About chronic myeloid leukaemia (CML)

Chronic myeloid leukaemia (CML) is a slow-growing type of blood cancer. It develops when white blood cells in your bone marrow multiply uncontrollably. Find out about the signs and symptoms of CML, tests you might have, and how CML is diagnosed.

Summary

- CML is a slow-growing type of blood cancer. It starts in blood-forming cells in your bone marrow called myeloid stem cells.
- We do not know exactly what causes CML. But it is not because of anything you have or have not done. You cannot catch CML or pass it on to anyone else.
- The signs and symptoms of CML vary from person-to-person. Some people have no symptoms and are diagnosed after a blood test for something else.
- CML is diagnosed on blood tests and bone marrow tests. You might have other tests to find out how CML is affecting your body.
- The outlook for CML is excellent. Most people with CML can expect to live as long as people who don't have CML.
- We have separate information about treatment for CML.

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What is CML?

CML is a slow-growing type of blood cancer. It starts in blood-forming cells in your bone marrow called myeloid stem cells.

If you have CML, these cells multiply too much. They divide and mature uncontrollably. This leads to an increase in the different types of white blood cells in your blood and bone marrow. As the leukaemia cells build up, they can fill up your bone marrow stopping it make enough healthy red and white blood cells.

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Who gets CML?

CML is quite rare. Only around 830 people in the UK are diagnosed with it every year. That's about one person in every 100,000.

CML can affect people of any age, but it is most common in people over 60 to 65.

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What causes CML?

We do not know exactly what causes CML. However, it is not because of anything you have or have not done. You cannot catch CML or pass it on to anyone else.

Some things can increase your chance of getting CML. These include:

- Age (your chance of getting CML increases with age)
- Sex (CML is slightly more common in males than females)
- Exposure to radiation

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Signs and symptoms of CML

The signs and symptoms of CML vary from person-to-person. They also depend on how many leukaemia cells you have in your body and where they are.

Some people with CML have no symptoms and are diagnosed after a blood test for something else. But symptoms could include:

- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia)
- Infections that last a long time or keep coming back
- Fever
- Fatigue
- Unexplained weight loss
- Night sweats
- Tummy pain, bloating or discomfort due to a swollen spleen (you may particularly notice this feeling under your ribs on the left side)
- A feeling of fullness after eating, again due to a swollen spleen

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- Bruising easily or bleeding when you wouldn't usually (for example, nose bleeds or bleeding gums when you brush your teeth)

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Diagnosis of CML

Your haematology team will diagnose CML based on:

- Blood tests
- Bone marrow tests
- Tests to look for genetic changes in your blood or bone marrow samples

Blood tests

A blood test called a full blood count measures the number of red blood cells, platelets and different types of white blood cells you have. If you have CML, this usually shows:

- High numbers of white blood cells
- Low numbers of healthy red blood cells

Your platelet count could be high or low.

A specialist also looks at your blood sample under a microscope to see what kind of white blood cells are there. With CML, there is usually a typical pattern of leukaemia cells and different white blood cells at various stages of development.

Depending on the results of your blood tests, your doctor may suggest more specialised tests.

Bone marrow tests

Bone marrow is the spongy part in the middle of some of the large bones in your body. It is where all your blood cells develop.

A bone marrow test helps your haematology team make an accurate diagnosis. It also helps them work out the phase of your CML and look for other changes that might affect your treatment options.

Genetic tests

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Leukaemia cells in people with CML show a particular pattern of genetic changes. We do not know why people with CML get these changes. **You do not get them from your parents and you cannot pass them on to any children you may have**.

If your haematologist thinks you might have CML, they will send your blood or bone marrow samples for genetic tests to confirm the diagnosis.

- The genetic change in people with CML is called the *BCR-ABL1* gene.
- In most people with CML, the *BCR-ABL1* gene forms when DNA swaps between chromosome 9 and chromosome 22. This makes a chromosome called the Philadelphia chromosome, which contains the *BCR-ABL1* gene.
- Doctors can see the Philadelphia chromosome under a microscope on specialised tests.
- Some people with CML do not have the typical Philadelphia chromosome but they still have the *BCR-ABL1* gene.
- The *BCR-ABL1* gene makes an abnormal version of a protein called tyrosine kinase. It is this protein that encourages the blood-forming cells in your bone marrow to make too many white blood cells.

Other tests

You might have blood tests to check how well your liver and kidneys are working. It is also routine to check you for undiagnosed infections such as hepatitis and HIV.

You might have other tests to find out more about how CML is affecting your body. These are not always needed, but they could include:

- An ultrasound scan to see how big your spleen is
- A lumbar puncture to find out if there are any leukaemia cells in the fluid around your brain and spinal cord
- Other tests recommended by your haematology team

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What are the phases of CML?

Your haematology team will use your test results to work out what phase your CML is in. This helps them recommend the most suitable treatment. There are two main phases:

- **Chronic phase**: this means that less than 10 to 20 in every 100 cells in your blood or bone marrow are leukaemia cells. Most people are in the chronic phase when they are diagnosed.
- **Blast phase**: this means your leukaemia is growing more rapidly and you have a higher level of abnormal cells in your blood or bone marrow. If your CML is in the blast phase, you need more intensive treatment.

In some people, test results or symptoms in the chronic phase suggest they might be progressing to the blast phase. Your haematology team might call this the **accelerated phase** or the **chronic phase with high-risk features**.

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Outcomes of CML

For people diagnosed in chronic phase CML, outcomes are usually excellent. In general, people diagnosed in the chronic phase of CML can expect to live as long as people who do not have CML.

Outcomes are less favourable for people with blast phase CML so it is important to monitor response regularly.

Outcomes vary from person-to-person and depend on many different factors. These include:

- Your age and overall fitness
- The phase of your CML when you were diagnosed
- Your white blood cell counts when you were diagnosed
- Your leukaemia cell type and the genetic changes it has
- Your response to treatment

> **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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