
Acute promyelocytic leukaemia (APL)

A Guide for
Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

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

Helpline

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

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

Support groups

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

Buddy support

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

Facebook groups

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

Leukaemia counselling service

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

Advocacy and welfare team

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

Cost of living service

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

Will service

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

Information

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

Leukaemia Care magazine

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

To access our services or find out more:

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



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

Introduction

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

Acute promyelocytic leukaemia is a fast-growing type of blood cancer. It develops from immature white blood cells.

Acute promyelocytic leukaemia is shortened to APL or sometimes APML. In this booklet, we call it APL. We cover what it is, how it is diagnosed and what treatment you may have. We also include practical information about living with APL.

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

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

- Dr Richard Dillon, consultant haematologist
- Charlotte Rollinson, haematology clinical nurse specialist
- Jamie, patient reviewer
- Julie, patient reviewer

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

About acute promyelocytic leukaemia (APL)

Summary

- Acute promyelocytic leukaemia (APL) is a fast-growing type of blood cancer. It needs urgent treatment.
- APL is very rare.
- It can cause symptoms such as:



Bleeding or bruising easily



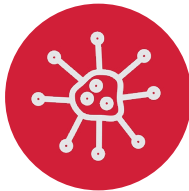
A skin rash



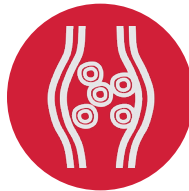
Blood in your poo or pee



Feeling tired, breathless or dizzy



Infections that last a long time or keep coming back



Blood clots



Liver or kidney problems

What is APL?

Acute promyelocytic leukaemia (APL) is a fast-growing type of blood cancer. It develops from immature white blood cells called promyelocytes.

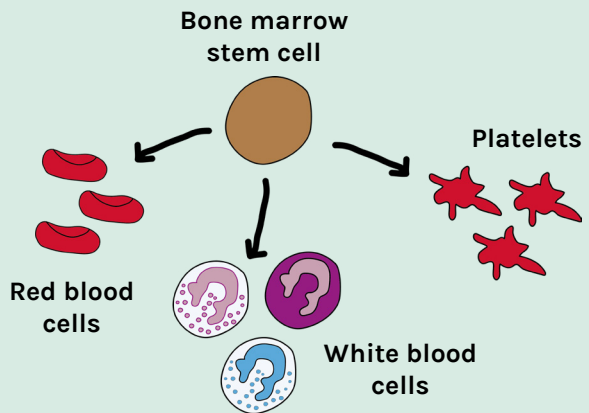
Promyelocytes usually mature into white blood cells that help your body fight infections. But if you have APL, the immature cells grow and divide uncontrollably. They build up in your bone marrow and stop it making enough healthy blood cells.

More about blood cells

Blood cells grow and develop in the spongy centre of some of your larger bones. This is called bone marrow.

There are three main types of blood cell:

- Red blood cells carry oxygen around your body.
- White blood cells fight infections.
- Platelets help your blood clot.



APL is a subtype of acute myeloid leukaemia (AML). But it is treated quite differently from other types of AML.

"My diagnosis was acute promyelocytic leukaemia (APL). I don't remember much of how the haematologist described what it was. But she insisted it was urgent for me to find someone to take me to the hospital, as they would have a bed waiting for me. Thus began the whirlwind (or so it seemed to me) of unfamiliar processes."

Patrick, diagnosed with APL in 2020

Who gets it?

APL is very rare. In the UK, only about 170 people a year get it.

The average age at diagnosis is around 55 but it can happen at any age.

APL can affect people of any ethnic background. It affects men and women equally.

What causes APL?

People with APL have a genetic change in their leukaemia cells called the PML-RARA gene. It happens by chance. You did not inherit it from your parents and you cannot pass it on to any children you might have.

We don't know exactly why this genetic change happens. It is not because of anything you have or have not done.

We have separate information about gene changes in AML. It explains how gene changes happen and how they might lead to cancer. It does not include information about the *PML-RARA* gene in particular. Scan the QR code, follow the link or search for 'gene changes in AML' at www.leukaemiacare.org.uk



Symptoms and signs of APL

APL causes low levels of healthy blood cells and high levels of immature white blood cells.

The immature white blood cells release chemicals that can make blood clots form and dissolve inside your blood vessels. This uses up the proteins your blood needs to clot, which can lead to serious bleeding. The blood clots can also block blood vessels, stopping blood reaching essential organs.

"I kept noticing unexplained bruising, and found I was bruising really easily if I knocked myself. I felt tired and had little energy."

Lisa, diagnosed with APL in 2014

APL can cause symptoms such as:



Nose bleeds or bleeding gums.



Bleeding more than usual from cuts or wounds.



Bruising when you wouldn't usually.



A rash of tiny dots that doesn't fade when you press on it. The dots look red or purple on light skin, or purple or darker brown on black or brown skin.



Blood in your poo, which could look bright red or black and tarry.



Blood in your pee.



Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia).



Infections that last a long time or keep coming back.



Chest pain or breathlessness due to a blood clot in your lungs.



Confusion, slurred speech or problems with your movement due to bleeding in your brain.



Headaches, being sick or problems with your vision due to a blood clot in your brain.



A red or darkened, swollen, painful leg due to a blood clot in your leg. This may be harder to see on black or brown skin.



Liver or kidney problems.

"I felt exhausted all the time and had trouble walking upstairs as I felt breathless. Exercising left me feeling like I would faint. I was also experiencing very painful gums and mouth ulcers. In addition, I had very heavy bleeding during my period. It would not stop. I had a banging headache where I could hear my heartbeat in my ears so loud my head felt like it was throbbing. I had purple spots on my jaw and I was covered in unexplained bruises. The night sweats were awful too, and I had a temperature and felt like I had the flu a few days before diagnosis."

Kate, diagnosed with APL in 2016

The symptoms and signs of APL can start suddenly and get worse quickly. If your doctor thinks you might have it, they'll admit you to hospital straight away for urgent tests.

How is APL diagnosed?

Summary

- Your haematology team diagnose APL based on blood tests and bone marrow tests. This includes urgent genetic tests.
- You might also need other tests or scans, depending on your symptoms.
- You'll start treatment before all the results are back.
- Your doctor will use your blood test results to class your APL as high risk or non-high risk. This helps them work out the best treatment plan for you.

It can be difficult getting an unexpected diagnosis. We are here for you if you need support. Email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Diagnosing APL

APL needs to be diagnosed and treated as quickly as possible. If your doctor thinks you might have it, they'll admit you to hospital for urgent tests. You'll start treatment straight away, even before all your test results are back.

You'll be under the care of a multidisciplinary team of healthcare professionals. We call this your haematology team. It might include:

- A haematologist
- A clinical nurse specialist (CNS)
- A pharmacist
- A physiotherapist
- A dietician



Tests for APL

You'll have blood and bone marrow tests to diagnose APL. The samples go to the lab for specialist testing.

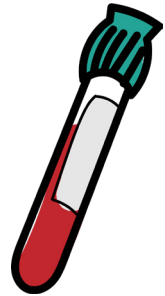
"The out-of-hours GP was brilliant. She did a urine sample, blood tests, everything. She said it would be a couple of hours before we got the results, so I opted to go home. She rang 2 hours later and said, 'Right we need to get you to A&E. There's something really wrong here.' And that was how it went. I spent the next 6 weeks in hospital."

Kate, diagnosed with APL in 2016

Blood tests

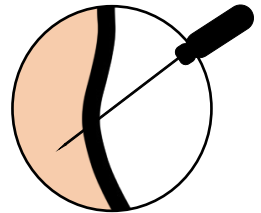
You will have blood tests to:

- Measure your numbers of red blood cells, white blood cells and platelets
- See how your blood cells look under a microscope
- Look for gene changes in your blood cells
- Check your blood clotting
- Check how well your liver and kidneys are working



Bone marrow tests

If your doctor thinks you might have APL, they may do a bone marrow test. This involves taking a sample of your bone marrow, usually from the back of your pelvis, with a local anaesthetic.

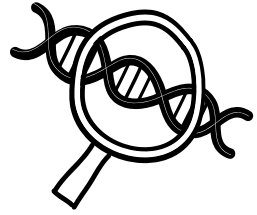


"I went to the GP for a routine blood test. They called me after to tell me my white blood cell count was incredibly low – in fact, all of my blood counts were below range. I had a second blood test, which then confirmed the very low blood count, and my GP referred me to the local hospital for a bone marrow biopsy. The next day, the haematologist rang to tell me my diagnosis."

Patrick, diagnosed with APL in 2020

Genetic tests

Your doctor will send your blood and bone marrow samples to the lab for urgent genetic tests. These look for a genetic change called *PML-RARA*. If your white blood cells have this change, it confirms the diagnosis of APL.

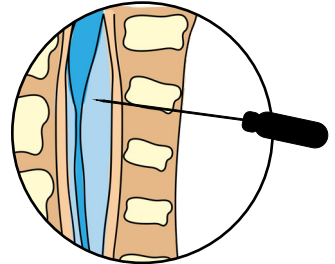


The results should be back within 24 hours. But you'll start treatment straight away, even before the results come back.

Other tests you might have

You might have a heart tracing or scan to check your heart health. This is because some APL treatments can affect your heart.

Once your risk of bleeding is under control, you might have a lumbar puncture. This is a test to collect a sample of the fluid that surrounds your brain and spinal cord. A doctor collects the sample through a needle in your back. A lumbar puncture checks for leukaemia cells in your central nervous system.



APL risk groups

Your doctor will use your test results to work out your risk group. This is based on your white blood cell count.

- If your white blood cell count is high, it's called high risk APL.
- If your white blood cell count is lower, it's called non-high risk APL. You might also hear your team call it:
 - Standard risk APL
 - Low to intermediate risk APL

People with high risk APL have a higher chance of serious bleeding and clotting problems. So they need more intensive treatment.

Your risk group helps your haematology team work out the best treatment plan for you.

How is APL treated?

Summary

- People with APL have a high risk of serious bleeding. You have treatment straight away to manage this.
- This involves a medicine called ATRA, alongside transfusions of blood or blood products, and sometimes other medicines.
- The main treatment for APL happens in two phases:
 - **Induction treatment** aims to get rid of as many leukaemia cells as possible.
 - **Consolidation treatment** aims to kill any leukaemia cells that may be left.
- The treatment you have at each phase depends on your risk group.
 - If you have non-high risk APL, you have a combination of medicines called ATRA and ATO.
 - If you have high risk APL, you have ATRA and ATO and a chemotherapy medicine.
- You also have treatment to prevent or manage symptoms or side effects.

Treatment options for APL

You'll probably start urgent treatment straight away, while you are waiting for some of your test results. Once all your results are back, your haematology team can make a definite diagnosis. They then work out the best treatment plan for you. This is based on your risk group ([page 17](#)). They also consider any other health problems you have.

"I had flu-like symptoms – joint pain, tiredness, fever, difficulty breathing – and saw my GP. Within an hour I was in the hospital having blood tests, a bone marrow biopsy, and pre-emptive treatment before a diagnosis was confirmed."

Jamie, diagnosed with APL in 2019

The main treatments you might have are:

- ATRA, which stands for all-trans retinoic acid. It's also known as tretinoin. ATRA is a medicine related to vitamin A. It makes immature white blood cells develop into healthy blood cells. It also stops them making chemicals that disrupt the normal clotting process.
- ATO, also known as arsenic trioxide. Its brand name is Trisenox. Like ATRA, it encourages immature white blood cells to develop into healthy white blood cells. It can also trigger them to self destruct.
- Chemotherapy medicines. These kill cells that are dividing rapidly, such as blood cells. The most common chemotherapy medicine used for APL is called idarubicin. Your haematology team will explain if you need chemotherapy, and what chemotherapy medicines they recommend.

You might have heard of arsenic as a poison. But in the doses used to treat APL, it's a very effective and safe medicine.

Whatever option your haematology team recommend, you have treatment in phases.

- **Induction treatment** aims to get rid of as many leukaemia cells as possible. You usually stay in hospital to have it at first. Once your condition is stable, you might be able to go home and have it as an outpatient.
- **Consolidation treatment** aims to kill any leukaemia cells that may be left behind. You usually have it as an outpatient.



Your treatment will involve some medicines that you have through a drip. You will also need regular blood tests. Your haematology team might fit a central line to make this easier.

More about central lines

A central line is a long, thin plastic tube that enters the skin in your arm or your chest. It runs underneath your skin and ends in a large vein near your heart. It can be used to give treatments straight into your veins, and to take blood samples.



If you need a central line, you have a local anaesthetic to numb the skin first so it does not hurt when the line goes in. You might have a sedative too, if you need one.

Your team will show you how to keep your central line clean and dry.

Urgent treatment

People with APL have a high risk of serious bleeding, which can be life threatening. You'll have treatment straight away to manage bleeding and clotting problems. This also helps prevent serious blood clots too.

"A lovely consultant came in and told me I had leukaemia. They weren't sure what type, but they started me on treatment that day so we could make a plan a few days later. It was such a shock."

Lisa, diagnosed with APL in 2014

You'll have:

- ATRA. This comes as capsules that you take by mouth.
- Transfusions of platelets, proteins that help your blood clot (clotting factors) or other blood products. You have these through a drip into a vein.



You'll have daily blood tests until your clotting is back to normal.

Other medicines you might have are:

- Idarubicin. This is a chemotherapy medicine you have through a drip. If you have a high white blood cell count, you will usually have one or two doses.
- Hydroxycarbamide. This is a gentler chemotherapy medicine that you have as a tablet. It can also help lower your white blood cell count.
- Dexamethasone or prednisolone. These are steroid medicines. You might have them to prevent or treat some of the side effects of APL treatment.

Induction treatment

Induction treatment lasts around 2 months.
During induction treatment:



- You have ATRA capsules twice a day every day.
- You have ATO treatment through a drip into a vein. This usually takes 1 to 2 hours. You have it every day for the first week. Then you have it twice a week for the next 7 weeks.
- If you have high risk APL, you also have idarubicin, or another chemotherapy medicine. You have it through a drip into a vein. You usually have two doses during the first week of treatment.

"I was told I had AML and I needed urgent chemotherapy. Two days into the chemo and after two bone marrow biopsies, I was told I actually had APL, which they said was the 'better' one of the two as it's more treatable. So, I started on a new chemo regimen. It was bright orange idarubicin. Or Irn Bru as I affectionately called it."

Kate, diagnosed with APL in 2016

Sometimes, your haematology team might suggest different treatment, depending on your circumstances. They will explain what they recommend for you.

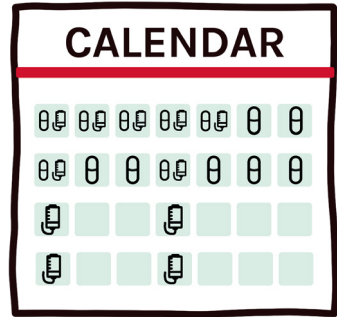
Consolidation treatment

You have consolidation treatment in cycles. Each cycle is 8 weeks long.

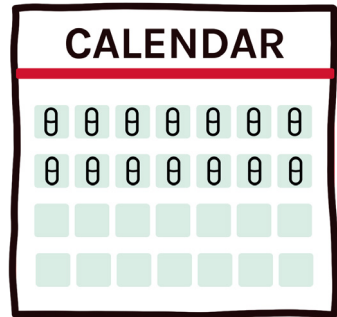
- You have ATRA capsules twice a day, in a pattern of 2 weeks on, 2 weeks off.
- You have ATO during the first 4 weeks of each cycle. You have it through a drip into a vein. It usually takes 1 to 2 hours.
 - In the first week of each cycle, you have ATO on 5 days.
 - In weeks 2, 3 and 4, you have ATO twice a week.
 - Then you have 4 weeks off.

You usually have four cycles of consolidation treatment.

Weeks 1 to 4



Weeks 5 to 8



"After talking with my care team I had slight changes made to my consolidation treatment, as 5 days of ATO in a row was too much for my body to cope with."

Jamie, diagnosed with APL in 2019

Supportive care

You'll also have treatment to prevent or manage symptoms or side effects. This is called supportive care. It does not treat APL itself, but it helps you feel better.

"I had six blood transfusions and four platelet transfusions."

Lisa, diagnosed with APL in 2014

Supportive care might include:

- Blood transfusions, if your blood counts are too low
- Clotting factors or other blood products, if you are at risk of bleeding
- Anti-sickness or anti-diarrhoeal medicines, if you need them
- Pain relief, if you need it
- Medicine to prevent or treat infections
- Mouthwashes to help with mouth ulcers or a sore mouth
- Food or drink supplements, if you are not able to eat or drink enough
- Steroids, which can help with many different symptoms and side effects

Supportive care is not only limited to the physical impact of APL. It can include:

- Psychological support
- Support with exercise or physiotherapy
- Social support
- Spiritual wellbeing

"I had multiple blood transfusions, platelets and plasma. At various stages I was taking anti-sickness, antibiotics, potassium, antidepressants, anti-anxiety medicines, two different mouthwashes, and a lot of painkillers!"

Jamie, diagnosed with APL in 2019

Your haematology team should talk to you to find out what support they can offer you. Let them know if you have any symptoms or side effects that you are finding hard to cope with.

Monitoring your response to treatment



You have regular blood tests throughout treatment to check your blood cell counts. This gives a good indication of how well your APL is responding.

"My daily blood count figures were slowly going up and I was promised a discharge home when my white blood cell count was high enough. This was achieved 5 weeks and 1 day after my admission."

Patrick, diagnosed with APL in 2020

At the end of consolidation treatment, you have blood and bone marrow tests. These go to the lab for a genetic test called PCR.

About PCR testing

- A PCR test assesses the level of the *PML-RARA* gene in your blood or bone marrow. This is a good measure of how much leukaemia is left in your body.
- PCR is very sensitive so it can detect extremely low levels of leukaemia in your body.
- If the test cannot measure any *PML-RARA* gene in your blood or bone marrow, it's called PCR negative or MRD negative. MRD stands for minimal residual disease.

If you are PCR negative at the end of consolidation treatment, the test cannot detect any leukaemia cells left in your body. This means your APL is in remission. This is the case for around 95 to 99 in every 100 people at the end of consolidation treatment for APL.

After you finish treatment:

- You'll have regular blood tests to check your blood counts. These happen every month at first and gradually get less frequent.
- If you have high risk APL, you might also have PCR tests every 3 months for 2 years. This is to check for any sign that APL has come back.
- If you have non-high risk APL, your risk of relapse is very low. So you do not need any more PCR tests.

Treatment if APL does not respond or comes back

APL usually responds well to treatment. But around 1 to 5 in every 100 people have some leukaemia cells left at the end of consolidation treatment. This is called refractory APL.

Occasionally, APL also comes back after treatment. This is called relapse.

If you have relapsed or refractory APL, you'll need more treatment. Your options depend on what treatment you've already had and how you responded to it. Your team will tell you what they recommend for you. They might suggest:

- Treatment as part of a clinical trial, if there is one suitable for you
- ATRA and chemotherapy, if your first treatment was ATRA and ATO
- ATRA and ATO, if your first treatment was ATRA and chemotherapy

If you respond well to your second treatment, your team might recommend a stem cell transplant. This aims to reduce the chance of APL coming back again.

This involves having high-dose chemotherapy or radiotherapy that kills blood-forming cells called stem cells in your bone marrow. These are replaced by healthy stem cells. They might be your own stem cells, collected before the chemotherapy. Or they might come from a matched donor.

A stem cell transplant is a very intensive form of treatment. It is not suitable for everyone.

We have separate [information on stem cell transplants](#). Scan the QR code, follow the link or search for 'stem cell transplant' at www.leukaemiacare.org.uk



What are the side effects of APL treatment?

Summary

- APL treatments can cause side effects. Some of these may be serious.
- Side effects of APL treatments include:
 - A serious reaction called differentiation syndrome. It happens when white blood cells release too many immune chemicals.
 - A rapid rise in your white blood cell count.
 - Changes to your heart rate or rhythm.
 - An increase in the pressure around your brain.
 - Low blood cell counts.
 - Changes in your liver function.
 - Changes in the levels of sugar and fats in your blood.
- Your haematology team will monitor you closely so they can treat side effects promptly.
- Treatment for APL harms unborn babies. Some treatments can damage sperm and eggs. You should not become pregnant, or make someone pregnant, while you are having treatment for APL.
- **Tell your team straight away if you have any symptoms or side effects.**

Important side effects of APL treatment

Treatment for APL is intensive. Like all medicines, it can cause side effects. Some of these can be serious. Side effects are different for everyone, and we cannot predict what side effects you may get.

Your haematology team will monitor you for serious side effects. You'll have regular checks, blood tests and heart scans. This means they can treat side effects promptly if they happen.

Tell your team straight away if you have any symptoms or side effects.

Your haematology team will explain the side effects you might get with your treatment. Here, we cover some of the important side effects of APL treatment in general. It is not a complete list.

Differentiation syndrome

ATRA and ATO can cause a serious problem called differentiation syndrome. It happens when white blood cells mature rapidly and release too many immune chemicals. This can trigger a life-threatening reaction.

Your team will monitor you for signs of differentiation syndrome so they can treat it promptly. If you notice any symptoms yourself, tell your team straight away.

If it happens, it can be treated with steroids. If it's severe, you might need to stop treatment for a while.

The signs and symptoms of differentiation syndrome include:

- Fever
- Cough, breathlessness or difficulty breathing
- Chest pain
- Weight gain or swelling of your arms or legs
- Low blood pressure
- Low blood oxygen levels

"I had differentiation syndrome twice, which is very rare. While the symptoms were being controlled I was given another chemotherapy drug - hydroxycarbamide - to keep working on the white blood cells. Thankfully when my levels recovered I was able to resume ATO and ATRA treatment."

Jamie, diagnosed with APL in 2019

High white blood cell count

Treatment for APL encourages immature white blood cells to develop into healthy white blood cells. This can make your white blood cell count rise rapidly. It usually peaks around 10 days after starting treatment.



If this happens, you might need a short course of chemotherapy capsules called hydroxycarbamide. These help lower your white blood cell count.

Heart problems

Treatment with ATRA and ATO can affect the electrical activity in your heart. This can sometimes change your heart rate or rhythm. It is more likely to happen if you have low levels of potassium or magnesium in your blood.



You'll have regular heart tracings (ECGs) to check the electrical activity in your heart. And blood tests to check the level of salts in your blood.

"Arsenic can affect your heart and so my twice weekly sessions were preceded by an ECG and more often than not a potassium infusion."

Kate, diagnosed with APL in 2016

If you get changes in your heart tracing:

- You might have to stop treatment for a while
- Your haematology team will stop any other medicines that could affect your heart
- You might have a drip to correct the balance of salts in your blood

Pressure around your brain

ATRA or ATO treatment can sometimes increase the pressure around your brain. This affects about 3 in every 100 people. So about 97 in every 100 do not get it.

It can cause symptoms like:

- Bad headache
- Double vision
- Feeling or being sick
- Hearing your heartbeat whooshing in your ears

If it happens, you may need painkillers to ease your headache. You might also have steroids or water tablets to lower the pressure in your brain. Or a doctor might remove some of the fluid surrounding your brain and spinal cord through a needle in your back.

Problems found on blood tests

You have regular blood tests during treatment to check your blood counts, blood sugar and fat levels, and how well your liver and kidneys are working.



- APL and its treatment can cause low blood counts. If this happens, you might need blood transfusions.
- ATRA and ATO can affect your liver. If your blood tests find any problems, your haematology team might reduce your dose or stop your treatment for a while.
- ATRA and ATO can affect the level of sugar and fats in your blood. This is not usually serious.

Neutropenia and infection risk

APL treatment can lower your white blood cell count. This is called neutropenia. It means your body can't fight infections as well as usual. So, you have a higher chance of getting infections, and any infections you do get may be more serious.

"Your body can become susceptible to other illnesses too, so it's important to take precautions with what you eat and how you look after yourself."

Jamie, diagnosed with APL in 2019

If your white blood cell count is low, there are things you can do to lower your risk of getting an infection. These include:

- Washing your hands frequently
- Avoiding crowded spaces
- Avoiding people who are unwell
- Storing and preparing food correctly to reduce the risk of food poisoning
- Making sure your kitchen is clean
- Regularly cleaning surfaces that you touch a lot, like light switches and door handles
- Having any vaccinations that you are eligible for

Your haematology team might also prescribe antibiotics or antiviral medicines to help prevent infections.

Contact your medical team straight away if you think you have an infection.

Other side effects you might get

Side effects vary from person to person. Other side effects you might get include:

- Feeling exhausted
- Feeling anxious, depressed, confused, dizzy or finding it hard to sleep
- Headaches
- Pins and needles
- Skin rash, flushing, sweating or itching
- Breathlessness, wheezing or chest pain
- Feeling or being sick
- Diarrhoea, constipation or tummy pain
- Dry nose or mouth
- Problems with your vision or hearing
- Hair loss
- Muscle or bone pain
- Fever or chills

"ATRA left my mouth dry and caused my lips to crack. I would strongly suggest trying to find a good intensive lip balm. Arsenic gave my sinuses a hard time, and I often had black eyes as a result."

Jamie, diagnosed with APL in 2019

Pregnancy and breastfeeding

Treatment for APL harms unborn babies. Some treatments can damage sperm and eggs. You should not get pregnant, or make someone pregnant, while you are having treatment for APL.

- If you could get pregnant:
 - **You must use effective contraception during treatment and for several months after.**
 - You will have a pregnancy test before treatment to make sure you are not pregnant.
 - You might have regular pregnancy tests during treatment too.
 - How long you must continue to use effective contraception after finishing treatment varies for different treatments. Your haematology team will tell you.
- If you think you might be pregnant, tell your haematology team as soon as possible. They will talk to you about your options.
- If you could make someone pregnant, you may need to use effective contraception during treatment and for several months after. It depends what treatment you are having. Your team will tell you.

Treatments for APL pass into breastmilk.

- You must not breastfeed during treatment.

Outcomes of APL

Summary

- Outcomes of APL vary from person to person. They depend on lots of different factors, including your age and your risk group.
- The main risk of APL is life-threatening bleeding or clotting problems in the first month after diagnosis.
- After this critical period, outcomes are usually very good.
- Survival rates are only averages. It is not possible to predict for certain what will happen for you.
- Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

Outcomes of APL

Outcomes for people with APL vary from person to person depending on their age, risk group and other factors. But it's impossible to predict for certain how APL will affect you, or how it may respond to treatment.

Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

The main risk of APL is life-threatening bleeding or clotting problems in the first month after diagnosis.

After this critical period, outcomes are usually very good. Almost everyone who survives the first 30 days responds well to treatment. And after successful treatment, it is unusual for APL to come back.

If you are interested in general survival rates for APL, we include some figures on the next page. You may prefer not to look at these.

It is important to remember that survival numbers cannot tell you what will happen in individual situations. They look at what happened to groups of people with a similar diagnosis in the past. They are based on data collected over many years, when people may not have received treatments available now.

In blood cancers, 5-year survival rates are commonly quoted. This is the proportion of people with a particular condition who are still alive 5 years after diagnosis.

Survival rates do not tell us anything about what people who are not alive 5 years after diagnosis died from. It may have been the condition or from another cause.

Overall, around 90 in every 100 people with APL are still alive 5 years after diagnosis. Around 10 in every 100 are not.

Your APL risk group may slightly affect your outcome. Your chance of being alive 5 years after diagnosis is estimated to be:

- Around 90 in 100 for non-high risk APL
- About 80 in 100 for high risk APL

These figures include people who were seriously ill when they came into hospital and may not even have had a chance to start treatment. It is extremely unusual for someone with APL to die after the first few weeks of treatment.

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

It is not possible to predict for certain what will happen for you. Your haematology team will only be able to give you an idea of what they expect for you.

If you are struggling to come to terms with your diagnosis, you can speak to us. Call our helpline on **08088 010 444**.

Living with APL

Summary

- Being diagnosed with APL can be overwhelming. Give yourself time to adjust before you decide when and how to tell other people.
- You may experience a variety of emotions. There is no right or wrong way to feel. But if you think you may be depressed, contact your GP.
- You probably have a lot of questions. Make a list of them so you don't forget to ask them when you see your haematology team.
- If you're going to be in hospital for a while, take things to make your stay more comfortable, including things to do.
- Don't be afraid to ask for help from family, friends, your haematology team or Leukaemia Care support services.
- Having APL can affect your work or finances. You may be eligible for financial support. If you're well enough to work or study, you are entitled to reasonable adjustments to help you cope.
- Try to keep active and eat a healthy, balanced diet if you can, to help you feel better physically and emotionally.

When you're first diagnosed with APL

Being diagnosed with APL can be overwhelming. You probably have a lot of questions and concerns. Here, we cover some of the things you may want to know.

You might find our [information for newly-diagnosed people](#) helpful. Scan the QR code, follow the link or search for 'just diagnosed' at www.leukaemiacare.org.uk



Questions you might want to ask

There's a lot to take in when you're diagnosed with APL. It can help to have a family member or friend with you for support.

Make sure you ask any questions you have. If you don't understand something, ask your haematology team to explain. They'll be used to this.

"The consultant visited me and explained a few things, but I was a bit sleepy and somewhat confused. It was an overload of unfamiliar medical terms about an illness that I had never heard of. He introduced to me the idea of five, 8-week cycles of treatment for my APL."

Patrick, diagnosed with APL in 2020

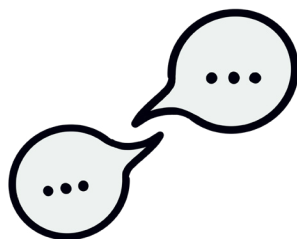
You could take notes to help you remember, or ask your doctor or nurse to write things down. Or you could ask if they're happy for you to record the conversation.

Here are some questions you might want to ask:

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

Telling other people

You may need to give yourself time to adjust before you decide when and how you tell others about it. People may be anxious to know what's happening, which can make you feel under pressure to tell them. Let them know that you need time to process the information yourself before you are ready to talk about it.



There will be some people you want to tell and others you prefer not to. It is up to you who you tell and how much you tell them. It can help to make a list and plan what you want to say beforehand. If you can, choose somewhere you can hear each other clearly and where you're not likely to be interrupted.

Try to speak slowly and calmly to give the other person time to take in the information. If you're struggling to know what to say, you could try:

- "This is going to be difficult, but I need to tell you something."
- "You know I've been feeling unwell. I've had some tests and they've found out what's wrong."
- "I've had some bad news, but now I've got a diagnosis, there's a plan for me to start treatment."

Repeating yourself to different people can be draining. You could ask family or friends to let other people know, so you don't have to tell everybody yourself.

Managing your emotions

Finding out you have APL can be overwhelming. You may experience a range of emotions, like:

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

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

Let your haematology team know how you're feeling. They can help you access support and may be able to refer you for counselling if you need it.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Call 111, scan the QR code or go to the 'mental health' section at www.nhs.uk



"Asking for help with your mental health is so important – remember that your consultant and haematology team are highly trained and focused on your blood cells, so you may have to speak up (or ask someone else to) if you are struggling with your feelings. After keeping things inside for a long time, I was able to get help for my anxiety, my panic attacks, and my sadness."

Jamie, diagnosed with APL in 2019

[We're here for you if you need support.](#) Scan the QR code, follow the link or search 'support for you' at leukaemiacare.org.uk to find out how we can help you. Our support services include:



- Helpline and advocacy services to provide information and support
- Support groups and a buddy service, where you can connect with people who understand your experience
- A counselling service where you can apply for up to six sessions of counselling free of charge

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

Talking to other people can help. It can be difficult to talk to loved ones, so you might prefer to speak to someone independent. It can also help to talk to other people who have gone through a similar experience.

Some people find relaxation techniques help them cope with difficult emotions, or use complementary therapies like acupuncture, massage or yoga. Some people find faith or spirituality helpful.

Macmillan have information on complementary therapies. Scan the QR code, follow the link or search for 'complementary therapies' at www.macmillan.org.uk



Practicalities of living with APL

Symptoms, treatment, tests and hospital appointments may all have an impact on your day-to-day life. Here, we cover some of the practicalities of living with APL.

Staying in hospital

If you know you're going to be staying in hospital, try to arrange for someone to look after your home while you're away. And pack things that will make your hospital stay more comfortable, such as:



- Comfortable clothes, underwear and nightwear – loose clothes work well because they can fit over a drip
- Socks and slippers
- Toiletries, including period products if you need them
- Essential items like your glasses, contact lenses or a hearing aid
- Things to do, like your phone, tablet or laptop (plus headphones and a charger), books, puzzles or crafts
- Photos, cards or other things that cheer you up
- A sleep mask and earplugs
- Your own pillow, towels and bedding, if your hospital allows them
- A list of all the medicines you usually take

Home life

A diagnosis of APL is likely to impact your home life while you are in hospital and after you go home. You may need help with shopping, childcare, looking after pets, housework or gardening.



You might find our [information for newly-diagnosed people](#) helpful. Scan the QR code, follow the link or search for 'just diagnosed' at www.leukaemiacare.org.uk



Ask for help if you need it, so you can focus on your recovery. It can be difficult for people to know how best to support you, so let them know what you'd like help with, and what you'd prefer to do yourself.

Work, education and money

APL is serious. You may need to stay in hospital for some time and you will need time off work, school or education. Once you are at home, you are likely to need time off when you're feeling unwell and to attend appointments. You'll need to keep your employer or education provider informed.

Depending on your employment contract, you may be entitled to sick pay. But whether or not you are working, there may be benefits or other financial support you are eligible for. You are also entitled to free prescriptions. Your haematology team can tell you how to apply.

Our [Cost-of-living hub](#) has information you might find useful. We offer financial support and have a welfare service that may be helpful. Scan the QR code, follow the link or search for 'cost of living service' at www.leukaemiacare.org.uk



If you are well enough to work or go to school or university, you are entitled to reasonable adjustments to help you cope. You may wish talk to your employer or education provider about what is happening and how they can support you.

Looking after yourself

It's important to look after yourself as well as you can. This can help you feel better physically and emotionally. If you're able to, try to eat a well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with your treatment

Some treatments for APL might affect your appetite or have side effects such as sickness, constipation or diarrhoea. This can make it difficult to eat a healthy diet. Try to eat what you can. If you're struggling, ask your haematology team for advice.

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



Staying active is also helpful. Exercise can improve your wellbeing, quality of life and physical health. It can also help you cope with your emotions. It doesn't have to be strenuous – even a gentle walk can help. Choose a level of exercise that works for you and how you're feeling.

If you have a high risk of bleeding, ask your haematology team what precautions you should take.

Words you might see or hear

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

Acute promyelocytic leukaemia (APL or APML): a rare subtype of acute myeloid leukaemia. It starts in immature blood cells called promyelocytes.

ATO (also known as arsenic trioxide or Trisenox): a common treatment for acute promyelocytic leukaemia.

ATRA (also known as tretinoin): a medicine used to treat acute promyelocytic leukaemia.

Bone marrow test: a test to take a sample of the spongy tissue from the centre of a bone, usually your hip bone.

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

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

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

Clinical trials: research studies that aim to find out what treatments work best for particular conditions.

Clotting factors: proteins that help your blood clot.

Consolidation treatment: treatment that aims to kill any leukaemia cells that may be left after induction therapy.

Differentiation syndrome: a life-threatening reaction to some cancer medicines. It can happen when white blood cells mature rapidly and release too many immune chemicals.

ECG: a test to check the electrical signals in your heart.

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

Idarubicin: a chemotherapy medicine.

Induction treatment: treatment that aims to kill as many leukaemia cells as possible.

Lumbar puncture: a test to collect a sample of the fluid that surrounds your brain and spinal cord through a needle in your back.

MRD (minimal residual disease): low levels of leukaemia cells left in your body after treatment. MRD negative means none can be detected.

PCR test: a lab test that looks for particular pieces of genetic code in your cells.

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

PML-RARA gene: a changed gene found in acute promyelocytic leukaemia.

Promyelocyte: a type of immature blood cell.

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

Refractory: cancer that does not respond well to your first treatment.

Relapse: when cancer comes back after successful treatment.

Stem cell transplant: treatment that replaces damaged or abnormal blood-forming cells in your bone marrow with healthy ones.

Steroids: medicines that reduce inflammation and have anti-cancer effects.

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

Useful contacts and further support

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

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

Here are some organisations you might find helpful.

Leukaemia Care

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

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

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Acute Leukemia Advocates Network (ALAN)

A network of patient organisations that aims to improve the lives of people affected by leukaemia.

acuteleuk.org

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888

bloodcancer.org.uk

Macmillan

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

0808 808 00 00

www.macmillan.org.uk

Maggie's

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

0300 123 1801

www.maggies.org

Carers UK

Offer advice, information and support for carers.

0808 808 7777

www.carersuk.org

Citizens Advice

Offer advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

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

How you can help us

Share your story

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

To share your story:

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



Volunteer with us

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

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

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

Tell us what you think of this booklet

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

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



You can also contact us for a list of the sources we used.

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

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

You can help

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

No fuss options

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

Contact our fundraising team

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



Plenty of ways to give

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

By bank transfer

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

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

By cheque

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

Online

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



By phone

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

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

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

Want to talk?

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

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

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

Leukaemia Care
YOUR Blood Cancer Charity



Version 3
Reviewed: 04/2025
Next review: 04/2028