Chronic myelomonocytic leukaemia (CMML)

Chronic myelomonocytic leukaemia (CMML) is a type of blood cancer that mainly affects white blood cells called monocytes. Find out what CMML is, the signs and symptoms, and how it is diagnosed and treated.

Summary

- CMML is a type of blood cancer known as a myelodysplastic-myeloproliferative neoplasm (MDS/MPN). It is usually slow growing.
- We don't know exactly what causes it. But it is not because of anything you have or have not done.
- Sometimes you might not have symptoms when you are first diagnosed. You may be diagnosed after a blood test for something else.
- Symptoms of CMML include extreme tiredness, repeated infections, bruising, night sweats or tummy pain and bloating. Some people get skin problems or complications in other parts of the body.
- Your haematology team will diagnose CMML based on blood tests and sometimes bone marrow tests.
- You may not need treatment straight away. Instead, you may have regular check-ups and blood tests.
- If you need treatment, your team are likely to recommend chemotherapy medicines called azacitidine or hydroxycarbamide. Other options include a stem cell transplant or a clinical trial, if these are suitable for you.
- You might also have treatment to prevent or manage symptoms or side effects.

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What is CMML?

Chronic myelomonocytic leukaemia (CMML) is a type of blood cancer. It starts in the bone marrow and mainly affects white blood cells called monocytes. It can also affect other

blood cells. These cells become abnormal and grow out of control. The abnormal cells fill up your bone marrow and stop it making enough healthy blood cells. The abnormal cells can also build up in your bloodstream, causing other problems.

CMML is a type of blood cancer known as a myelodysplastic-myeloproliferative neoplasm (MDS/MPN). This means it has features of two different types of blood cancer:

- Myelodysplastic syndromes (MDS). These are blood cancers where your bone marrow makes abnormal, immature blood cells that do not work properly.
- Myeloproliferative neoplasms (MPNs). These are blood cancers where cells in your bone marrow grow out of control and make too many blood cells.

CMML is the most common type of MDS/MPN.

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Who gets CMML?

CMML is rare. Around 650 people are diagnosed with it each year in the UK.

It can affect people of any age, but it is more common in people over 70. It is more common in men than in women.

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What causes CMML?

We do not know the exact cause of CMML.

People with CMML develop genetic changes in cells called stem cells in their bone marrow. Stem cells usually make all the blood cells your body needs. The genetic changes mean they don't work properly. They might make abnormal blood cells, or too many of some types of blood cells (including monocytes).

Most of these changes happen by chance during your lifetime. You did not get them from your parents and you cannot pass them to any children you have.

In most cases we do not know why these genetic changes occur. These changes are not because of anything you have or have not done.

- Having chemotherapy or radiotherapy for another type of cancer in the past can slightly increase your risk of developing CMML. If this happens, it is called therapy-related CMML. But most people with CMML have never had chemotherapy or radiotherapy before.

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Signs and symptoms of CMML

You might not have symptoms when you are first diagnosed. You may be diagnosed after a blood test for something else.

You might get some signs and symptoms over time. These vary from person to person. They might include:

- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia).
- Feeling tired for no obvious reason (fatigue).
- Infections that last a long time or keep coming back.
- Bruising or bleeding easily (for example, nose bleeds or bleeding gums when you brush your teeth).
- Night sweats.
- Tummy pain, bloating or discomfort due to a swollen liver or spleen. You may particularly notice this feeling under your ribs.
- Feeling full quickly when eating due to a swollen spleen. This may affect your appetite.
- Fever, for no obvious reason.
- Bone pain.
- Losing weight without trying to.
- Skin problems, which can look like:
    - Reddish purple or red-brown raised bumps (these may look different on black or brown skin)
    - A reddish-pink rash of small spots or bumps (this may look different on black or brown skin)
    - An itchy rash
    - Small pus-filled, blisters or open round sores

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Complications of CMML

CMML can cause complications in different parts of your body. Your medical team can explain the complications and symptoms you may get. They can also advise you on when to seek help.

We cover some of the main complications of CMML here.

> **If you have any symptoms you're worried about, tell your haematology team.**

Autoimmune conditions

An autoimmune condition happens when your immune system mistakenly attacks parts of your own body.

- About 2 to 3 in every 10 people with CMML get an autoimmune condition. About 7 to 8 in every 10 do not.
- We do not know exactly why it happens. It may be due to your stem cells making immune system cells that don't work properly.

Autoimmune complications of CMML can affect different parts of the body. They include:

- Joints and muscles
- Skin
- Eyes
- Blood cells
- Blood vessels
- Heart and lungs
- Bowel
- Thyroid
- Nerves and nervous system

Tell your haematology team about any symptoms you have, even if you don't think they are related to CMML.

Kidney problems

- Around 3 to 4 in every 10 people with CMML get kidney problems. Around 6 to 7 in every 10 do not.

It might happen if abnormal blood cells build up in your kidneys. It might also happen if leukaemia cells release chemicals or activate immune cells that may damage your kidneys.

Your team might notice kidney problems on a blood test.

Transformation of CMML

CMML is a generally slow-growing blood cancer. Sometimes, though, it can develop or transform into a fast-growing blood cancer called acute myeloid leukaemia (AML). If this happens, you will need different treatment.

There is a lot of overlap between AML symptoms and CMML symptoms. If your CMML transforms, your symptoms might get worse. Your haematology team will also monitor you for signs your CMML may have transformed so they can treat it promptly if it happens.

The chance of developing AML varies from person to person.

- In general, around 2 to 3 in every 10 people with CMML develop AML. Around 7 to 8 in every 10 people with CMML do **not** develop AML.

Your haematology team will talk to you about your risk group and your chance of developing AML.

Other complications

Rarely, people with CMML may have a build up of fluid around the lungs, heart or tummy. This might cause symptoms like breathlessness, chest pain or bloating.

Tell your haematology team about any symptoms you have.

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Diagnosis of CMML

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

> **It can be difficult waiting for tests and test results. Our Helpline is here for you if you need support.**

Blood tests

You will have blood tests to:

- Measure your numbers of red blood cells, white blood cells and platelets. This is measured using a basic blood test called a full blood count.
    - If you have CMML you'll have higher than normal levels of abnormal monocytes, and possibly some other types of white blood cell.
    - You may also have low levels of other healthy blood cells.
- Measure the number of immature, abnormal blood cells, known as blast cells. This can help doctors work out the risk of your CMML progressing.
- See how your blood cells look under a microscope. The abnormal cells look different from healthy white blood cells.

You might also have blood tests to:

- Check how well your liver and kidney are working
- Check for signs that you may be at risk of getting complications

Bone marrow tests

If your haematology team think you might have CMML, they may do a bone marrow test to confirm it. 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 samples to the lab for specialist tests. They will check what proteins are on the surface of your leukaemia cells, and what genetic changes they may have. The results can help them work out the most suitable treatment for you.

Other tests you might have

You might have an ultrasound or CT scan to check for a swollen spleen, liver or lymph nodes, although this is often not needed. Depending on your symptoms, you might have other tests or scans.

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Types of CMML

Your haematology team will use your test results to work out what type of CMML you have.

CMML can be typed in different ways. It may be based on the genetic changes in your leukaemia cells, your white blood cell count, or how many blast cells are in your blood and bone marrow.

There are two basic subtypes of CMML, depending on your white blood cell count:

- Myelodysplastic CMML (MD-CMML) is when you have a normal or only slightly raised white blood cell count
- Myeloproliferative CMML (MP-CMML) is when you have a high white blood cell count

You might also hear your doctor mention the subgroup of CMML you have. There are two subgroups based on the number of blast cells in your blood or bone marrow. These are called CMML-1 and CMML-2.

Your team will let you know what type of CMML you have and what you can expect.

CMML risk groups

Your haematology team will also use your test results and other factors to work out how much of a risk CMML is to your health. Based on these factors, your team will work out if your CMML is:

- Lower risk
- Intermediate (medium) risk
- Higher risk

This helps them work out the best treatment for you.

They will work out your risk group based on:

- Your age
- Your overall fitness
- Whether or not you have any other medical conditions
- Your symptoms
- Your level of red blood cells, white blood cells and platelets
- The genetic changes in your leukaemia cells
- The number of immature blood cells called blasts in your blood and bone marrow
- Your subtype of CMML

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Treatment for CMML

Some people with CMML do not need treatment straight away. If you do need treatment, your haematology team will explain what treatment they recommend and what you can expect from it. They will base this on many factors, including:

- Your age
- Your overall fitness
- Whether or not you have any other medical conditions
- Your risk group
- Your symptoms
- Your blood counts
- The genetic changes in your leukaemia cells
- The number of immature blood cells called blasts in your blood and bone marrow
- Your preferences

Most treatments for CMML aim to keep it under control. They do not usually cure it.

Active monitoring

If your CMML is not causing symptoms, you may not need treatment straight away. Instead, you might have regular check-ups and blood tests to monitor how CMML is affecting you. This is called active monitoring. Some people call it watch and wait.

It can be difficult to hear you have a blood cancer but are not starting treatment. However, active monitoring is a safe approach for slow-growing blood cancers. If you're feeling well, there may be 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 if or when you need it.

You are likely to start treatment if:

- Your blood tests show low levels of healthy blood cells or high levels of abnormal blood cells
- You start to develop symptoms or your symptoms become worse

Chemotherapy

Chemotherapy for CMML aims to reduce your symptoms and improve your quality of life.

The main chemotherapy medicines used to treat CMML are called azacitidine and hydroxycarbamide. These medicines are less intensive than many other types of chemotherapy. You do not usually have to stay in hospital to have them.

Stem cell transplant

If your CMML is classed as high risk, your haematology team might suggest a stem cell transplant. Stem cell transplants have the potential to cure CMML, but they are very intensive. They are only suitable for people fit enough to have them, so may not be an option for most people with CMML.

Your haematology team will let you know if a stem cell transplant is an option for you. They will discuss it with you and give you a chance to ask questions.

Clinical trials

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is where new treatments, or different ways of using existing treatments are tested to find out if they are better than standard treatments.

If there is a clinical trial suitable for you, your team should explain what it involves and the risks and benefits of it. It is your choice whether to take part.

Having your spleen removed

If your spleen becomes very swollen and does not improve with medicines, your team may suggest an operation to remove it. This is needed very rarely.

Supportive treatment

You might also need treatment to prevent or manage symptoms, complications or side effects. This is called supportive treatment. It does not treat your CMML itself, but it helps you feel better.

You might have supportive treatment on its own, or you might have it alongside treatment to control your CMML. Supportive treatment might include:

- Blood transfusions or injections of EPO (a medicine that stimulates the production of red blood cells), if you have a low red blood cell count.
- Platelet transfusions, if you have a low level of platelets.
- Iron chelation therapy. If you have frequent blood transfusions you may have high levels of iron in your body. This treatment helps remove excess iron through your pee and poo.
- Medicines to prevent or treat infections.
- Medicines to help with autoimmune problems.
- Anti-sickness or antidiarrhoeal medicines.
- Medicine to relieve constipation.
- Medicine to prevent high uric acid levels and gout, which can be a side effect of some CMML treatments.
- Medicines to prevent injection site reactions or irritation.

Supportive care can also 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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Outcomes of CMML

Your outcome varies depending on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person. They depend on lots of different factors, including:

- Your age and overall fitness
- Whether or not you have any other medical conditions
- Your symptoms
- Your blood counts
- The genetic changes in your leukaemia cells
- The number of leukaemia cells in your blood and bone marrow
- How well you respond 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.

Helpline and WhatsApp →

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