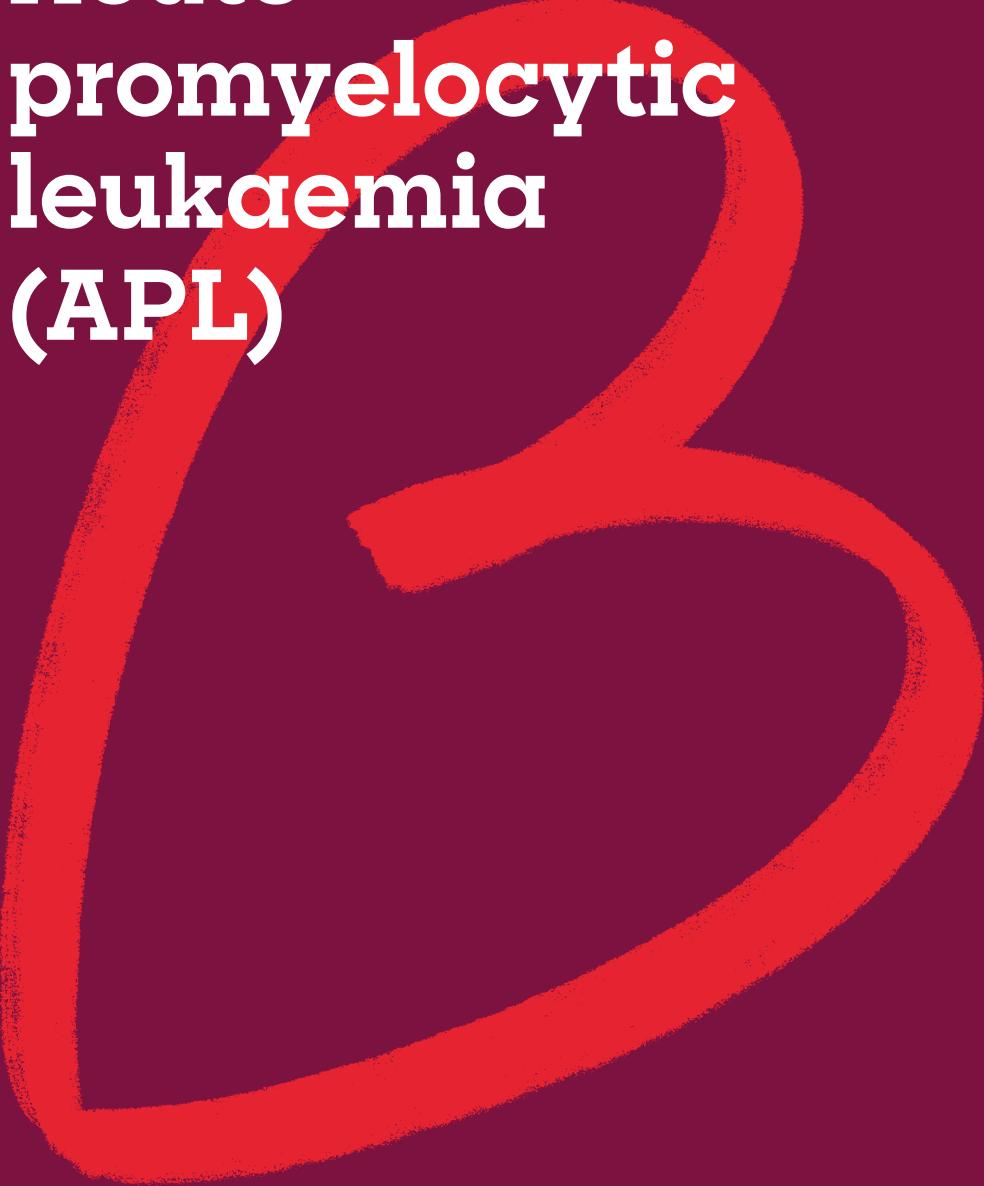


Acute promyelocytic leukaemia (APL)



Blood
cancer
UK

About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Consultant Haematologists Dr Richard Dillon, Dr Steven Knapper and Professor David Grimwade; and Research Nurse Anita Immanuel for their support checking the content of this booklet.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 113.

[bloodcancer.org.uk](https://www.bloodcancer.org.uk)

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

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

Disclaimer

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this booklet is correct at the time it was printed (November 2019)

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Introduction

This is a booklet for people with acute promyelocytic leukaemia (APL), and for their family and friends.

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you'll ever have to hear.

There's sure to be a lot of information to take in at this time.

We hope this booklet will help you to understand your condition and feel in control. We'll cover the key aspects of diagnosis and care along the way, including symptoms, tests, treatment, living with APL, and where you can get support.

Our Support Services Team offers practical and emotional support for anyone affected by blood cancer. Contact us on **0808 2080 888** or email **support@bloodcancer.org.uk**





Every person is different, with a different medical history. So when you're deciding what's right for you, always talk to your specialist as well as getting information from this booklet and other trustworthy places.

Acute promyelocytic leukaemia (APL) at a glance

Most people will respond well to treatment for APL and will go into remission (where there's no sign of leukaemia cells).

What is APL?

Leukaemia is a type of blood cancer that affects your white blood cells. APL is a type of leukaemia (and a subtype of acute myeloid leukaemia, also known as 'AML') that occurs when there is damage to a particular gene (called retinoic acid receptor alpha or 'RARA').

This change means that white blood cells called promyelocytes don't mature properly and become cancerous. These cancerous cells don't work as they should and take up space in the bone marrow and blood, leaving less room for healthy cells.

Who gets APL?

APL is more common in adults than children and is equally common in men and women.

What's the outlook?

The outlook for people with APL is generally very good, and much better than for many other types of blood cancer. Most people will respond well to treatment and will go into remission.

What are the treatments for APL?

Treatment for APL aims to get rid of the leukaemia cells, allow healthy cells to grow back, and reduce the risk of relapse (the leukaemia coming back).

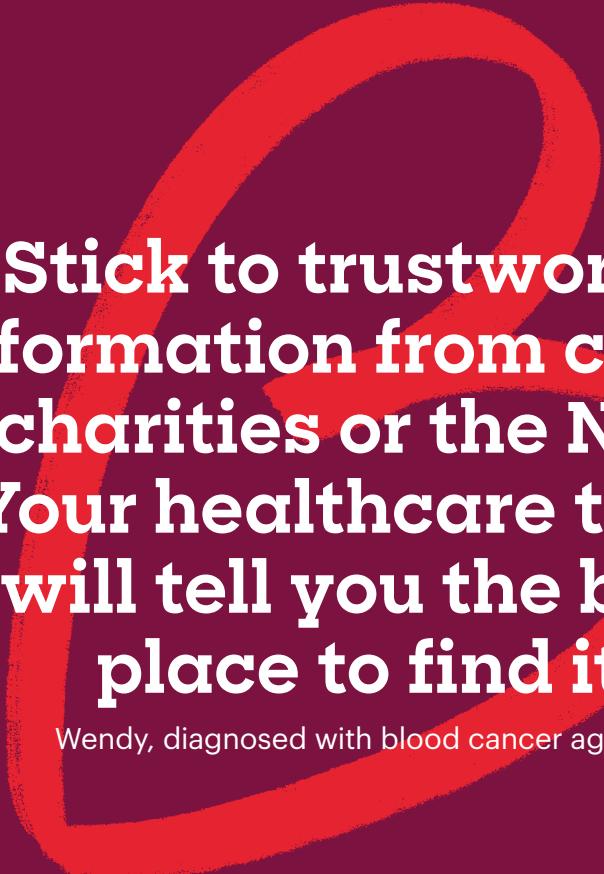
Everyone diagnosed with APL will receive a drug called 'all-trans retinoic acid' (ATRA), given in tablet form, as part of their treatment. Most people take these tablets in combination with a second drug called arsenic trioxide, which is given through a drip (intravenously). Some people are given chemotherapy instead of arsenic trioxide.

If you do relapse, you may need further treatment with different drugs. You may also need a stem cell transplant as part of this treatment.

There are no big differences in the way that APL is treated in adults and children, so the information in this booklet is relevant to adults, young people and parents of children with APL.

You can find out more about AML in our **Acute myeloid leukaemia (AML)** booklet. To find out how to order or download a copy, see **page 111**.





**Stick to trustworthy
information from cancer
charities or the NHS.
Your healthcare team
will tell you the best
place to find it.**

Wendy, diagnosed with blood cancer aged 46

**Knowing the basics about
blood, bone marrow and
your immune system
is useful.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Blood, bone marrow and your immune system

You might find it helpful to know a bit about your blood, bone marrow and immune system, as your healthcare team will talk to you about them.

Blood cells

Your body is made up of trillions of tiny building blocks called cells. Your blood contains three types of cell: red blood cells, white blood cells and platelets. Each type has several different jobs to do. You'll learn all the terms below as your treatment goes on. Your healthcare team will talk to you about them regularly too.

Red blood cells

These contain a protein called haemoglobin, which carries oxygen to all the tissues in your body. Muscles and other tissues need oxygen to use the energy you get from food.

White blood cells (leukocytes)

These are an important part of your immune system (the network of cells, tissues and organs that protects your body against infection). There are several different types of white blood cell, but they can be divided into three groups:

- lymphocytes
- monocytes
- granulocytes (most granulocytes are called ‘neutrophils’, so you may hear your healthcare team talk about your ‘neutrophil count’).

Platelets

These stick together and form clots to stop you bleeding, for example, if you have a cut or a bruise.

Bone marrow and how blood cells are made

The cells in your body are constantly dying and being replaced by new cells. This is how the body grows and repairs itself. Cells are made through a process called cell division and proliferation, which is when a cell divides and multiplies to make new cells.

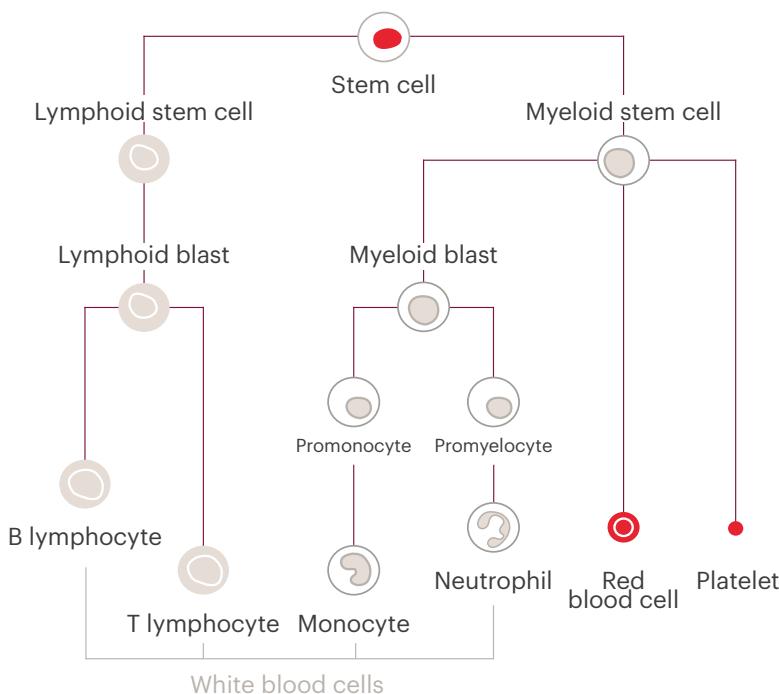
For blood cells, this process starts in the soft material inside your bones (your bone marrow) with a 'starter' cell called a stem cell.

When blood stem cells first divide, they create two types of more specialised stem cells:

- lymphoid stem cells
- myeloid stem cells.

These stem cells then divide to make lymphoid blasts or myeloid blasts. After dividing further, lymphoid blasts eventually end up as 'mature' cells called lymphocytes. At this stage, they're released into the bloodstream.

Blood cell production



Myeloid blasts go through a few more stages before maturing into granulocytes, monocytes, red blood cells and platelets. Then they're also released into the bloodstream.

In people with APL, cells get stuck when they reach the 'promyelocyte' stage (shown in the diagram above).



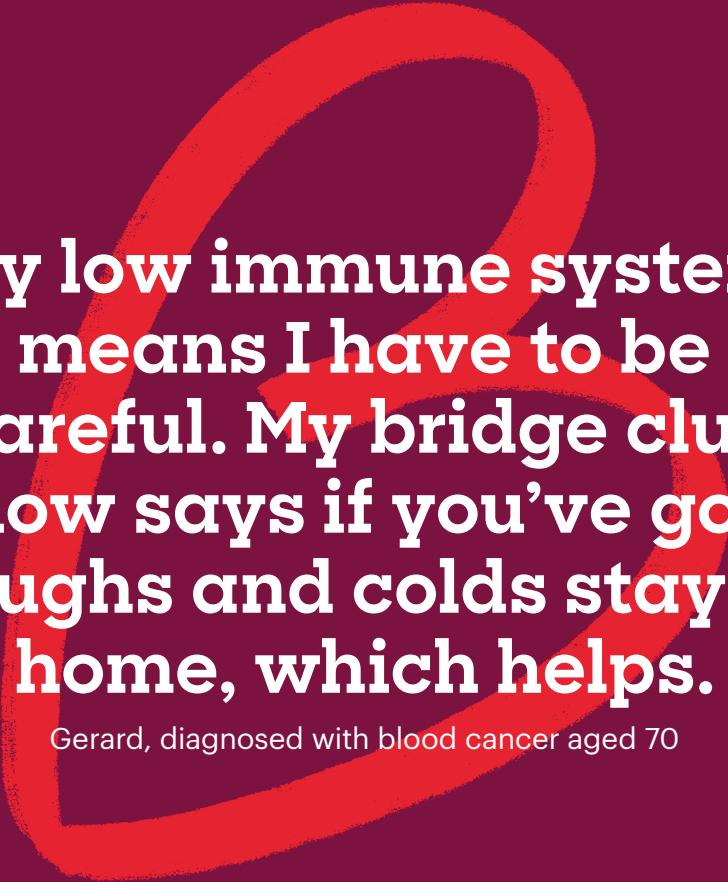
How many of each type of blood cell should you have?

Your bone marrow produces a huge number of blood cells every second. If everything's working normally, your body makes the right number of each type of cell to keep you healthy. You may feel unwell if your body makes too many or too few of any type of blood cell.

Everyone has slightly different numbers of each type of blood cell. If you're healthy, the amount you have of each type normally stays more or less the same, with slight changes up and down over time. This table shows the normal ranges for a healthy person:

Blood cell or substance	Levels found in a healthy person
Haemoglobin (Hb) level (for red blood cells)	130–180 g/l (men) 115–165 g/l (women)
Platelets	150–400 x 10 ⁹ /l
White blood cells (WBC)	4.0–11.0 x 10 ⁹ /l
Neutrophils	2.0–7.5 x 10 ⁹ /l
Lymphocytes	1.5–4.5 x 10 ⁹ /l

Your blood values depend on a number of different things, including sex, age, and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. So this table should only be used as a rough guide. Your healthcare team can explain what your results mean for you.



**My low immune system
means I have to be
careful. My bridge club
now says if you've got
coughs and colds stay at
home, which helps.**

Gerard, diagnosed with blood cancer aged 70

Our researchers are continually making new discoveries that help us understand APL, how it develops and how we can treat it.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

What is APL?

Leukaemia is a type of blood cancer that affects your white blood cells. APL is a rare, fast-developing type of leukaemia where specific white blood cells called promyelocytes build up and cannot mature. Each year, around 160 people are diagnosed with APL in the UK.

What is leukaemia?

In leukaemia, the lymphoid blast or myeloid blast cells in your bone marrow become cancerous, which means they start to divide and multiply in an unusual way. As more abnormal cells are produced, these start to crowd out the normal blood cells. This affects your ability to fight infection and stay healthy.

Leukaemia can be acute or chronic. Acute leukaemia develops very quickly and usually needs treatment straight away. Chronic leukaemia develops more slowly.

What is APL?

APL is a type of leukaemia that occurs when there is damage to a particular gene (called retinoic acid receptor alpha or 'RARA'). This change means cells get stuck at an early (immature) stage. The immature cells are called promyelocytes.

When you're healthy and everything is working normally, promyelocytes develop (mature) to make granulocytes.

In a person with APL, they build up in the bone marrow until eventually there's no room for normal blood cells to be made there. So your body doesn't have enough white blood cells, red blood cells or platelets to work properly.

All cells in your body contain a set of instructions that tell the cell what to do and when to do it. These instructions are stored in structures called chromosomes inside your cells. There are 23 pairs of chromosomes in each cell in your body.

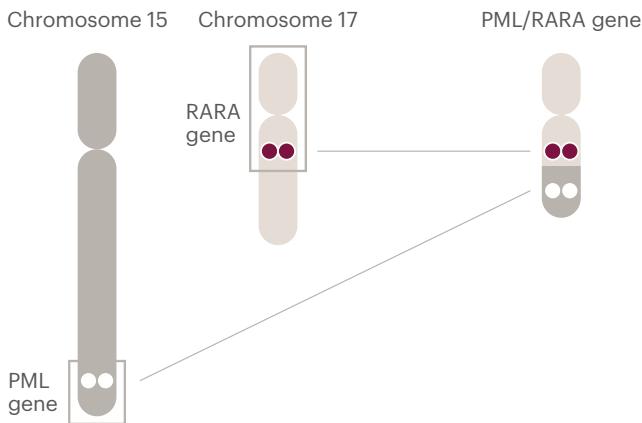
Your chromosomes are made up of a chemical called DNA, which is arranged in sections called genes. Each gene is a code that helps the body make different proteins.

When cells divide to make new cells, the chromosomes normally stay the same in each new cell. But in people with APL, this process goes wrong and two chromosomes (chromosomes 15 and 17) get mixed up. During this process, two genes (one from each chromosome) join to form a new, faulty gene called PML/RARA – see next page.

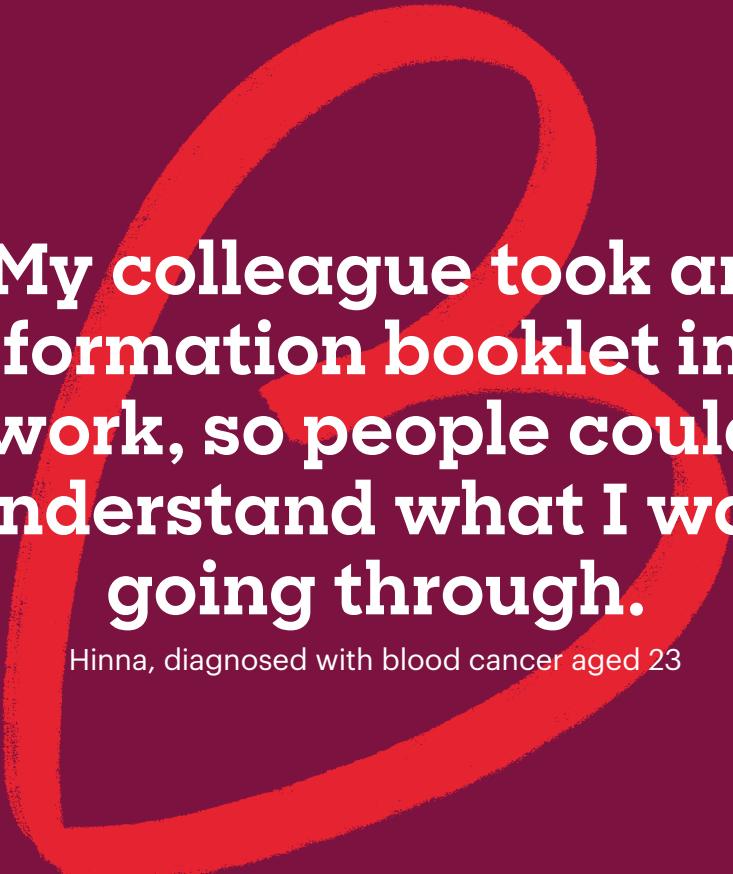


For more information about the tests needed to diagnose APL, turn to **pages 33–37**.

The PML/RARA gene



Most people with APL (around 95%) have the PML/RARA gene in their leukaemia cells, so if doctors can spot it, this can help them to diagnose APL.



My colleague took an information booklet into work, so people could understand what I was going through.

Hinna, diagnosed with blood cancer aged 23

You can't catch APL from others or pass it onto anyone else, and there's nothing you could have done to prevent it.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

What causes APL?

We don't know exactly what causes APL, but there are some things that affect how likely you are to develop the condition.

Age

APL affects adults more often than children and is most common in people aged 30 and over. We don't know why the risk is different for different age groups.

Sex

APL is equally common in men and women.

Genetics

Although people with APL have a genetic fault in their leukaemia cells, there's no evidence to suggest this is something you can inherit from your parents or pass on to your children.

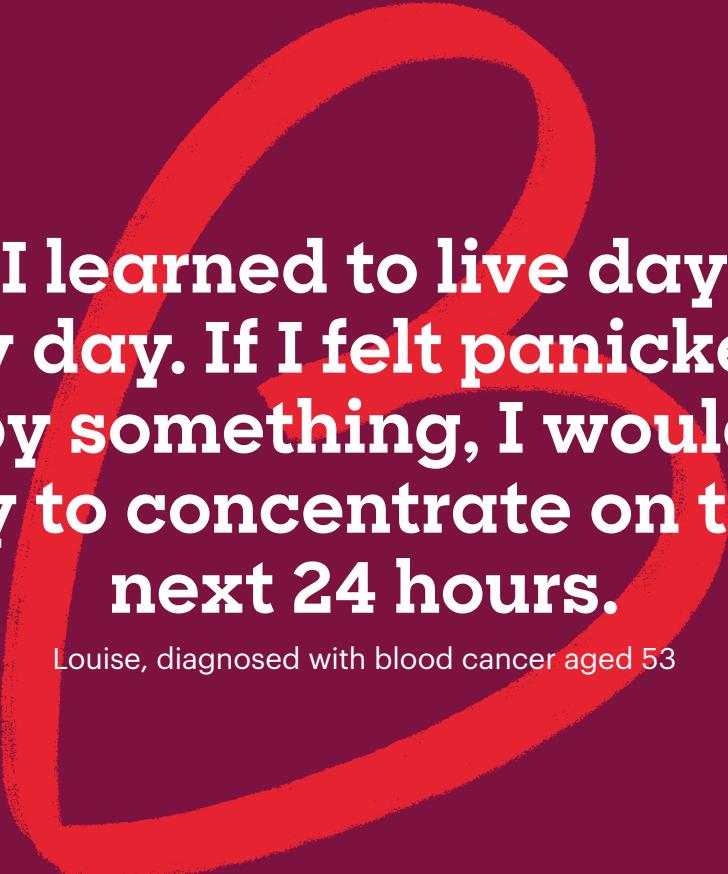
Previous treatment for cancer

Some people can develop APL following treatment with chemotherapy or radiotherapy for another cancer or condition – most commonly for breast cancer. This type of APL is called therapy-related APL (tAPL). You're most at risk of developing tAPL in the first five years after treatment for another cancer.

It's important to remember that none of your lifestyle choices have contributed to this condition.

For more information about treatments for APL and tAPL, turn to the Treatment chapter on **page 49**.





I learned to live day by day. If I felt panicked by something, I would try to concentrate on the next 24 hours.

Louise, diagnosed with blood cancer aged 53

**It's important to remember
that not everyone will get
all of these symptoms.
Each person is different.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Symptoms

The main symptoms of APL are a result of you not having enough healthy cells in your blood and bone marrow.

Common symptoms

Bruising and bleeding

This is caused by a low number of platelets and clotting factors in your blood (which happens as a result of APL). Platelets are the blood cells that stop bleeding by making the blood clot and clotting factors are proteins that help platelets do this.

If your blood can't clot normally, this can mean:

- bruising easily
- bleeding gums
- bleeding from wounds that's hard to stop
- black, tarry poo or poo that's streaked with red, because of bleeding in your gut
- headaches, difficulty speaking or difficulty moving parts of the body (like a stroke), because of bleeding in the brain.

In people with APL, bleeding can become life-threatening if it's not treated straight away, so it's important that doctors monitor you closely for this – particularly around the time that you're first diagnosed and when you start treatment. You'll have regular clotting tests as part of this monitoring, and you'll receive regular blood, platelet and plasma transfusions to reduce your risk of bleeding.

Find out more about the steps taken to prevent and manage the risk of bleeding on **pages 55**.



Blood clots

Because APL affects the blood's clotting factors, it can also cause blood clots to form in the wrong places. This can lead to:

- a painful or swollen leg due to clots in the leg or lower abdomen (tummy area)
- chest pain and difficulty breathing due to blood clots in the lungs
- headache, being sick (vomiting) and visual disturbance due to blood clots in the brain.

It is really important to tell your doctor immediately if you have any of these symptoms, or if you have any symptoms at all that you are worried about, especially in the first month of treatment.

Fatigue

Fatigue is when you feel drained in body or mind – even when you've rested or slept well. It's caused by low numbers of red blood cells in your blood (a low red blood cell count).

The medical name for this is anaemia.

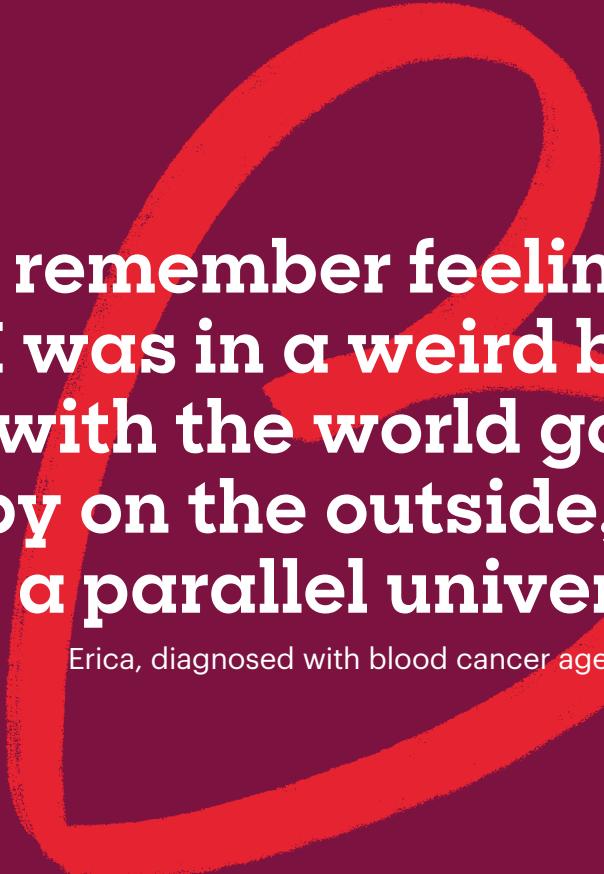
Anaemia can also make you feel breathless, even when you're resting, and can lead to chest pain.

Infections

A low white blood cell count can lead to infections and fevers that last for longer or happen more often than normal.

Weight loss

This is caused by a high metabolism, which is the rate you burn energy from food. We don't completely understand why the metabolism speeds up in people with APL.



**I remember feeling as
if I was in a weird bubble
with the world going
by on the outside, like
a parallel universe.**

Erica, diagnosed with blood cancer aged 53

It's important to know and understand your diagnosis. You could keep a record of it on the inside back cover of this booklet, so you have it to hand.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Diagnosis

You'll have a set of tests to confirm whether you have APL. At any time, you can ask your healthcare team to explain why you're having a certain test and what the results mean.

Tests to diagnose APL

It can be hard to understand how doctors know you have leukaemia, especially since there's no lump you can see, as you might get with other cancers. Your doctors diagnose leukaemia by looking at your blood, your bone marrow and your genes. They will need the results of a number of tests to confirm a diagnosis of APL.

Full blood count (FBC)

This measures the number of each type of cell in your blood: red blood cells, white blood cells and platelets. Your GP might send you for this test because you're unwell and they don't understand why, or you might have one as part of a routine check-up.

You'll have a blood sample taken, then, in the laboratory, automated machines will count your blood cells. If the count is too high or too low, a small drop of your blood is smeared onto a slide and the doctor or a senior scientist will look at it under the microscope.

Following diagnosis, you'll have regular FBCs so your doctors can monitor your condition during and after treatment.

Bone marrow biopsy

It's not normally possible to make a diagnosis from a blood sample alone, because there may be leukaemia cells in your bone marrow that aren't circulating in your blood yet. So your doctors will also usually take a bone marrow sample (a biopsy).

You'll lie on your side while a doctor uses a small needle to give you some local anaesthetic to numb the area around the back of your hip bone. The doctor will then use a larger needle to take a small sample of bone marrow from your hip bone.

This procedure is sometimes called a 'bone marrow aspirate' because an 'aspirate' is the name of the needle that's used.

Taking the sample is usually quite quick, but it may feel painful while it's being done. For this reason, you might be offered a tablet to make you feel sleepy (a sedative), if you want it. Or, you might be offered gas and air to help with the pain. You'll be advised not to take ibuprofen-based painkillers (such as Nurofen) during this time, as they can cause bleeding – which is especially dangerous if you have a low platelet count.

Your doctors will then look at the sample under a microscope to check for leukaemia cells.



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Tests to confirm your diagnosis

Although the results of an FBC and bone marrow biopsy might suggest that you have APL, doctors will need to run a few more tests on your blood and bone marrow samples to be sure.

These tests are known as ‘genetic tests’. They look for specific changes in the chromosomes, genes and proteins that make up your abnormal blood cells – changes that you would expect to see in someone with APL.

It’s likely that you’ll start treatment before you’ve had all of these tests and before your diagnosis has been confirmed. This is because if there’s a chance that you have APL, you’ll need to start treatment straight away, to prevent the risk of bleeding (a common symptom of APL).

Cytogenetic tests

‘Cytogenetics’ is the name for the study of chromosomes. In people with suspected APL, cytogenetic tests are usually done on cells taken from blood and bone marrow samples.

These tests involve doctors looking through a microscope at chromosomes 15 and 17 in your abnormal cells. If these chromosomes are mixed up, this confirms a diagnosis of APL.

PCR test

Your doctor will also check cells from your bone marrow sample for the PML/RARA gene, which is unique to people with APL. They'll do this using a 'polymerase chain reaction (PCR)' test.

Flow cytometry (immunophenotyping)

Doctors sometimes use blood or bone marrow samples to look at the pattern of proteins on the surface of leukaemia cells.

This is called 'flow cytometry' or 'immunophenotyping'. Together with the tests already mentioned, it helps your doctors to determine whether you have APL or another type of leukaemia. This helps them decide on the best treatment for you.



For more information about the swapping of chromosomes 15 and 17, and the PML/RARA gene, go to **page 19–20**.

Other tests

Blood clotting system tests

APL can interfere with the blood clotting system, so it can increase the risk of bleeding and blood clots. For this reason, clotting tests are particularly important and you'll have them regularly (at least once a day) in the early phases of your treatment.

General health tests

You'll also have a general health assessment to help your healthcare team assess how you're likely to cope with the side effects of treatment. This will involve a range of tests to check your general health, including your heart, liver and kidney function, and may include screening for HIV and hepatitis.

Your healthcare team

If you're diagnosed with APL, your hospital will give you the names and contact details of your specialist doctor (consultant), clinical nurse specialist (CNS) and other members of your healthcare team. There's space to write them at the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you're not at the hospital.

Your specialist doctor (consultant)

Most people with a blood cancer are treated by a haematologist – a doctor who specialises in treating people with blood diseases. Some people are treated by an oncologist (a cancer specialist). Either way, your consultant at the hospital will be an expert in treating your specific disease.

Your clinical nurse specialist (CNS)

People with cancer are normally given a key worker, usually a clinical nurse specialist (CNS). They're your point of contact with the rest of your healthcare team. You may like to have a meeting with them when you're first diagnosed, to discuss your condition. Your CNS will be with you every step of the way, so do make use of their help and expertise if and when you need it. They can also be a useful link to reach out to your doctors between your appointments.

Research nurse

If you decide to receive treatment as part of a clinical trial, you may also be allocated a research nurse or research practitioner, who will have a similar role to your clinical nurse specialist. They will explain what your participation in the trial will involve, coordinate your clinic appointments and procedures, monitor your health and keep you safe throughout your treatment and during follow up.

Your multidisciplinary team (MDT)

Your condition should be discussed at regular MDT meetings. An MDT brings together doctors, nurses and other specialist staff who will be looking after you, as well as the laboratory staff who help to make the diagnosis. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you're taking. They may need to check with your specialist or GP before giving you some types of treatment.

If you have questions about your care

If you're unhappy with any aspect of your care, speak to someone in your healthcare team. Or, ask your hospital or treatment centre who is best to speak to outside of the team.

Sometimes, asking your doctor or another member of the team to explain your diagnosis again can clear up any concerns you may have.

You can also ask for a second opinion from another doctor at any stage – before, during or after treatment.

There are services that provide support and information for people who have concerns about their healthcare. In England this is the Patient Advice and Liaison Service (PALS), in Scotland it's the Patient Advice and Support Service (PASS), and in Wales it's the Community Health Councils (CHCs). In Northern Ireland, you need to ask your hospital for a copy of their complaints procedure.



Go to **[citizensadvice.org.uk](https://www.citizensadvice.org.uk)** for more information about your local patient advice or complaints service.

See **pages 57-58** for more information about clinical trials.

Finding out more

After you've been diagnosed, it's worth taking time to think about what information you want to know, when and how. For some people, this is a way to have some control over what's happening.

- Let your consultant and CNS know how much information you'd like, and in what form. You can always ask for more information later.
- Write down any questions you have and keep them handy for when you see your consultant or CNS. If they can't answer your questions, they'll be able to tell you who to speak to.
- You might prefer to ask your CNS questions rather than your consultant, but do whatever works for you.
- Most people say they find it useful taking someone with them to appointments. If you think you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take – it doesn't have to be a family member.
- If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It could be useful to ask in advance what time the consultant is likely to see you, so you can try to arrange for someone to be with you at that time.

- When you're in the clinic or staying in the hospital you may be looked after by a more junior doctor, such as a senior house officer or a registrar. These are qualified doctors who are training to be consultants. They'll be able to answer many of your questions, but if they can't then they'll ask the consultant. All doctors in training are supervised closely by more senior colleagues.
- Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation. Being able to share similar experiences might also help you.
- You might want to ask your consultant or CNS if you can talk to someone who's had the same diagnosis and treatment as you. If you do this, remember that someone else's experience won't always be the same as yours. For example, some people will experience side effects from a drug and others won't.



You can find a list of places you can get help and support on **pages 97-103**.

You can talk to other people living with blood cancer in our online community forum at **forum.bloodcancer.org.uk**

Telling people

Many people tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on your behalf. Another idea is setting up a blog or Facebook page, so you or other people can post information on it that everyone can read.

You might not want to tell many people – or anyone at all – about your condition. This is ok too. It's entirely up to you.

Talking to children and teenagers

Talking to children and teenagers about your condition can be a difficult thing to do. There are many organisations to support you and offer advice on how to explain it to children of different ages.

Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you're having. They'll usually send your GP a letter with this information. As the patient, you'll often be sent a copy too.

These letters can have a lot of medical terms in them that you might not have heard before, or there might be something in one that worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

Cancer and work

You may want to consider telling someone at work about your diagnosis. It can be hard asking for time off at short notice if no one knows about your illness, and your colleagues and HR department might be able to offer support.



Macmillan Cancer Support has some useful advice about cancer and work online. Go to **macmillan.org.uk** then search for 'work'.

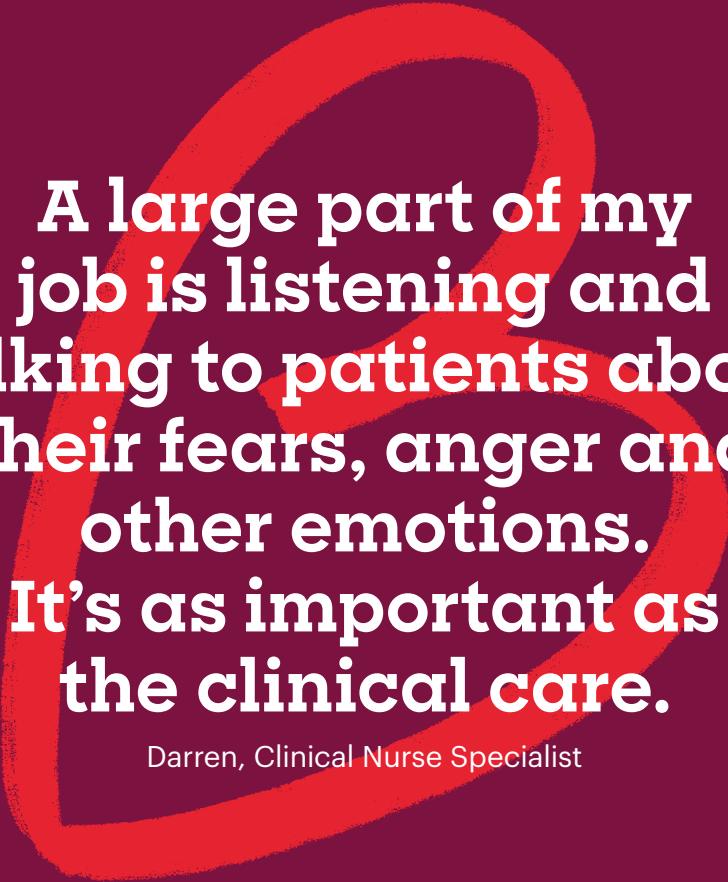
Macmillan Cancer Support also has information on talking to children about cancer. Go to **macmillan.org.uk** then search for 'talking to children and teenagers'.

There's more information about cancer and how it can affect your work or study on **pages 90–91**.

Questions for your healthcare team

It can be a good idea to write down any questions you have before your next appointment. Here are some things you might want to ask while you're waiting to receive your diagnosis, or once you've been diagnosed.

- What tests will I have?
- What will they show?
- Where will I have them done?
- Do these tests carry any risks?
- Will any of the tests be painful?
- Do I need to know anything about preparing for
 - the tests (for example, not eating beforehand)?
- How long will it take to get the results?
- Who will explain the results?
- What is my exact diagnosis?



A large part of my job is listening and talking to patients about their fears, anger and other emotions. It's as important as the clinical care.

Darren, Clinical Nurse Specialist

**Your treatment will
depend on your individual
condition, your general
health and your wishes.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Treatment

Throughout your treatment, your healthcare team will discuss your treatment options with you. They'll want to hear what you think, answer your questions, and explain anything you're unsure about.

Treatment planning

If your doctor suspects that you have APL, you're likely to start treatment before your diagnosis is confirmed. This is because, until you start treatment, you're at risk of serious bleeding, so it's important that doctors take steps to prevent this as soon as possible. If your diagnosis and treatment plan then change, the treatment you've already received won't do you any harm.

Your doctor will recommend a treatment plan and talk to you about what it will involve. Treatment plans are tailored to each individual, so you won't necessarily receive the same treatment as someone else with the same diagnosis. What's right for you depends on your age, your general health and the type of APL you have. Your wishes will always be taken into account.

Some people find it hard to fully understand the details of their treatment when they're trying to cope with the stress of being diagnosed with leukaemia. There isn't a single 'best' way to deal with this situation, or a right way to feel. Don't be afraid to ask as many questions as you need to.

Types of treatment

Generally, treatment for APL can be divided into:

- Active treatment, which aims to get rid of the leukaemia cells (put you in remission) and help your bone marrow work normally again.
- Supportive care, which helps you feel better and supports your body through some of the problems caused by APL and its treatment.

There are several different 'active' treatment options, depending on the type of APL you have.

Most people with APL (around 95%) have the PML/RARA gene (described on pages 19–20), which means they're likely to respond to the standard drugs used to treat APL. These are the treatments we describe in this chapter.

But there are also several very rare types of APL, where this gene isn't present and where standard treatment may not be as effective. If you're diagnosed with one of these rarer types, treatment might involve all-trans retinoic acid (ATRA) with chemotherapy (described on page 54) or one of the drug combinations used to treat acute myeloid leukaemia (AML). Your doctor will talk to you about which alternative course of treatment might be best for you.



There's more information about treatment planning and making treatment decisions on our website. Visit bloodcancer.org.uk/treatment

For more information about treatments for AML, order or download our **Acute myeloid leukaemia (AML)** booklet. See **page 111** for details.

First-line therapy

First-line therapy is the first treatment you'll try if doctors suspect that you have APL. It's given in two stages:

- remission induction
- consolidation.

The aim of the remission induction stage is to put you into 'complete remission' (also sometimes called 'morphological remission'). This is where the level of leukaemia cells in your bone marrow is less than 5% and doctors can't see any leukaemia cells under the microscope. You're likely to spend all or most of this stage in hospital, with your healthcare team close by.

Consolidation treatment is then given in rounds (or cycles) to clear any leukaemia cells that might remain in your blood and bone marrow. These cells can't be seen through a microscope but can be picked up by a PCR test, which you'll have after each cycle of treatment. When the PCR test can't pick up any leukaemia cells, this is called 'complete molecular remission'.

You might be able to have some of your consolidation treatment as an outpatient, which means you won't need to stay in hospital overnight. But you should be prepared to spend quite a bit of time in hospital.

Your first-line therapy will be one of two treatments, described below.

ATRA with arsenic trioxide

In the UK, if you have a lower white blood cell count when you're diagnosed, you'll usually be treated with a combination of drugs called 'arsenic trioxide' and 'all-trans retinoic acid' (ATRA).

ATRA is given as a tablet. It works by stopping your white blood cells from getting "stuck" as immature promyelocytes (leukaemia cells) and allowing them to mature into healthy white blood cells. Arsenic trioxide works in a similar way and is given to you through a drip (intravenously).

If your doctor recommends this treatment option, you'll start taking ATRA capsules straight away. Once your diagnosis is confirmed, you'll then start receiving intravenous arsenic trioxide.

You'll receive arsenic trioxide in combination with ATRA as remission induction therapy for two months. The same treatment will then be given in cycles of consolidation therapy, with short breaks in between, for a total of eight months.

You may be worried if you've heard of arsenic before, as it can be poisonous when used in high doses. But smaller doses of arsenic can be used safely in medicine, and arsenic trioxide is a very effective treatment for APL.

ATRA with chemotherapy

If you have a higher white blood cell count when you're diagnosed, you'll usually be given ATRA with chemotherapy (which kills leukaemia cells), rather than arsenic trioxide.

The group of chemotherapy drugs used to treat APL are called 'anthracyclines'. They are given through a drip (intravenously), usually into a vein in your arm.

If you're treated with a combination of ATRA and anthracyclines, you'll receive one cycle of induction treatment and then a further three cycles of consolidation treatment. Each cycle of treatment will last a few days, and you'll usually have a four-week recovery period before moving on to the next cycle. You may start taking anthracyclines at the same time as ATRA or you may start a few days afterwards.

Supportive care

As well as active treatment for your illness, you'll need other treatments to support your body through some of the problems caused by APL and its treatment. Your healthcare team may refer to these treatments as 'supportive care'.

Here are some examples of supportive care you might be offered.

Blood transfusions

You'll need regular blood transfusions (blood that has been donated from someone else) to help your blood clot and lower your risk of bleeding. When you receive a blood transfusion, you won't receive whole blood – you'll just be given the parts you need (these parts are often called 'blood components' or 'blood products'). You'll receive these blood products through a plastic tube into a vein in your arm (intravenously).

People with APL usually receive fibrinogen, cryoprecipitate, platelets and fresh frozen plasma (FFP) transfusions, as these blood products all help the blood to clot by topping up low levels of clotting factors and platelets.

Most people with APL will have frequent transfusions as soon as their doctor suspects they have APL, and will continue to have them until their blood can clot normally.

You may also receive red blood cell transfusions as part of your treatment, to help replace the blood cells that have been crowded out by the leukaemia cells.

Anti-sickness drugs

Treatment for APL can make you feel sick – though not everyone will experience this. If you do, there are anti-sickness drugs (also called anti-emetics) that can help. Anti-sickness drugs can be given as tablets, injections or skin patches.

Managing infections

Because APL affects your immune system, you'll be at greater risk of catching infections. If you do pick up an infection, your doctor will put you on a course of one of the following treatments:

- antibiotics (which treat bacterial infections)
- anti-viral medicines (which treat viruses)
- anti-fungal treatments (which treat fungal infections).

We have fact sheets on **Blood transfusions**, **Managing sickness and vomiting**, and **Understanding infection**. See **pages 110-111**.



These can all be given as tablets or through a vein (intravenously). Anti-viral medicines and anti-fungal treatments can also be given as a cream.

Clinical trials

All new treatments are thoroughly tested before they're made available. After tests in a laboratory, they're tested on people in research studies called 'clinical trials'.

Clinical trials are done for several reasons, including to look for new treatments and to improve existing ones. Taking part in one has many advantages, including the opportunity to try a new treatment that may benefit you, or others like you in the future.

If there's a clinical trial available that's suitable for you, your doctor may ask if you'd like to consider taking part. If you're not given information about trials and you think you would be interested, speak to your healthcare team.

If you decide to take part in a trial, your safety and wellbeing are always the priority. You'll be very closely monitored during and afterwards – and you can choose to withdraw at any time.

Taking part in a trial does come with uncertainties and risks, and there's no guarantee the treatment being tested will be better than the approved alternative. If you don't want to be in a trial, or there isn't a suitable one available, you'll be offered the best treatment available that's appropriate for you.

You can find out more about clinical trials at
bepartofresearch.nihr.ac.uk



Treatment for refractory or relapsed APL

Most people (between 90% and 95%) go into complete molecular remission by the end of their first-line treatment. However, if you don't, this is known as refractory APL.

For those who do go into complete remission, a small number will go on to experience a relapse (where the cancer comes back). This is especially rare if you were treated with ATRA and arsenic trioxide.

If you have refractory APL or you relapse after being in remission, it's important to know that there are more treatment options available. The treatment you have at this stage will largely depend on the first-line therapy you had. Your healthcare team will discuss the best way forward with you.

ATRA with arsenic trioxide (if you had ATRA with chemotherapy as a first-line treatment)

If you have ATRA with chemotherapy as a first line treatment and you don't go into remission or you relapse, your doctor may suggest you try ATRA with arsenic trioxide as a second-line treatment (see pages 53–54 for an explanation of ATRA with arsenic trioxide).

ATRA with chemotherapy (if you had ATRA with arsenic trioxide as a first-line treatment)

If you have ATRA with arsenic trioxide as a first-line treatment and you don't go into remission or you relapse, your doctor may suggest you try ATRA with chemotherapy as a second-line treatment (see page 54 for an explanation of ATRA with chemotherapy).

Treatment for an extramedullary relapse

In a small number of people who relapse (between 3% and 5%), the leukaemia can affect other parts of the body, like the central nervous system (the brain and spinal cord). This is known as an 'extramedullary relapse'.

If you experience an extramedullary relapse, your doctor may recommend the standard relapse treatment alongside something called 'intrathecal therapy' (ITT). ITT involves injecting chemotherapy drugs and steroids into the fluid in your spine (cerebrospinal fluid or CSF).

Stem cell transplants

After having these treatments for relapsed or refractory APL, you might be offered a stem cell transplant (sometimes called a bone marrow transplant). This treatment aims to give you healthy stem cells, which then produce normal blood cells.

There are two types of stem cell transplant:

- an autologous transplant (or autograft) – this uses your own stem cells
- an allogeneic transplant – this uses stem cells from a donor.

If you've relapsed more than once or your doctor thinks you might be at risk of relapsing again after successful relapse treatment, you may be offered an autologous transplant, to prevent the APL from returning again. If you are going to have an autologous transplant, your own stem cells will be collected and stored (harvested) when you are in complete remission.

An allogeneic transplant can also be very effective if you have refractory or relapsed APL. However, because it's a higher-risk procedure, your doctors will only recommend this in particular circumstances – for example, if the PCR test result is still positive after you have finished your relapse treatment, or if the APL comes back after an autologous transplant.



There's more information on stem cell transplants in our booklet: **Blood stem cell and bone marrow transplants: the seven steps**. See page 111 to download or order.

Side effects

People can have a range of responses to treatment. Some responses are good – they mean the treatment is working. Other responses are unwanted, and these are known as side effects. Some side effects are temporary and will stop during, or soon after you finish, treatment. But others can last longer, and some can be life-long.

Different people will experience different side effects. So you might not get all, or even any, of the side effects associated with the particular treatment you're having. Try to bear this in mind when you read about them.

If you do experience side effects, let your healthcare team know as they may be able to help with them. There are medicines you can take to help with feeling or being sick, for example.

Side effects to be aware of if you're treated with ATRA or arsenic trioxide

Both ATRA and arsenic trioxide work by forcing leukaemia cells to mature into healthy white blood cells. They do this by targeting and overriding the faulty gene that causes APL.

This is an important part of treating APL, but sometimes this happens too quickly and your body can struggle to cope.

This is known as 'differentiation syndrome' (sometimes called 'retinoic acid syndrome' or 'RA syndrome') and it's most likely to happen in the first three weeks of treatment.

Signs and symptoms of differentiation syndrome include:

- difficulty breathing
- fever
- weight gain
- swelling (caused by fluid build-up)
- low blood pressure
- coughing
- chest pain
- feeling unusually tired or weak
- feeling sick or being sick
- frequent watery poos (diarrhoea)
- dehydration
- weeing (urinating) more than usual
- confusion
- drowsiness.

Differentiation syndrome is a serious condition, so if you show any of these signs of symptoms, you should tell your doctor or nurse straight away. Your doctor may recommend that you stop taking ATRA/arsenic trioxide for a few days and they'll also give you steroids to treat the syndrome. These will be given to you twice a day as injections or tablets, until you no longer have symptoms.

If you have a high white blood cell count when you're diagnosed, you may be at higher risk of developing differentiation syndrome. Your doctor may suggest you take steroids as a precaution to try and stop it happening. In this situation, or if your white blood cell count goes up once treatment starts, you may also receive a gentle type of chemotherapy to bring your white blood cell count down.

It's also important to know that ATRA may be harmful to a baby developing in the womb (uterus). So you'll need to use contraception (take steps to avoid becoming pregnant or fathering a child) while you're having this treatment.

Other short-term side effects from arsenic trioxide

If you're having arsenic trioxide in combination with ATRA, you may experience some other side effects. Below are some common side effects of arsenic trioxide:

- headache
- dizziness
- muscle pain
- numbness or tingling
- rash or itching
- fast heartbeat.

You should tell your doctor straight away if you notice one of the following side effects, as these may be signs of an allergic reaction:

- difficulty breathing
- fever
- sudden weight gain
- swelling (caused by fluid build-up)
- fainting
- feeling a strong heartbeat in your chest (palpitation).

Because arsenic trioxide is a relatively new treatment, we don't yet know whether there are longer-term side effects.

Short-term side effects from chemotherapy

If you're having ATRA combined with chemotherapy, you may experience some short-term side effects caused by the chemotherapy, such as:

- infections
- extreme tiredness
- loss of appetite
- feeling sick or being sick
- frequent watery poos (diarrhoea)
- stomach pain
- a sore mouth or mouth ulcers (mucositis)
- hair loss
- reddish coloured urine 1-2 days after taking the medicine
- fever or chills
- aches or pain
- bruising or bleeding

- slow, fast or irregular heartbeat, or chest pain
- problems with your sight
- swelling
- shortness of breath or coughing
- skin rash, redness or itching
- sweating.

Long-term side effects from chemotherapy

The long-term effects of chemotherapy depend on which drugs you take, the intensity of your treatment and, in some cases, the total amount of the drug you take. Your doctor will discuss these potential side effects with you before you start your treatment.

Heart problems

It's important to be aware that anthracyclines can cause heart problems. The likelihood of you developing this will depend on the type and amount of anthracyclines you need to take. Your healthcare team will be able to tell you more about this risk.

Fertility problems

Before your treatment starts, you should talk to your healthcare team about how it might affect your ability to have children, if that's relevant and important to you.

Chemotherapy given for APL can affect fertility – particularly in men. Because treatment for APL has to start so quickly, there usually isn't time to preserve a woman's eggs. Men sometimes have a chance to freeze their sperm for the future.

If you do go on to have children after you've finished treatment, studies have shown that the treatment you've had won't affect their health.

Your healthcare team will be able to discuss your options with you, and refer you to a fertility department, if appropriate.

Follow-up appointments

The aim of follow-up appointments is to look out for signs of relapse and treatment complications. These appointments are really important so do make sure you get to them.

For the first year after your treatment, you'll normally have a check-up every one to two months. After a year, your check-ups will become less frequent, typically occurring every three to four months during the following two years.

If you were treated with ATRA and arsenic trioxide, you'll have a very low risk of relapse, so your doctors won't normally monitor you for relapse using a PCR test during your follow-up – as long as the test at the end of your treatment didn't pick up any leukaemia cells. Instead, you'll have regular blood tests so doctors can measure your full blood count.

If you've received ATRA and chemotherapy, because your risk of relapse is slightly higher, your doctors will use this test to monitor you throughout your follow-up. This will allow them to detect a relapse early in most cases. Your follow-up might also include regular testing of your bone marrow using a bone marrow aspirate, like you had when you were diagnosed.

Questions for your healthcare team

It's easy to forget the questions you wanted to ask when you're sitting with your healthcare team, trying to take in lots of new information. Here are some questions you can use as prompts, if you want to find out more about your treatment.

Types of treatment

Will I need to have treatment? If so, when?

Is there a choice of treatments?

What's the recommended treatment?

What does the treatment do?

Will I be given tablets or injections? Or will I receive my treatment through a drip?

Will I need to stay in hospital?

If not, how often will I need to go to hospital?

How long will my treatment last?

Will my treatment be continuous, or will there be breaks in between?

What's likely to happen if I decide not to have the treatment my healthcare team recommend?

Is there a clinical trial I could join?

Stem cell transplant

Is a transplant an option for me?

If I'm having a transplant:
How long will I be in hospital for?

Do I have to be in isolation?

How long will it be before I can get back to my usual routine?

Side effects

What side effects could I get from my treatment?

Can side effects be treated or prevented?

Will they affect me all the time or only while I'm taking certain drugs?

What are the fertility risks with treatment and what options are available to protect my fertility?

Follow-up

How will the cancer be monitored after my treatment?

How often will I need to have follow-up appointments?

Is there anything I need to watch out for after my treatment ends?

Who can I contact if I have any questions or worries?

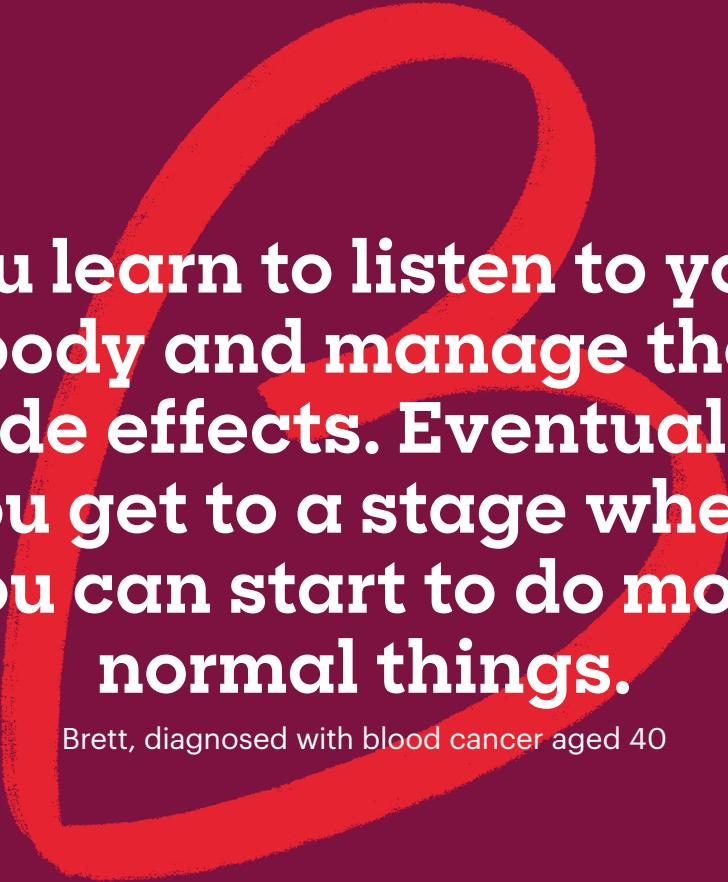
Relapse

How will doctors know if the cancer is progressing?

What are the options for more treatment?

What will the treatment involve? Will it be different from my initial treatment?

What side effects could I get from more treatment?



You learn to listen to your body and manage the side effects. Eventually you get to a stage where you can start to do more normal things.

Brett, diagnosed with blood cancer aged 40

**If you'd like to know more
about your outlook, your
healthcare team are the
best people to speak to.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

The outlook

Some people will want to know how APL will affect them in the long term (this is known as your 'outlook'), while others will prefer to take things step by step. Whatever works for you is fine, and you can tell your healthcare team if your outlook is something you'd rather not talk about. You can change your mind at any time.

What can affect my outlook?

Your outlook is individual to you and depends on a number of things, including:

- your age and general fitness
- how high your white blood cell count was when you were diagnosed
- how successful your treatment is.

No one can know exactly what will happen to you or how you'll respond to treatment. But your healthcare team should be able to give you an idea based on the outcomes of other people with APL who have had similar treatments to you.

What's the general outlook for people with APL?

Most serious problems for people with APL happen within the first two to three weeks after diagnosis, when you are most at risk of bleeding, blood clots and differentiation syndrome. After this period has passed, most people (over 90%) with APL respond well to first-line therapy and will go into remission.

A very small number of people will develop refractory disease (where the leukaemia doesn't respond to first-line therapy).

Of those who do respond to first-line therapy, between 10% and 20% of those treated with ATRA and chemotherapy, and less than 2% of those treated with ATRA and arsenic trioxide will relapse (where the leukaemia comes back).

Refractory and relapsed APL can be harder to treat, but there are still several treatment options available (your doctor may refer to these treatments as 'salvage therapy'). Most people (between 80% and 90%) will go back into remission (where there's no sign of leukaemia cells) after receiving salvage therapy.

Getting emotional support

You might find it difficult understanding or coming to terms with your outlook. Our Support Services Team is here to listen and offers emotional support over the phone or by email. Contact us on 0808 2080 888 or support@bloodcancer.org.uk



To read more about treatment options for refractory or relapsed APL, turn to **pages 59–61**.

Questions for your healthcare team

If you decide you would like to ask your healthcare team about your outlook, you might find the following questions helpful.

What are the aims of my current treatment plan?

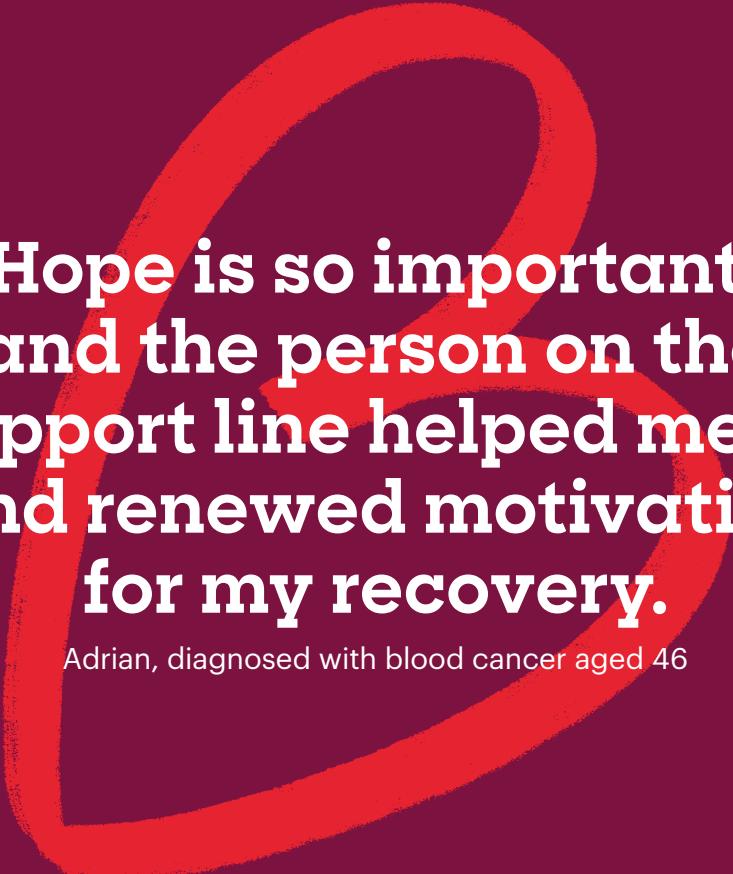
What is my outlook at the moment?

What's the best outcome I could hope for?

Is my outlook likely to change in the future?

What can I expect in the next few weeks, months or years?

Are there any statistics that can help me understand more about my outlook?
Can you explain them to me?



**Hope is so important,
and the person on the
support line helped me to
find renewed motivation
for my recovery.**

Adrian, diagnosed with blood cancer aged 46

**Your healthcare team
should look after your
emotional needs, as well
as your physical ones.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Living with APL

If you've been diagnosed with APL you may experience a range of emotions at different times. There can be a physical impact on your day-to-day life too.

Looking after yourself emotionally

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. Friends and family may be able to offer support, but it may be harder for them to understand the long-term emotional impact that you might experience.

Your healthcare team should discuss your emotional, spiritual, social, practical and physical needs with you and talk about how they can be met. This is called a holistic needs assessment. You should have one a few times throughout the course of your treatment and beyond, as your needs might change.

Looking after yourself physically

Changes in your condition

You might need to live with symptoms for a long time, but your healthcare team will be able to give you advice on how to cope with them.

When you've finished your treatment, it's important to contact your healthcare team at the hospital straight away if you notice any new symptoms. Don't wait for your next check-up.

You can talk to other people living with blood cancer or read their experiences at **forum.bloodcancer.org.uk**

We have more information and tips about coping with emotions and keeping active on our website at **bloodcancer.org.uk/live-well**



Symptoms to watch out for include:

- bruising and bleeding
- infections that occur more often or last longer than normal
- unexplained weight loss.

Keeping active

You might feel tired a lot (fatigued). This might be caused by the APL or its treatment and isn't the same as normal tiredness which improves with rest and sleep.

While even the idea of doing something can be tiring if you've got fatigue, try to keep as active as you can because evidence shows that this could help to reduce the symptoms of fatigue.

Although there's no evidence that any particular exercise programme can improve your condition or how you respond to treatment, we do know that staying active is good for your general physical wellbeing and your mood.

Eating well

There's no evidence that any special diet will improve your condition or how well your treatment works.

If you're having chemotherapy as part of your treatment, this can make you lose your sense of taste and your mouth may be sore. In time, this will go back to normal, but you may find that you don't enjoy food you previously liked and might even enjoy food you didn't like before. So it's important to make sure there are plenty of snacks around that you like. You could also try eating small meals more often throughout the day.

While you're having treatment, don't worry too much about trying to eat healthily, even if that's what you normally do.

The important thing is to get as much energy as possible, and that means eating whatever you feel like eating.

You will need to take extra care to avoid infections that you might get from food, because your immune system won't be working as normal. This means that your body won't be able to destroy germs and fight off infection as easily, so follow basic food hygiene rules like paying attention to use-by dates and keeping raw meat separate from ready-to-eat foods in the fridge.

You may also be advised to be extra careful about takeaway food and eating out while you're having treatment.

Your healthcare team will advise you on any changes you need to make to your diet to help you avoid infections (sometimes known as following a 'neutropenic diet').

If you notice any changes in your appetite or reactions to certain foods following treatment, tell your healthcare team so they can advise you.

Other infection risks

If you're having chemotherapy, speak to your healthcare team about whether it's ok for you to do gardening and housework. Some gardening jobs such as raking leaves or cutting down dead bushes can put you at risk of fungal infection. You should also avoid touching fresh cut flowers, changing the water in vases and changing cat litter, because these activities could also bring you into contact with germs.



There's more information and practical tips about eating well on our website at **bloodcancer.org.uk/live-well**

Our booklet **Eating well with neutropenia** has advice on how to avoid infections from food – see **page 110**.

Shingles

Shingles is the infection of a nerve and the skin around it. It can only affect you if you've had chickenpox in the past – even if you had it a long time ago – but you're more likely to get it if you have APL.

Because of this, it's important to be aware of the symptoms of shingles, and let your doctor know as soon as possible if you spot any.

These include:

- a rash (with blisters filled with fluid which burst, form sores and then crust over), usually on one side of the body
- pain where the rash is
- an itching, tingling or burning feeling.

It's also best to avoid direct physical contact with people who have shingles or chickenpox – and to let your healthcare team know straight away if you do. This is because, although you can't catch shingles from someone else, you can catch chickenpox from someone with an open shingles sore if you haven't had chickenpox already.

If you're receiving active treatment for APL, you might be given a drug called aciclovir, which can prevent shingles. You should take this until your healthcare team tell you your immune system has recovered.

Vaccination

It's a good idea for all people with APL to have the flu vaccine each year. Your GP might contact you about this – but if they don't, you can request the vaccine yourself. It might not work as well for people with APL but will still offer some protection. It is also sensible for the people you live with to be vaccinated against flu.

You should also avoid having any live vaccines while you're having active treatment. Fortunately, only a few vaccines used in the UK are live. The most commonly used ones are MMR (measles, mumps and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas, is also a live vaccine.

Smoking

If you smoke, it's best to give up. Smoking is especially harmful to those who've previously had chemotherapy and it increases your risk of developing a new, second cancer or lung problems in the future.

Of course, when you're stressed it's even more difficult than usual to stop smoking. Talk to your healthcare team as they can prescribe nicotine patches if you decide to give up.

Sex and pregnancy

If you're a woman receiving ATRA, arsenic trioxide or chemotherapy, it's very important to avoid becoming pregnant while you're having treatment. Once you're in remission, talk to your doctor if you are planning to have a child.

People who are having chemotherapy should use condoms (and continue to do so for a week after their treatment has finished) because chemotherapy drugs can be present in all bodily fluids. We also do not fully understand what effect chemotherapy may have on sperm.

Complementary therapies

Complementary therapies are treatments like massage, meditation or acupuncture that are used alongside standard medical treatments with the aim of making you feel better.

There's no evidence to suggest that these therapies can treat or cure blood cancer, but there's some that suggests some of them may help you manage your symptoms or the side effects of your treatment. Other therapies may just help you relax or improve your general sense of wellbeing.

Alternative therapies

There's an important difference between complementary therapies, which are used alongside standard medical treatments (like chemotherapy), and alternative therapies, which are offered instead of these treatments. We don't recommend that you use any alternative therapy in place of proven medical care, but you may be interested in using complementary therapies alongside your treatment.

Keeping yourself safe

If you're thinking about using complementary therapies, you should let your healthcare team know, so you can discuss what's safe for you. They may advise you to avoid certain therapies because of specific risks to do with your condition or the treatments you're receiving. In other cases, they may say a therapy is ok as long as you take specific precautions, like visiting a complementary therapist who's a member of the relevant professional association or register. Your healthcare team can explain how to check this.

Some hospitals will have a complementary therapies team that offers sessions free of charge, while others might have a specialist who visits once or twice a week. Sometimes these therapies are there for your partner or close relatives, too. Your healthcare team will be able to tell you what's on offer.

If your hospital doesn't offer complementary therapies, there may be a local cancer centre or charity that you could visit instead. Speak to your healthcare team to see if they can recommend anywhere nearby.

Some people choose to see an independent complementary therapist. If you do this, it's important to make sure they will keep you safe. Speak to your healthcare team about what you need to keep in mind when finding a therapist.

Practical support

Work, education and home life

If you work or are studying, you might want to contact your employer or college, or ask someone to do it for you.

You might need to make a short-term arrangement with your employer or college when you're diagnosed so you can have time off when you need to be at the hospital. If you have to stay in hospital for your treatment, or you're not well enough to go to work or college, you'll probably need to make a more formal agreement. Similarly, if you're studying at college or university, you might want to think about whether you want to continue with your course, or delay it for a short time.

If you're a parent or a carer, you may need support during your treatment. You might have unplanned stays in hospital because of infection, for example – it's helpful to have plans in place just in case.

Cancer and the law

People with a disability are protected by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland. For the purposes of these Acts, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with cancer and can't discriminate against them. An example of a reasonable adjustment would be allowing you time off to go to hospital for treatment.



We have more information and practical tips about dealing with work when you have blood cancer at **bloodcancer.org.uk/live-well**

Getting to hospital

If you're being treated as an outpatient (not staying in overnight) you might need to be at the hospital a lot over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if you can have any of your treatment nearer to where you live.

It might not always be possible but sometimes it is – it depends on the healthcare facilities close to your home and the type of treatment you're having.

If this isn't possible and transport is a problem, you can ask about hospital transport. You might also be able to apply for support with travel costs. If you'd like to find out more about this support, you can speak to your team at the hospital or a benefits advisor. Macmillan Cancer Support have benefits advisers - call them on 0808 808 00 00.

Financial support

There are lots of places you can get help and advice if you are worried about money.

Your hospital will normally have social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. This might be especially useful if you're on a low income or are unemployed. If you're worried, ask to speak to an advisor as soon as possible after your diagnosis. Alternatively, your hospital may be able to arrange for an advisor from somewhere else to visit you.

In England, prescriptions are free for people with cancer. If you normally pay for your prescriptions but are being treated for cancer (including the effects of cancer or its treatment) you can apply for a medical exemption certificate for any medicine you need to support your care. Application forms are available from your GP surgery or hospital clinic.

In Scotland, Wales and Northern Ireland, prescriptions are free for everyone.



We have more information and tips on dealing with the financial impact of cancer on our website at
bloodcancer.org.uk/live-well

Questions for your healthcare team

Most cancer treatments will affect your everyday life in some way. Here are some questions you might want to ask your healthcare team about the impact that treatment might have on your daily routine.

What effect is the treatment likely to have on my daily life?

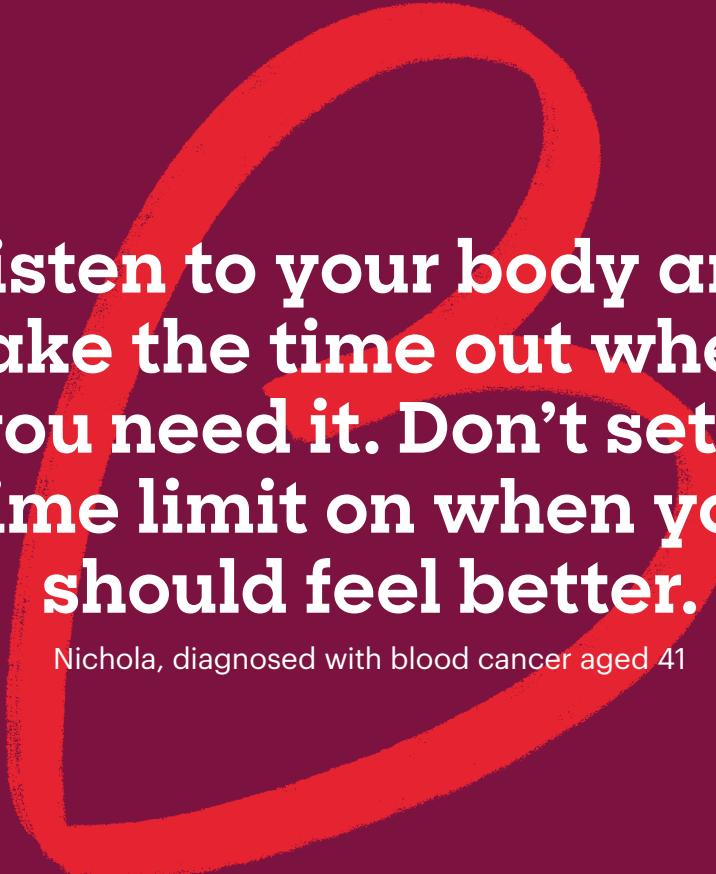
Will I be able to carry on working/studying?

Will I need to take special precautions, for example against infection?

Will I be able to plan taking drugs around my meal times, or will I need to change when I eat?

Who do I contact if I feel unwell when I'm away from the hospital?

Who can I contact if I have any questions?



**Listen to your body and
take the time out when
you need it. Don't set a
time limit on when you
should feel better.**

Nichola, diagnosed with blood cancer aged 41

**Blood Cancer UK offers
information and support
to anyone affected by
blood cancer. You'll find
other useful organisations
listed here as well.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Places you can get help and support

Blood Cancer UK

We are here for anyone affected by blood cancer, whether it's you who's been diagnosed or someone you know.

We offer free and confidential support by phone or email. We provide information about blood cancer and life after a diagnosis. And we have an online forum where you can talk to others affected by blood cancer.

- bloodcancer.org.uk
- 0808 2080 888
- (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)
- support@bloodcancer.org.uk
- forum.bloodcancer.org.uk

Macmillan Cancer Support

Offers practical, medical, financial and emotional support.

- 0808 808 0000
- macmillan.org.uk

Cancer Research UK

Offers information about different conditions, current research and practical support.

- 0808 800 4040
- cancerresearchuk.org

Leukaemia Care

Offers patient information, a support line and support groups for people affected by leukaemia, lymphoma, myeloma and other blood disorders.

- 08088 010 444
- support@leukaemiacare.org.uk
- leukaemiacare.org.uk

Cancer on Board

Supplies 'cancer on board' badges to people with cancer, to help with public transport journeys.

- canceronboard.org

African Caribbean Leukaemia Trust (ACLT)

Aims to increase the number of black, mixed race and ethnic minority people on UK stem cell registries by raising awareness and running donor recruitment drives.

- 020 3757 7700
- info@aclt.org
- aclt.org

Anthony Nolan

Runs the UK's largest blood stem cell and bone marrow register, matching donors to patients with leukaemia and other blood-related disorders who need a stem cell transplant.

- 0303 303 0303
- anthonymolan.org

Maggie's

Has centres across the UK, run by specialist staff who provide information, benefits advice and psychological support.

- 0300 123 1801
- enquiries@maggies.org
- maggies.org

Marie Curie

Runs nine hospices throughout the UK and offers end-of-life support to terminally-ill patients in their own homes, free of charge.

- 0800 090 2309
- mariecurie.org.uk

Shine Cancer Support

Provides support to adults in their 20s, 30s and 40s who have experience of a cancer diagnosis.

- shinecancersupport.org
- hi@shinecancersupport.org

MedicAlert

Offers personalised jewellery that provides vital medical information to emergency professionals.

- 01908 951045
- info@medicalert.org.uk
- medicalert.org.uk

Tenovus (Wales)

Provides an information service on all aspects of cancer, plus practical and emotional support for people with cancer and their families living in Wales.

- 0808 808 1010
- tenovuscancercare.org.uk

Teenage Cancer Trust

Offers a range of information, advice and practical support for young people who have been diagnosed with cancer.

- 020 7612 0370
- hello@teenagecancertrust.org
- teenagecancertrust.org

Financial advice

Citizens Advice

Offers advice on benefits and help with filling out benefits forms.

- 03444 111 444 (England)
- 0844 477 2020 (Wales)
- In Scotland or Northern Ireland, contact your local Citizens Advice
- citizensadvice.org.uk

Department for Work & Pensions (DWP)

Responsible for social security benefits. Provides information and advice about financial support, rights and employment.

- gov.uk/government/organisations/department-for-work-pensions

Travel insurance

Macmillan Cancer Support

Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 0808 808 0000
- macmillan.org.uk

British Insurance Broker's Association (BIBA)

Offers advice on finding an appropriate BIBA-registered insurance broker.

- 0370 950 1790
- enquiries@biba.org.uk
- biba.org.uk



Glossary

Anaemia

Anaemia is where you don't have enough haemoglobin (found in red blood cells) in your blood. This can mean that your muscles don't get as much energy as they need, most commonly leading to tiredness or shortness of breath.

Arsenic trioxide

A drug used to treat APL, given through a drip (intravenously). It works by targeting the PML/RARA gene and forcing leukaemia cells to mature into healthy white blood cells.

All-trans retinoic acid (ATRA)

A drug used to treat APL, given as a capsule. It works by overriding the damaged RARA gene and forcing leukaemia cells to mature into healthy white blood cells.

Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

Bone marrow

The spongy material inside your long bones that produces blood cells.

Central nervous system

Part of the body's nervous system, consisting of the brain and spinal cord.

Chemotherapy

Treatment using anti-cancer drugs. It can be a single drug or a combination of drugs. Chemotherapy is used to kill cancer cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells, causing side effects.

Clinical nurse specialist (CNS)

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers, while others may specialise in leukaemia, lymphoma, myeloma, or another specific area. Your CNS can provide information and expert advice about your condition and treatment and can be a good link between you and your doctors.

Clinical trial

A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You need to sign a consent form to take part in a clinical trial, so you'll always be aware if your treatment is part of a trial.

Cytogenetics

The study of the structure of chromosomes (which are made up of genes). Cytogenetic tests are carried out on samples of blood and bone marrow taken from people with leukaemia. They aim to find any genetic changes that could be linked to the disease. They can also help doctors to decide on the best treatment to recommend.

Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It may be caused by the APL itself or it might be a side effect of treatment. It's one of the most common problems that people with cancer can have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.

Genetic fault (mutation)

A small genetic change in the DNA of a cell. Mutations can happen following exposure to hazardous chemicals, or by copying mistakes when a cell divides. If the mutation affects the way cells normally work, it can lead to diseases like cancer.

Immune system

The network of cells, tissues and organs that protect your body against infection.

Intrathecal

A way of giving drugs by injecting them into the fluid in your spine (cerebrospinal fluid or CSF), which bathes and protects the brain and spinal cord.

Leukaemia

A type of blood cancer that's divided into many different subtypes: some that develop faster (acute), and others that develop more slowly (chronic). People with leukaemia have large numbers of abnormal white blood cells, which take over the bone marrow and often spill out into the bloodstream.

Neutropenia/neutropenic

An abnormally low number of neutrophils (a type of white blood cell that helps fight off infections) in your blood.

Promyelocytes

A group of white blood cells. APL happens when promyelocytes don't mature properly and become cancerous. These cancerous cells don't work as they should and take up space in the bone marrow and blood, leaving less room for healthy cells.

Stem cells

Cells that develop into other cell types. Stem cells act as a repair system for your body and create a new supply of cells to replace the ones that die. Blood stem cells are found in the bone marrow.

Steroids

Steroids are made naturally in the body, but they can also be made artificially. Some steroids are taken as tablets. Others are given by injection into a vein (intravenously).



At times I felt overwhelmed with the treatment and side effects, but having a chat with my CNS always made me feel so much better.

Emma, diagnosed with blood cancer aged 35

Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

Booklets

Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

Treatment and beyond

- Blood stem cell and bone marrow transplants:
the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

My information folder

An A5 folder to keep your information in.

Fact sheets

Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

To order or download information

Visit bloodcancer.org.uk/information

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email support@bloodcancer.org.uk

Or use the order form on **page 120**



We're a
community
dedicated to
beating blood
cancer.

About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

Because it's time to beat blood cancer.

Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: **bloodcancer.org.uk/campaigns**

Because we'll beat it together

Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

bloodcancer.org.uk/donate

Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **bloodcancer.org.uk/fundraise**

Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities: **bloodcancer.org.uk/local-community-groups**

Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **bloodcancer.org.uk/volunteer**

Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us: **bloodcancer.org.uk/corporate-partnerships**

Or call us on **0808 169 5155**



**I love being part of the
Blood Cancer UK family.
Being involved has
helped me and my family
cope with my diagnosis.**

Anna, diagnosed with blood cancer aged 39

Notes



Go to bloodcancer.org.uk/donate, call us on **0808 169 5155** or complete and send this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George Street, Edinburgh, EH2 4JN**

Full Name

Address

Email

Phone

As a supporter, you're at the heart of everything we do. We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**

I'd like to donate £10 £25 £50 Other

I enclose a cheque/CAF voucher made payable to Blood Cancer UK

OR please debit my Visa Maestro Mastercard CAF card

Cardholder's name

Card number (Maestro only)

Start date Expiry date Issue number

**Make your donation worth an extra 25p
for every £1 at no extra cost to you!**

I'd like Blood Cancer UK to claim Gift Aid on this donation
and any donations I make in the future or have made in the past 4 years.

gift aid it

*By ticking this box I confirm that I'm a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it's my responsibility to pay any difference.

*Today's date

If you stop paying tax, change your name or address, or if you have any further questions about Gift Aid, please contact our Supporter Relations Team on **0808 169 5155**.

Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

You can order more information by:

- visiting bloodcancer.org.uk/information
- emailing support@bloodcancer.org.uk
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST
PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

Please send me some information

Full Name



Address

Email

Phone

Please tell us the publications you would like us to send you, free of charge (see page 110)

Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email hello@bloodcancer.org.uk

My details

My name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually CNS)

Haematology ward

Haematology clinic

Out of hours

Other contacts

Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Your feedback on this booklet can help us improve – please send any comments to **information@bloodcancer.org.uk**



**Blood
cancer
UK**

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