spontaneously, and nobody really knows why.**
> Jeremy, living with PV since 2018



What does the future look like?

Although treatment can't cure PV, it aims to manage the problems PV can cause, such as heart attacks and strokes.

Many people say that they expected the worst when they were told they had a type of blood cancer, but in time they realised that PV was something they could live with.

You may find you need to pace yourself and make a few changes to your routine. There's more information about managing the effects of PV and looking after yourself on page 43.

The risk of developing another blood cancer

In a few cases, PV can develop into another MPN called myelofibrosis (MF), or a type of leukaemia called acute myeloid leukaemia (AML).

The chance of this happening is very low. But it's not something that's easy to hear and it's understandable if it makes you feel anxious.

Talk to your hospital team if you are worried about the future. If you think you would benefit from counselling or other psychological support, they can refer you. Or you can refer yourself – see page 61 to find out how.

Our online community forum is also a good place to find emotional support and understanding. Take a look at the conversations at **bloodcancer.org.uk/our-forum**

Research and clinical trials

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

If you need treatment for PV or any other blood cancer, 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**.

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:

- What's my risk of blood clots or bleeding?
- Do I have a JAK2 genetic mutation?
- If I don't have JAK2, what does this mean for my prognosis?
- How does my age affect my prognosis?
- How will having PV affect how I live my life?
- Who can I talk to about my feelings?

More information

To find out more about research developments which will help doctors treat and cure blood cancer, go to **bloodcancer.org.uk/researching**

For more information about clinical trials to find new, kinder treatments for people with blood cancer, visit **bloodcancer.org.uk/clinical-trials**

Treatment and monitoring for PV

Treatment can't cure the PV, but it can manage the symptoms and give you a good quality of life.

Treatment for PV 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 PV. If you're not sure why you're being offered a particular treatment, it's OK to ask your doctor to explain.

Treatment often 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 PV at the time the booklet was published. For the most up-to-date information about PV treatments, go to **bloodcancer.org.uk/pv-treatment** or call us.

> **It's now under control. They just keep an eye on it every few months with blood tests and tweak the medication level slightly. It's very subtle changes, but it has a noticeable effect.**
> Jeremy, living with PV since 2018

Decisions about your treatment

Your doctor will recommend a treatment based on:

- your age
- your haematocrit and other test results (see page 37)
- whether you have other conditions like high blood pressure or diabetes that raise your risk of blood clots.

Your age is relevant because some treatments are better than others for people at a certain life stage.

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.

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. We have more information at **bloodcancer.org.uk/clinical-trials**

You may need to change treatment if it stops working, causes too many side effects, or your personal circumstances change, such as wanting to start a family. It's common to stay on the same treatment for many years, although the dose may go up and down. You'll have regular check-ups so your doctor can monitor your blood.

Taking aspirin

Most people will start taking a low daily dose of aspirin when they're first diagnosed with PV. 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 PV. Some people can't take aspirin but there is an alternative called clopidogrel, which works in a similar way. To find out more, go to **bloodcancer.org.uk/pv-treatment**

It can be confusing to be told you have blood cancer but only need to take aspirin. Many people with blood cancer are in a similar situation. They are on "watch and wait" which means they have regular check-ups but no treatment.

Although aspirin is treatment, you may find you have feelings in common with people on watch and wait. Read our information at **bloodcancer.org.uk/watch-and-wait**

Venesection

Venesection aims to reduce the thickness of your blood. It’s a simple procedure that’s similar to giving blood, although the blood taken can't be used.

What happens when you have venesection?

You will have venesection in hospital as a day patient. A doctor or nurse will insert a needle into a vein in your arm and slowly draw the blood out. The amount they take will depend on your size and the thickness of your blood, based on your blood test results.

After the blood is taken, your body quickly replaces the white blood cells, platelets and the liquid part of your blood (the plasma). But because it takes longer to make red blood cells, it takes a while for your blood to become too thick again. When that happens, you will have another venesection.

Usually, you’ll need venesection more often when you start the treatment, but you may need it less often over time.

Alex

What advice would you give to someone who needs venesection?

“Don’t watch the needle go in. Make sure you eat properly beforehand. And make sure you drink lots of water. The process only takes 15 to 20 minutes. They stick a bit of gauze over the wound, take my blood pressure and give me a biscuit before I go on my way.”

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

Treatment to control your blood cell counts

Some drug treatments for PV aim to keep the number of red blood cells in your blood at a stable, low level. Doctors call this cytoreduction or talk about cytroeductive drugs – this just means drugs that reduce the number of cells.

Cytoreduction is usually recommended for:

- people over 60
- people who have previously had blood clots
- people with another condition that increases the risk of blood clots, for example, high blood pressure, diabetes or heart disease
- people with more serious symptoms of PV
- people whose blood cell counts can't be controlled with venesection alone.

You're likely to take aspirin alongside cytoreductive drugs. You may have venesection as well if needed. See page 28.

The next two pages give you more information about the most commonly used drugs used to control your blood cell counts when you have PV.

Find out more online

For more detailed information about current treatments for PV go to **bloodcancer.org.uk/pv-treatment**

If you don’t use the internet, call us free on **0808 2080 888**.

You will find support from people with PV and other blood cancers on our online community forum: **bloodcancer.org.uk/our-forum**

Hydroxycarbamide

- Hydroxycarbamide is a capsule you can take at home.

- Most people take a very low dose of hydroxycarbamide and have few side effects.

- It is classed as a type of chemotherapy, so there may be warnings on the drug packaging that seem alarming if you’re not expecting to see them.

- 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.

- 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 women can carry on taking it during pregnancy.

Ruxolitinib

- Ruxolitinib is taken as a tablet at home.
- It is a targeted drug called a JAK2 inhibitor. For many people it causes few side effects.
- It is usually recommended if hydroxycarbamide does not control the PV, stops working after a time, or causes severe side effects. At the time of printing, it is not approved for use in all nations of the UK. For up-to-date information, go to **bloodcancer.org.uk/pv-treatment**.
- If you're taking ruxolitinib you must avoid foods containing grapefruit and Seville oranges (including their juices) as these can affect how the drug works.

Busulfan

- Busulfan is taken as a tablet at home. It is classed as a type of chemotherapy.
- It is usually only used when other drugs have stopped working or aren't suitable for you, and is mainly given to older people as it can affect your ability to have children.
- Busulfan increases the chance of developing acute myeloid leukaemia (AML) if it is taken over a long period of time.

Treatment side effects

As with most drugs, there's a chance that treatment for PV 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 to know is that there are medicines and self-help tips that can make a difference. Side effects can be mental as well as physical so do tell your hospital team if your mood changes, especially if you're taking interferon.

There's information about managing your mental and physical health in the next chapter. But always speak to your hospital team if you notice anything new, or something you've noticed before becomes more of a problem.

You'll find general information about common side effects at **bloodcancer.org.uk/side-effects** but remember that you won't have all the possible side effects and may have none.

> **I found out about the online community forum, and that's when I felt a lot better – speaking to someone with PV is really, really helpful. And puts your mind at ease.**
> Vij, living with PV since 2020

Sex and fertility

You must use a barrier method of contraception if you or a sexual partner are taking chemotherapy drugs such as hydroxycarbamide or busulfan. 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 PV. Ask your GP or contraception clinic 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.

You may have the option of fertility treatment such as freezing your eggs or sperm before you start treatment for PV, but fertility treatments themselves can raise your risk of blood clots, so speak to your hospital team about this.

We have more information at **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.

Your check-up appointments

You will have tests to monitor the PV and check how your treatment is working. Your doctor will discuss the results with you at a regular 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.

A few days before your check-up appointment, you will have a blood test called a full blood count or FBC. It's OK to ask your hospital team or GP to go through the results and explain what the figures mean.

The full blood count will measure:

- your haemoglobin level – the substance in red blood cells that carries oxygen around the body (Hb)
- your haematocrit – the proportion of red blood cells in your blood (Hct)
- the overall number of white blood cells in your blood (WCC or WBC)
- the number of platelets in your blood (Plt)
- the number of white blood cells called neutrophils in your blood (Neut)

The words in brackets are what you may see written on your test results.

Some people like to keep their own record of their results as it gives them a feeling of control. They can see for themselves whether there is a change in their results over time. So you might want to have a pen and paper or your phone handy to note down your blood results and anything else the doctor or nurse has to say.

> **I'm just trying to remain positive and embrace change, and I'm always looking to do something extra like raising money for research.**
> Alex, living with PV
> since 2019

Bone marrow biopsy

If your blood tests show that things are changing or you have new symptoms, your doctor may want to take a bone marrow biopsy. This is not a routine test and you won’t have it done regularly.

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 tissue 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 may take longer. Check with your doctor or nurse how long you are likely to wait.

People’s experiences of having a bone marrow biopsy vary. Some people feel a pulling or pushing sensation which may be uncomfortable. Others find it painful even with local anaesthetic.

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

- Take paracetamol before and after the biopsy.
- Make sure you wear comfortable, loose clothes so nothing presses on the sore area.
- 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.
- If you can, ask someone to take you home afterwards in case your back is sore.

> **I had a really nice nurse who stood beside me and talked nonstop. That made me forget about what was going on really, and it was OK, slightly uncomfortable.**
> Jacqui, living with PV
> since 2021

Waiting for your test results

Waiting times for test results can vary. Ask your doctor or nurse when the results are likely to come in. If you don't hear by that time, it’s perfectly OK to contact them.

It’s natural to worry while you're waiting for test results. 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 and your feelings about them. Expressing your worries out loud can often help you manage them. You can call our Support Service on **0808 2080 888** or find others in a similar situation on our online community forum.

- **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**

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?

Looking after yourself with PV

Many people with a PV diagnosis want to know if there is anything they can do to help themselves.

Using self-help strategies can give you a sense of control, especially if your diagnosis has come as a shock. There's an emotional side to blood cancer as well as a physical side, so it's important to consider your mental health alongside your physical wellbeing.

In this chapter, you'll find general advice on healthy living and suggestions about looking after yourself mentally as well as physically. Many of these are things other people with blood cancer have found helpful.

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

> **I've got two names for it: polycythaemia vera, for when I'm feeling OK, and blood cancer when I'm feeling bad. For me, it's been more mental than physical.**
> Vij, living with PV since 2020

Looking after your mental health

There are small things 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 videos to show you what to do at **bloodcancer.org.uk/mind-emotions**

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 your health can really help to lift your mood.

Keep up your hobbies, or start a new one

Anything you enjoy and which keeps your mind occupied can give you a break from worry.

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.

So 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 more easily now, but if I pace myself I can still do the things I enjoy."

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.

Talk to someone

Trying to keep things to yourself can add extra pressure and make things harder. Talking about things can make them feel more normal and less scary, even when that thing is blood cancer.

If you prefer not to talk to friends and family, contact our Support Service and talk to us. Or visit our online community forum (**bloodcancer.org.uk/our-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.

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 PV.

Vij

What has helped you look after your mental health?

“I discovered the Blood Cancer UK online community forum and spoke to others going through something similar, if not the same, as me. Communicating with people who just got things, and were incredibly knowledgeable through their own experiences (good and bad), helped me so much.”

Read Vij’s story at **bloodcancer.org.uk/vij-pv** or call us and we’ll post you a copy.

Supporting 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 concerned about how someone you know is taking your news, talk to 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 PV, 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**

Looking after your physical health

Following general advice on healthier living will certainly help 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 PV.

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 to advise you how much fluid you should aim to drink each day.

Stopping smoking

PV 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** 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 56).

- **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**

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 walking 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 to 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.

High iron levels can make PV harder to control, so check with your hospital team before taking iron supplements or eating foods that are rich in iron (such as liver).

We have more tips for making cooking and eating easier if you’re tired at **bloodcancer.org.uk/eating-well**

Managing itching

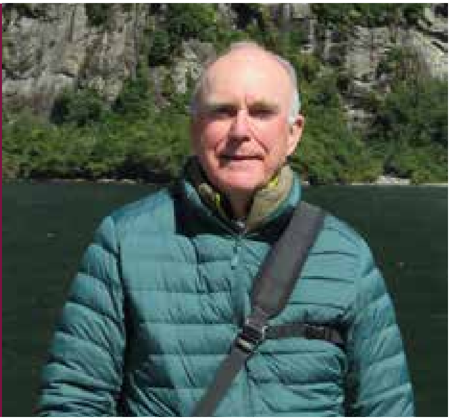
Itching is a common effect of PV. It can come and go, and can range from mild to very severe. There's usually nothing visible on the skin. Many people find the itching is worse after a shower or a bath.

Talk to your hospital team as they can prescribe medicines and skin creams that may help. You can also try some self-help tips, suggested by other people with PV:

- Lower the temperature of your shower so it's luke warm.
- Follow a hot shower with a cold shower.
- Pat yourself dry gently rather than rubbing.
- If the itching flares up, switch to a sponge wash for a while.

Visit **bloodcancer.org.uk/our-forum** to connect with other people and find out what works for them.

> **For a long time, I found that when my skin got wet, I had very intense itching. Now, if I have a hot shower, I finish off with cold water – as cold as I can stand it – and then it's fine.**
>
> Jeremy, living with PV 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**, including personal stories from people who have learned what helps from experience.

Call us free on **0808 2080 888** if you don‘t use the internet.

Managing your daily life

Working with PV

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.

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). You may be eligible for 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 PV 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?

If you have income protection insurance or critical illness cover, contact your provider to see if you can make a claim.

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. Call us 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 PV 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 883 300**.

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 PV or MPN support groups.

Travel advice

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

- 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 PV: **bloodcancer.org.uk/pv**
- 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. Thanks to Alex, Jacqui, Jeremy, Vij and everyone who gave us their insights into what it's like to live with PV. 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

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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**

Blood
cancer
UK

Trusted
Information
Creator

Patient Information Forum

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