Acute promyelocytic leukaemia (APL)

Acute promyelocytic leukaemia is a fast-growing type of blood cancer. It develops from immature white blood cells. Find out about the signs and symptoms, tests you might have, and how it is treated.

Summary

- Acute promyelocytic leukaemia (APL) is a rare, fast-growing type of blood cancer.
- We do not know exactly what causes it. But it is not because of anything you have or have not done.
- The main symptoms of APL are bleeding, bruising and blood clots. These can be very serious.
- APL needs to be diagnosed and treated as quickly as possible.
- Doctors diagnose it from blood and bone marrow tests.
- You'll have urgent treatment straight away, while you are waiting for some of your test results.
- The main treatments for APL are:
    - A medicine called ATRA. This comes as capsules that you take by mouth.
    - A medicine called ATO. You have this through a drip into a vein.
    - Transfusions of platelets, proteins that help your blood clot and other blood products.
    - Two doses of chemotherapy, if your white blood cell count is high.
    - Medicines to prevent or treat symptoms or side effects.
- **We are here for you if you need support.**

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What is APL?

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

- If you have APL, these immature cells grow and divide uncontrollably. They build up in your bone marrow and stop it making enough healthy blood cells.
- They also 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.

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

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Who gets APL?

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.

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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.

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What are the signs and symptoms of APL?

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.

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How is APL diagnosed?

> **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 have blood and bone marrow tests to diagnose APL. The samples go to the lab for specialist testing.

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.

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 a heart tracing or heart 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.

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How is APL treated?

You have treatment for APL in phases.

- 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.
- 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.
- 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.

Urgent treatment

You'll have urgent treatment straight away, while you are waiting for some of your test results. This is to manage bleeding and clotting problems. It also helps prevent serious blood clots too.

You'll have:

- A medicine called ATRA.
- This stands for all-*trans* retinoic acid. It's also known as tretinoin. ATRA is a medicine related to vitamin A.
- ATRA makes immature white blood cells develop into healthy blood cells. It also stops them making chemicals that disrupt the normal clotting process.
- It 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.
- If your white blood cell count is high, you might also have some doses of chemotherapy to help lower it. You might have these through a drip or as tablets.

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 involves induction treatment and consolidation treatment.

Induction treatment

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.

Induction treatment lasts around 2 months. During induction treatment:

- You continue taking ATRA capsules. You have these twice a day every day.
- You also have a medicine called ATO.
- ATO stands for arsenic trioxide. Its brand name is Trisenox. 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.
- ATO encourages immature white blood cells to develop into healthy white blood cells. It can also trigger them to self destruct.
- You have it through a drip into a vein. Each dose usually takes 1 to 2 hours.
- You have it every day for the first week of induction treatment. Then you have it twice a week for the next 7 weeks.
- If you have a high white blood cell count, you also have a chemotherapy medicine.
- This is usually called idarubicin, but your haematology team might suggest a different medicine. You have it through a drip into a vein.
- You usually have two doses of idarubicin during the first week of treatment.

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

Consolidation treatment

Consolidation treatment aims to kill any leukaemia cells that may be left behind after induction. You usually have it as an outpatient.

You have consolidation treatment in cycles. You usually have four 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.

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.

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 medications, 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

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.

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Side effects of treatment

APL treatments can cause side effects. Some of these may be serious.

> **Your haematology team will monitor you closely so they can treat side effects promptly. Tell them straight away if you notice any symptoms or side effects. They can offer treatments or suggest things to help.**

Side effects of APL treatments include:

- A serious reaction called differentiation syndrome. It happens when white blood cells release too many immune chemicals. It can be treated with steroids.

- 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.
- Infections.
- 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.

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After treatment

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

- Around 95 to 99 in every 100 people have no leukaemia left at the end of consolidation treatment. This means you are in remission. You'll have blood tests and check-ups to make sure you stay well.
- Around 1 to 5 in every 100 people have some leukaemia left at the end of consolidation. If this happens, you will need more treatment. Your team will tell you what they recommend. If you respond well to your second treatment, they might suggest a stem cell transplant. This aims to reduce the chance of APL coming back again.

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Outcomes of APL

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.

Outcomes of APL vary from person to person. They depend on lots of different factors, including your age and your test results. Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

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