T-cell prolymphocytic leukaemia (T-cell PLL)

T-cell prolymphocytic leukaemia (T-cell PLL) is a rare blood cancer. It affects white blood cells called T cells. Find out what T-cell PLL is, signs and symptoms you might get, how T-cell PLL is diagnosed, and what treatment you may have.

Summary

- T-cell PLL is a rare blood cancer that affects white blood cells called T cells.
- Some people don't have symptoms when they are diagnosed. But symptoms you may get include swollen lymph nodes or tummy pain or discomfort from a swollen liver or spleen. You may also have a rash or get swelling around your eyes or in your legs.
- You'll have blood tests and sometimes bone marrow tests to diagnose T-cell PLL.
- If you don't have symptoms, you may not need treatment straight away. Your team will monitor you closely instead.
- Most people need treatment within 1 to 2 years of diagnosis.
- Treatment varies from person to person. You might have antibody therapy, treatment as part of a clinical trial, chemotherapy or a stem cell transplant.
- Your haematology team will tell you what treatment they recommend for you.

Download our factsheet about T-cell PPL

What is T-cell PLL?

T-cell prolymphocytic leukaemia (T-cell PLL) is a rare blood cancer. It starts in white blood cells called T cells. T cells are part of your immune system. They help your body recognise and fight infections. But if you have T-cell PLL, they become abnormal and divide uncontrollably. The abnormal cells build up in your bone marrow, lymph nodes and bloodstream.

Not everyone with T-cell PLL experiences it the same way.

- In around 7 to 8 in every 10 people, T-cell PLL is fast-growing and aggressive.

- In 2 to 3 in every 10 people, it can be slow-growing at first. It usually becomes aggressive within 1 to 2 years of diagnosis.

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Who gets T-cell PLL?

T-cell PLL is very rare. Around 70 people are diagnosed with it each year in the UK. This is why you might not have heard of T-cell PLL or met anyone with it before.

T-cell PLL can affect people of any age, but it is more common in people over 60. It is also more common in people with a genetic condition called ataxia telangiectasia. If you have this condition, you may get T-cell PLL at a younger age. T-cell PLL affects men and women equally.

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What causes T-cell PLL?

We do not know the exact cause of T-cell PLL. People with T-cell PLL have genetic changes in their leukaemia cells that make the cells grow out of control. We do not know why these genetic changes happen. **It is not because of anything you have or have not done.**

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Symptoms of T-cell PLL

You might not have symptoms when you are first diagnosed. Some people are diagnosed after a blood test for something else. But you might get some signs or symptoms over time.

The signs and symptoms you might get vary from person to person. They might include:

- Tummy pain, bloating or discomfort due to a swollen spleen or liver
- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia)
- Bruising or bleeding easily (for example, nose bleeds or bleeding gums when you brush your teeth)
- Swollen lymph nodes

- Skin lesions or a reddish rash (this may look different on black or brown skin)
- Fever
- Night sweats
- Losing weight without trying to
- Swelling around the eyes or in the legs, due to a build up of fluid.

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Diagnosis of T-cell PLL

You'll have blood tests and sometimes bone marrow tests to diagnose T-cell PLL. 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. If you have T-cell PLL, you'll have high levels of abnormal T cells. You may have low levels of healthy blood cells.
- Look at your blood cells under a microscope to check for abnormal blood cells.

You might also have blood tests to:

- Check how well your liver and kidneys are working
- Check if you have any infections that could flare up during treatment

Bone marrow tests

You might have a bone marrow test to confirm the diagnosis, but this may not be needed. This involves taking a sample of your bone marrow, usually from the back of your pelvis, with a local anaesthetic.

Lab tests

Your doctor will send your blood and bone marrow samples to the lab for specialist tests. They may check what proteins are on the surface of your leukaemia cells, or what genetic changes they have. The results from these tests can sometimes take a few weeks to come back.

Other tests you might have

You might need other tests, like a CT scan to check for swollen lymph nodes in your neck, chest or tummy. Your haematology team will tell you about any tests you need.

Your test results may take a little while, which can be a worrying time for you. It is important for your haematology team to have all the results so they can make an accurate diagnosis. It can also help them work out the most suitable treatment options for you.

We are here for you if you need support while you're waiting for your results. Email us at support@leukaemiacare.org.uk, message us on WhatsApp at 07500 068 065 or call our freephone helpline on 08088 010 444.

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Treatment for T-cell PLL

Because it is so rare, it is difficult for researchers to carry out trials to work out the best treatments for people with T-cell PLL. So, at the moment, there are no definite treatment guidelines and different doctors might use different approaches.

Some people with slow-growing T-cell PLL may not need treatment straight away.

If you do need treatment, your haematology team will explain what they recommend and what you can expect from it. They will base this on many factors, including:

- Your symptoms and test results
- Your age and overall fitness
- Whether or not you have any other medical conditions
- Your preference on how you wish to be treated

T-cell PLL can be difficult to treat. Some treatments might work better than others, but responses are usually limited. When you need treatment, your team will explain the options. They will recommend what they think is most suitable for you.

Active monitoring

If your T-cell PLL is slow-growing and is not causing symptoms, you may not need treatment straight away. Instead, you will have regular check-ups and blood tests to monitor how T-cell PLL is affecting you. This is called active monitoring.

It can be difficult to hear you have cancer but are not starting treatment. However, there is no evidence to show that early treatment of T-cell PLL can improve your outcome. If you're feeling well, there is no benefit to starting treatment before you need it. This means you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it.

Most people need to start treatment within 1 to 2 years of being diagnosed.

You are likely to start treatment if:

- Your level of abnormal T cells is increasing rapidly
- You have low levels of healthy blood cells
- You start to develop symptoms or your symptoms get worse
- Your liver, spleen or lymph nodes are swelling very quickly
- Your leukaemia has affected other parts of your body

Treatment options

There are a number of treatment options your haematology team might consider. These might include:

- **An antibody therapy** called alemtuzumab. This is a lab-made antibody that sticks to proteins on the surface of cancer cells. This helps your immune system recognise and destroy the cells. You have antibody therapy as an injection or through a drip. You might have it with chemotherapy.
- **Chemotherapy**. Chemotherapy medicines kill cells that are dividing rapidly, such as blood cells. If your doctor suggests chemotherapy, they will tell you exactly what medicines they suggest and how you have them.
- **Treatment as part of a clinical trial**. This could let you access treatments that would not be available otherwise. If there is a trial suitable for you, your team should explain what it involves and the risks and benefits of it. It is your choice whether or not to take part.
- **A stem cell transplant**. If you respond well to your first treatment, your team might recommend a stem cell transplant. This aims to stop T-cell PLL coming back.

A stem cell transplant is very intensive and is only suitable for people who are fit enough to have it. If it's an option for you, your team will discuss it with you.

Your haematology team will let you know what treatment they recommend, how you will have it, and what you can expect.

Supportive treatment

You might also need medicine to prevent or treat symptoms or side effects. This is called supportive treatment. It does not treat your T-cell PLL itself, but it helps you feel better.

Supportive treatment might include:

- Blood transfusions or medicines called growth factors, if your blood counts are low
- Medicine to prevent or treat infections
- Medicine to prevent or treat side effects
- Medicine to prevent or treat allergic reactions to your treatment
- Steroids, which can help with many different symptoms

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Outcomes of T-cell PLL

T-cell PLL is an aggressive type of cancer. It can be difficult to treat, and it often comes back.

As with most cancers, outcomes vary from person to person. They depend on lots of different factors, including:

- Your age and overall fitness
- Your test results
- Any other health conditions you have
- How well you respond to your first treatment

Your consultant is the best person to advise you on your outlook. They can take account of your individual circumstances and test results.

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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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