Newly diagnosed with chronic myelomonocytic leukaemia (CMML)

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@leukaemiacare.org.uk

Support groups

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

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 CMML.

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

In this booklet

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.

Chronic myelomonocytic leukaemia (CMML) is a type of blood cancer. It mainly affects white blood cells called monocytes. In this booklet we cover what CMML is, how it is diagnosed and what treatments you may have. We also include practical information about living with CMML.

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:

- Professor Steven Knapper, consultant haematologist, Cardiff and Vale University Health Board
- Dr Daniel Wiseman, consultant haematologist, Christie NHS Foundation Trust and group leader of Oglesby CMML Research Laboratory
- Patient reviewers Adrian, Chris and Elliot

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 chronic myelomonocytic leukaemia (CMML)

Summary

- Chronic myelomonocytic leukaemia (CMML) is a type of blood cancer. It mainly affects white blood cells called monocytes but it can also affect other blood cells.
- CMML can affect people of any age, but it is more common in people over 70. It is more common in men than in women.
- We do not know the exact cause of CMML. It is not because of anything you did or did not do.

About 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 types of blood cell. 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.

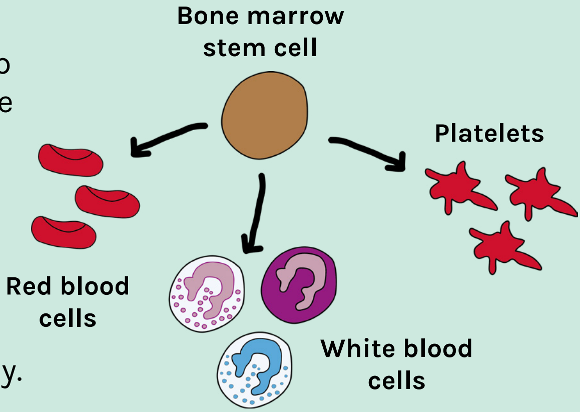
Monocyte

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. There are different types, including monocytes.
- Platelets help clot your blood.



More about CMML

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.

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.

Causes of 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 genetic 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.

But there are some factors that can increase your chance of getting CMML. These include:

- Your age – CMML is more common in people over 70.
- Your sex – CMML is more common in males than in females.
- Having chemotherapy or radiotherapy for another type of cancer in the past, including blood cancer. This 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.

Symptoms, complications and diagnosis of CMML

Summary

- You might not have any symptoms of CMML when you are diagnosed. You might start to get signs and symptoms over time.
- Common symptoms include extreme tiredness, repeated infections, bruising, night sweats or tummy pain and bloating.
- CMML can also cause problems with your skin such as itching or a rash (this may look different on black or brown skin).
- You may have other symptoms if you develop complications such as immune system problems or kidney problems.
- Sometimes CMML can develop into a fast-growing blood cancer called acute myeloid leukaemia (AML). If this happens, you will need different treatment.
- Your haematology team will diagnose CMML based on blood tests and sometimes bone marrow tests.
- Depending on your symptoms, you might have other tests or scans.

It can be difficult waiting for test results. We are here for you if you need support. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Signs and symptoms of CMML

You might not have symptoms when you are first diagnosed. So, you may be diagnosed after a blood test for something else. You might get some signs or 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).
- Fatigue (feeling tired for no obvious reason).
- 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

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.

Other complications

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.

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.

Transformation of CMML

CMML is generally a 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.

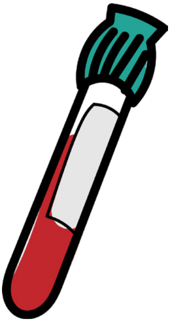
Your haematology team will talk to you about your risk group (page 18) and your chance of developing AML.

For more information on acute myeloid leukaemia (AML), follow the link, scan the QR code or search for 'AML' at leukaemiacare.org.uk

Diagnosis of CMML

You'll have blood tests and bone marrow tests to diagnose CMML. 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. This is measured using a basic blood test called a full blood count.
  - If you have CMML, you'll have high levels of abnormal monocytes, and probably some other types of white blood cell.
  - You may also have low levels of 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 to AML.
- 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 kidneys 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.

Cancer Research UK have more information on having a bone marrow test. Follow the link, scan the QR, or search 'bone marrow test' at cancerresearchuk.org

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 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.

Your test results may take a little while, which can be worrying. 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 whilst you are waiting for your results. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

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.

Risk grouping

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 sub-type of CMML (page 17)

Treatment of CMML

Summary

- If your CMML is not causing symptoms, you may not need treatment straight away. Instead, you will have regular tests and check-ups. This approach is called active monitoring.
- You will usually start treatment if:
    - You have low levels of healthy blood cells
    - You have high levels of abnormal blood cells
    - You start to develop symptoms
    - Your test results suggest you have higher risk CMML
- You may have chemotherapy to help control your CMML as much as possible, but it is unable to cure it.
- If your CMML is classed as higher risk, your haematology team might suggest a stem cell transplant.
- Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you.
- You will also have treatment to prevent or manage symptoms, complications or side effects.

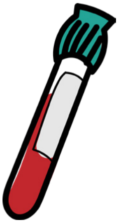
Treatment options

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 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

We have separate information on active monitoring. Follow the link, scan the QR code or visit leukaemiacare.org.uk and search 'active monitoring'.

Chemotherapy

The aim of chemotherapy is to keep your CMML under control as much as possible with as few side effects as possible. This aims to reduce your symptoms and improve your quality of life. But it does not cure your CMML.

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.

Azacitidine

Your team might recommend azacitidine to lower your blast cell count and help improve your symptoms. Azacitidine can turn on cancer-suppressing genes that are often turned off in CMML cells. This can stop them from growing and dividing.

- You usually have azacitidine injections in a cycle of 28 days. Most people have seven azacitidine injections over the first 7 to 9 days of each cycle, followed by a break.
- You have them as an injection just under your skin, usually in your tummy, thigh or upper arm.
- You usually go to a hospital day unit to have each injection and go home the same day.

Your haematology team will let you know what they recommend and how often you will have it.

For more information on azacitidine injections, including possible side effects, follow the link or scan the QR code. Or search 'downloads' at www.leukaemiacare.org.uk and search for azacitidine on our downloads page.

Hydroxycarbamide

If you have a high white blood cell count, your team might recommend hydroxycarbamide to help lower it. It is sometimes called hydroxyurea.

It blocks an enzyme that cells need to grow and divide. Blocking this enzyme can help stop CMML cells from growing and dividing.

- Hydroxycarbamide comes as capsules that you take at home.
- You may need to take them every day or only on certain days of the week.
- Your team will work out the best dose for you. They may adjust the dose if your other blood cell counts drop too low.

You have regular blood tests to check how well the treatment is working for you and how you are coping with it.

Your haematology team will let you know what they recommend and how often to take it.

For more information on hydroxycarbamide, including possible side effects, follow the link or scan the QR code. Or search 'downloads' at www.leukaemiacare.org.uk and search for hydroxycarbamide on our downloads page.

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 who are fit enough to have them, so may not be an option for most people with CMML.

A stem cell transplant involves having chemotherapy and sometimes radiotherapy. This kills the blood-forming cells in your bone marrow, called stem cells. These are then replaced by healthy stem cells. Over time, these produce a completely new, healthy blood system. For most people with CMML, the healthy stem cells come from a matched related donor, such as a brother or sister, or from an unrelated matched donor.

Your 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.

We have separate information on stem cell transplants. Follow the link, scan the QR code or search 'stem cell transplants' at www.leukaemiacare.org.uk

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.

Macmillan have more information about clinical trials. Follow the link, scan the QR code or search for 'clinical trials' at www.macmillan.org.uk

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 only 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 is not only limited to the physical impact of CMML. 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.

We’re here for you if you need support. Scan the QR code, follow the link, or search ‘support for you’ at www.leukaemiacare.org.uk to find out how we can help you.

Outcomes of CMML

Summary

- The outcome of CMML depends on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person.
- Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

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
- Your 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.

CMML is generally a slow-growing blood cancer. Treatment usually aims to control it rather than cure it.

Sometimes, though, it can develop or **transform** into a fast-growing, more aggressive type of blood cancer called acute myeloid leukaemia (AML) (page 14). 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.

For more information on acute myeloid leukaemia (AML), follow the link, scan the QR code or search for 'AML' at leukaemiacare.org.uk

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

It’s 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 that are available now.

In people with cancer, overall survival rates are commonly quoted. These are averages. They do not tell you what will happen for you.

For CMML, outcomes vary depending on risk group:

- For lower risk CMML, average survival is around 6.8 years. Some people do not live as long as this and others live much longer.
- For intermediate (medium) risk CMML, average survival is around 3.6 to 3.9 years. Some people do not live as long as this and others live much longer.
- For higher risk CMML, average survival is around 1.8 years. Some people do not live as long as this and others live much longer.

> **"After I was first diagnosed with CMML in 2008, I found a leaflet which said that the average survival for CMML was 12 to 24 months. I became so depressed as, by that time, I had been diagnosed for nearly 2 years and thought I wouldn’t make my 60th birthday! I’m so happy to say that this year will mark 17 years since CMML so unexpectedly and spectacularly entered my life. I have had active monitoring and have not needed any treatment."**
>
> Chris, diagnosed with CMML in 2008

You might also read about 5-year survival rates. 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 it may have been from another cause, or even old age.

On average, around 22 in 100 people with CMML are still alive 5 years after their diagnosis. Around 78 in 100 are not. But we do not know whether they died because of CMML or because of something else. Most people with CMML are over 70 and may have several health conditions.

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

Living with CMML

Summary

- Being diagnosed with CMML 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.
- Like all medicines, treatment for CMML can cause side effects. These include:
  - A higher chance of getting infections. Any infections you do get may be more serious.
  - Extreme tiredness (fatigue).
- 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.
- Don't be afraid to ask for help from family, friends, your haematology team or Leukaemia Care support services.
- Having CMML 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.

Living with CMML

Being diagnosed with CMML can be overwhelming. It is something that can affect you both physically and emotionally. Symptoms, the effects of treatment, and hospital appointments, may all impact your day-to-day life. Here, we cover some practical information about living with CMML and where to get support if you need it.

You might find our newly-diagnosed webpage helpful. Follow the link, scan the QR code or search 'just diagnosed' at leukaemiacare.org.uk.

Managing your emotions

Finding out you have CMML is difficult. You may need emotional and practical support. It is likely you will experience a range of complex thoughts and 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.

Tell your haematology team how you’re feeling, even if you say you are confused about your feelings. They can help you access support. They may be able to refer you for counselling if you need it.

Sadness and depression

You might be feeling low, which is a natural effect of your diagnosis and treatment. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, it is important to contact your GP. They can help you access the support and treatment that you need.

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

Where to seek support and how to cope

There are several places where you can seek emotional support, such as:

- Loved ones and caregivers
- Your clinical nurse specialist, if you have one
- Your consultant
- Charities and other organisations

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 Buddy Service, where you can connect with people who understand your experience
- A counselling service where we can help you access 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, including mindfulness. Scan the QR code, follow the link or search 'complementary therapies' at macmillan.org.uk

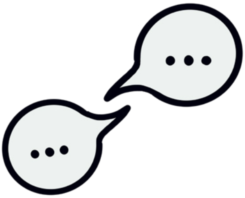
> **"Everyday will bring something new; the journey is like a rollercoaster. Ensure you reach out for all the support available and don't suffer in silence."**
>
> Elliot, diagnosed with CMML in 2023

Telling people

When you are first diagnosed with CMML, there is a lot to take in. 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 you need time to process the information before you are ready to talk about it.

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

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.



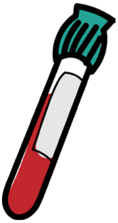
If you can, choose somewhere where you can hear each other clearly and where you're not likely to be interrupted. Try to speak slowly and calmly to give the other person time to take in the information.

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

In the conversation with your loved ones, you might want to:

- Explain that you have a type of blood cancer.
- Explain what symptoms you get (maybe you feel tired or get infections a lot).
- If you have a high risk of infections, tell them that if they are unwell, they should stay away from you until they have recovered.
- Explain your needs. Your family and friends may be happy to know they can help support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. People who care about you will help you as best as they can.
- Have a print-out or factsheet with you. This means you don’t have to remember everything that your friends and family might want to know. Or you could give them a copy of this booklet.

Coping with treatments and side effects



Like all medicines, treatment for CMML 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 and blood tests. This means they can treat side effects promptly if they happen.

Tell your medical 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.

Infection risk

CMML treatment can cause a low level of white blood cells called neutrophils. 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.

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

- A high temperature (38°C or higher)
- Aching muscles, shivering or chills
- Sore throat, blocked or runny nose or cough
- Burning or stinging when you pee, or peeing more often than usual
- Diarrhoea, being sick or tummy pain
- Headache or stiff neck
- Pain or redness around any cuts or wounds
- Feeling very tired or generally unwell

Infections can get worse quickly if you have a weakened immune system, so it is important to get treatment as soon as possible. Your haematology team should tell you who to contact if you think you have an infection.

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 and consider wearing a mask
- 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 medicines to help prevent infections.

Fatigue

CMML and its treatment can cause fatigue. This is a feeling of physical or mental exhaustion that doesn’t get better with sleep or rest.

Fatigue can be frustrating as it cannot be treated with medicines. But there are things you can do to help manage it.

Tips for coping with fatigue

Make plans and pace yourself.

- Prioritise things that are important to you and reserve energy for these.
- Build time to rest around planned busy periods.
- Allow yourself to rest as and when you need.

Keep to a regular sleep schedule.

- Try to go to bed and wake up at around the same time each day.
- Keep your bedroom quiet and a comfortable temperature.
- Avoid eating or drinking alcohol, coffee, tea or chocolate before bedtime.
- Avoid using laptops, tablets or mobile phones before going to bed.

Do regular, gentle exercise to maintain your fitness levels.

Accept help with household tasks.

Make sure to tell your haematology team if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

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

The NHS website has information and guidance on eating a healthy, balanced diet. Follow the link, scan the QR code or search ‘eat well’ at 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 are feeling.

If your blood counts are very low, ask your haematology team if you need to take any precautions.

The NHS website has information on exercise in older adults and examples of different types of exercise. Follow the link, scan the QR code or search ‘exercise for older adults’ at nhs.uk

Going to appointments

You may need to attend regular appointments with your haematologist, clinical nurse specialist (if you have one) or sometimes your GP.

Appointments often involve a lot of waiting around. You could download a podcast or TV programme to keep you occupied while you wait. Or take something physical like a book or travel game.

Once you're in your appointment, it can be hard to take in everything your doctor or nurse tells you. Below are some tips to help you get the most from your appointment:

- It can help to take a family member or friend with you for support.
- Ask any questions that you may have. If you don't understand something, ask your medical team to explain. They will be used to this.
- You could take notes on your phone or paper to help you remember. Or you could ask your doctor or nurse to write things down or ask if they're happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping.

Questions for appointments

Sometimes it can be overwhelming to know what to ask in your appointments. Some questions you might want to ask include:

- What tests will I need?
- What might the tests show?
- How long will it take to get the results back?
- 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 food or medicines that I need to avoid?
- Will I be able to go back to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

Work, education, money and driving

Being diagnosed with CMML and having to juggle work or education with hospital or GP appointments can be challenging. You may need to take time off work or education when you're feeling unwell or to attend appointments.

You'll probably need to keep your employer or education provider informed. Your consultant or GP can write letters to confirm your diagnosis and explain how this may affect your work or education. Depending on your employment contract, you may be entitled to sick pay. If you are at university, you may want to consider deferring your attendance for a while.

If you are well enough to work or study, you are entitled to reasonable adjustments to help you cope. You may wish to have an open conversation with your employer or education provider about how they can support you.

CMML may impact your ability to drive, especially if you have a low level of platelets. You might need to tell the DVLA about your diagnosis. You can ask your medical team for more information.

Having CMML can affect your finances, whether or not you are working. Being diagnosed with leukaemia can come with extra costs such as extra heating costs, travel to and from hospital and childcare costs. You may be eligible for financial support.

If you have CMML, you are entitled to free prescriptions. Your haematology team or GP can tell you how to apply for this.

Charities and financial support

We have a range of services that can help you when living with CMML, including a welfare service and cost of living hub. Follow the link, scan the QR code or search ‘support for you’ at leukaemiacare.org.uk

Macmillan have information on benefits and financial support you might be able to access. Follow the link, scan the QR code or search for ‘benefits and financial support’ on www.macmillan.org.uk for more information.

Words you might see or hear

Active monitoring: a way of monitoring your health when you have a blood cancer that doesn't need immediate treatment. You have regular check-ups and you also monitor your own symptoms.

Acupuncture: a type of complementary therapy where fine needles are inserted into certain areas of your body.

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

Anaemia: a low red blood cell count.

Anaesthetic: a medicine to numb part of your body (local anaesthetic) or send you to sleep (general anaesthetic).

Antibody: an immune system protein that helps fight infections by sticking to targets on the surface of cells that don't belong in your body.

Autoimmune condition: a condition that happens when your immune system mistakenly attacks your own body.

Azacitidine: a chemotherapy medicine used to treat CMML and some other blood cancers.

Blasts: immature blood cells.

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

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

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

Chronic myelomonocytic leukaemia (CMML): a rare type of blood cancer that mainly affects blood cells called monocytes. It can also affect other blood cells.

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.

CT scan: a scan that uses X-rays and a computer to make detailed pictures of the inside of your body.

Fatigue: extreme tiredness or lack of energy that can interfere with your usual activities and doesn't get better when you rest.

Genetic changes: changes to genes that can affect the proteins a cell makes. This may change how a cell behaves and grows. They are also known as genetic variants or mutations.

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

Haematology: the branch of medicine that deals with diseases of the blood and bone marrow.

Immune system: the cells and systems in your body that protect you from infection.

Inflammation: your body's response to an illness, injury or something that doesn't belong in your body.

Leukaemia: a group of cancers that usually start in the bone marrow and lead to high numbers of abnormal blood cells.

Monocyte: a type of white blood cell that helps fight infections.

MRI scan: a scan that uses strong magnets to take detailed pictures of the inside of your body.

Mutations: changes to genes that can affect the proteins a cell makes. This may change how a cell behaves and grows. They are also known as genetic changes or genetic variants.

Myelodysplastic syndromes (MDS): a type of cancer where your bone marrow produces immature, abnormal blood cells that do not work properly.

Myelodysplastic-myeloproliferative neoplasm (MDS/MPN): blood cancers that have features of both a myelodysplastic syndrome (MDS) and a myeloproliferative neoplasm (MPN).

Myeloproliferative neoplasms (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Neutropenia: a low level of white blood cells called neutrophils.

Neutrophils: white blood cells that help you fight inflammation and infection.

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

Proteins: the building blocks of every cell, tissue and organ in your body. Your body needs proteins for growth, repair, and to fight infections.

Radiotherapy: treatment that uses high doses of radiation to kill cancer cells.

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

Spleen: a fist-sized organ that sits under your ribs on the left side. It filters and stores blood and makes some blood cells.

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

Stem cells: immature cells in your bone marrow that can develop into all the different blood cells your body needs.

Supportive treatment: medicine to prevent or treat symptoms or side effects.

Transformation: when one type of blood cancer develops into another type, usually a faster-growing one.

Transfusion: having blood or blood products through a drip into a vein.

Ultrasound: a scan that uses sound waves to look at the inside of your body.

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

Useful contacts and further support

Coping with CMML 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

Blood Cancer UK
Leading charity into the research of blood cancers.
0808 2080 888
bloodcancer.org.uk

MPN voice
Provides information, community and advocacy for MPN patients, their families and carers.
07934 689 354
www.mpnvoice.org.uk

MDS UK

Provides support to patients with MDS or CMML.

020 7733 7558

www.mdspatientsupport.org.uk

Cancer Research UK

Leading charity dedicated to cancer research.

0808 800 4040

www.cancerresearchuk.org

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 CMML, sharing your story can help others in a similar situation. It can also help people understand CMML 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 with us 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 support. 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 if you'd like a list of the sources we used for this booklet.

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@leukaemiacare.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.leukaemiacare.org.uk**
- **support@leukaemiacare.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

Trusted Information Creator
Patient Information Forum

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