Newly diagnosed with Chronic Myeloid Leukaemia (CML)

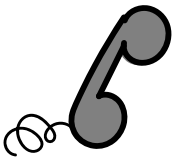
A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

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.

Our services

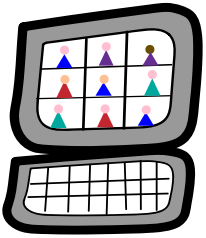


Helpline

Our helpline is available 9am to 5pm Monday to Friday. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9am to 5pm.

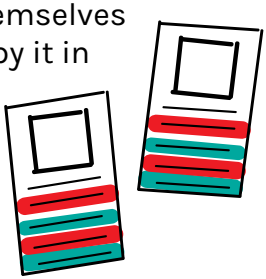
Support groups



Our nationwide support groups are a chance to meet and talk to other people who have been affected by a CML diagnosis. For more information, scan this QR code:

Buddy support

We offer one-to-one phone support with volunteers who have had CML themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

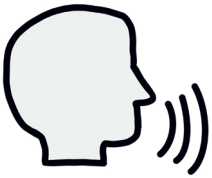


Counselling service

Our counselling service helps CML patients and their loved ones access up to six sessions of counselling. To apply, scan this QR code:

Advocacy and welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding a CML diagnosis. These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.



Cost of living fund

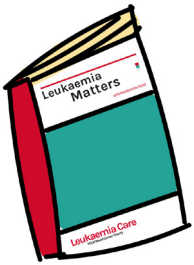
This fund provides grants to patients and families affected by CML, to help with essential living costs. All applications must be made via the form which can be found by scanning the QR code:

Write a free will

Using our complimentary service, you can write a simple will so you know what happens to your estate when you die. To start writing your free will today, scan this QR code:

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe to our magazine, scan this QR code:



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, and much of it will not be applicable to you. Your haematology team is best placed to give you information that is specific to you because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Look for a quality mark, such as the Patient Information Forum (PIF) tick.

Introduction

Chronic myeloid leukaemia (CML) is a type of blood cancer that involves the white blood cells. It develops slowly over many years. In this booklet, we cover what CML is, who gets it, how it is diagnosed and what treatments you might have.

There is another condition that used to be called 'atypical CML'. This is a completely different disease that used to be confused with CML. Its treatment is very different, and its name has been changed to stop the confusion. It is now called MDS/MPN with neutrophilia.

We have **separate information about this**. Follow the link, search 'atypical' at **shop.leukaemiacare.org.uk** or scan the QR code.

This booklet is only a guide of what you might experience. Your haematology team will give you a copy of your specific treatment plan.

This booklet was reviewed by consultant haematologists and by patient reviewers, Colin and Lesley. We thank them all for their valuable contribution.

Throughout this booklet, you will see QR codes and URLs that link to webpages for further support. To open a link, either click on it or access your phone camera and hover it over the QR code (suitable for Android, iPhone 7 and above). If you are not able to access the webpages, please email **information@leukaemiacare.org.uk.**

About chronic myeloid leukaemia (CML)

Summary

- Chronic myeloid leukaemia (CML) is a slow-growing type of blood cancer. It happens when white blood cells in your bone marrow multiply uncontrollably. These cells do not work properly. They can build up in your bone marrow and stop it making enough healthy red and white blood cells.
- CML is quite rare. Only around 830 people in the UK are diagnosed with it every year – about 1 person in every 100,000.
- The average age to be diagnosed with CML is around 57, but it can affect people of any age, including children.
- We do not know exactly what causes CML. However, you cannot catch it or pass it on to anyone else.
- The most common symptoms and signs of CML are:

Fatigue | Anaemia | Unexplained weight loss | Night sweats | Fever | Tummy pain or bloating

A feeling of fullness | Bleeding or bruising | Infections | Bone pain | Discomfort under ribs

About 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, blood-forming cells in your bone marrow multiply too much. These 'leukaemia stem cells' divide and mature uncontrollably. This means there is 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.

People affected by CML

Every year, CML is diagnosed in around 830 people in the UK. This is about 1 in every 100,000 people.

CML can affect people of any age, but it is most common in older people (over 60 to 65 years old). The average age at diagnosis is around 57.

- Over 20 in every 100 people with CML are over 70.
- Fewer than 5 in every 100 people are children or young adults (under 20).

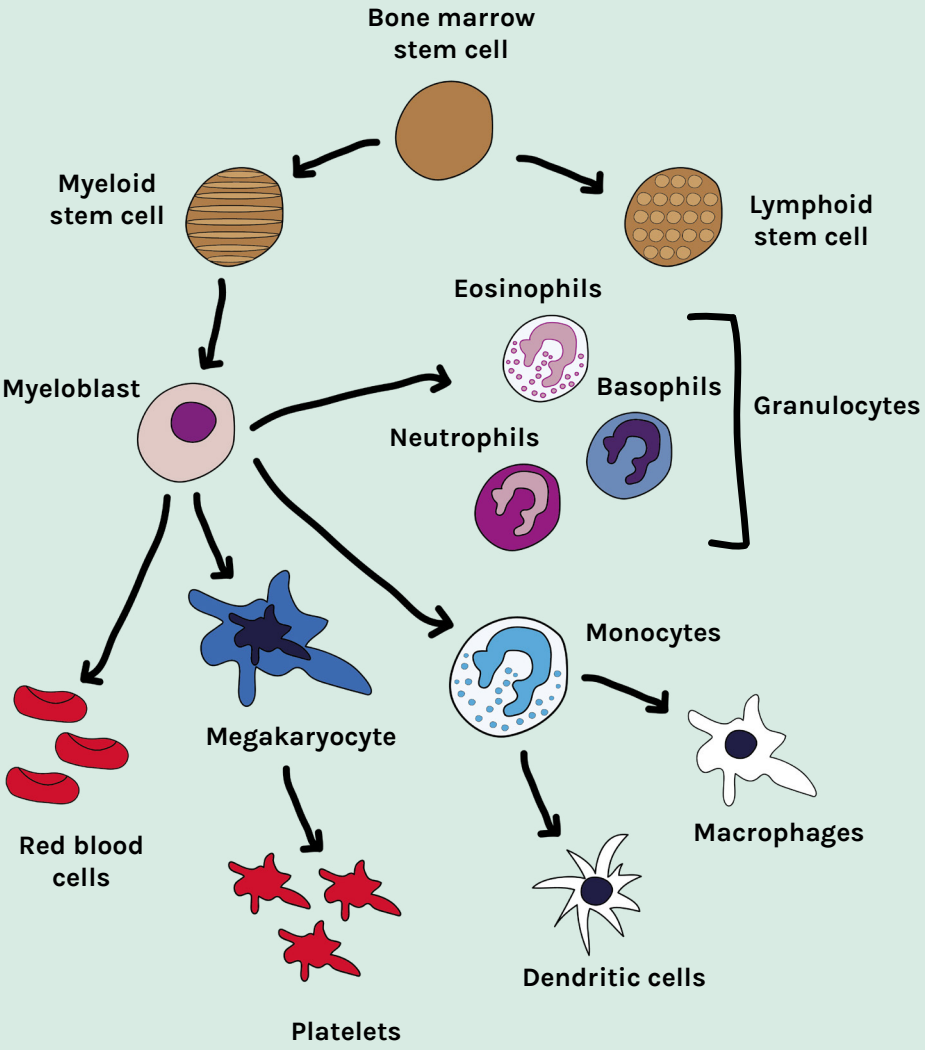
Causes of CML

We do not know exactly what causes CML, but there are some things that might increase your chance of getting it.
These include:

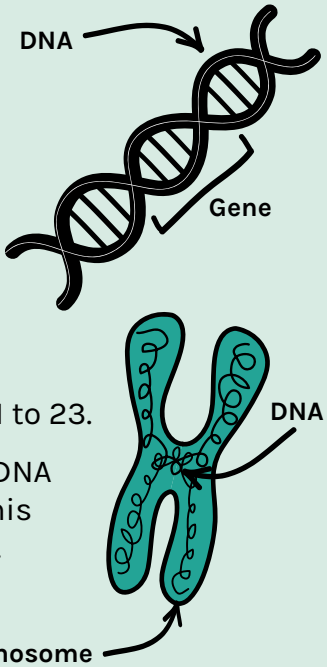
- Age: the risk of getting CML increases with age
- Sex: CML is slightly more common in males than females
- Exposure to radiation: this can increase the chance of getting CML
- Genetic changes

More on blood cell development

Blood-forming cells called myeloid stem cells usually develop into immature white blood cells called myeloblasts. In turn, myeloblasts develop into white blood cells called granulocytes and monocytes, which fight infections. They also turn into red blood cells and platelets.



About genes and chromosomes

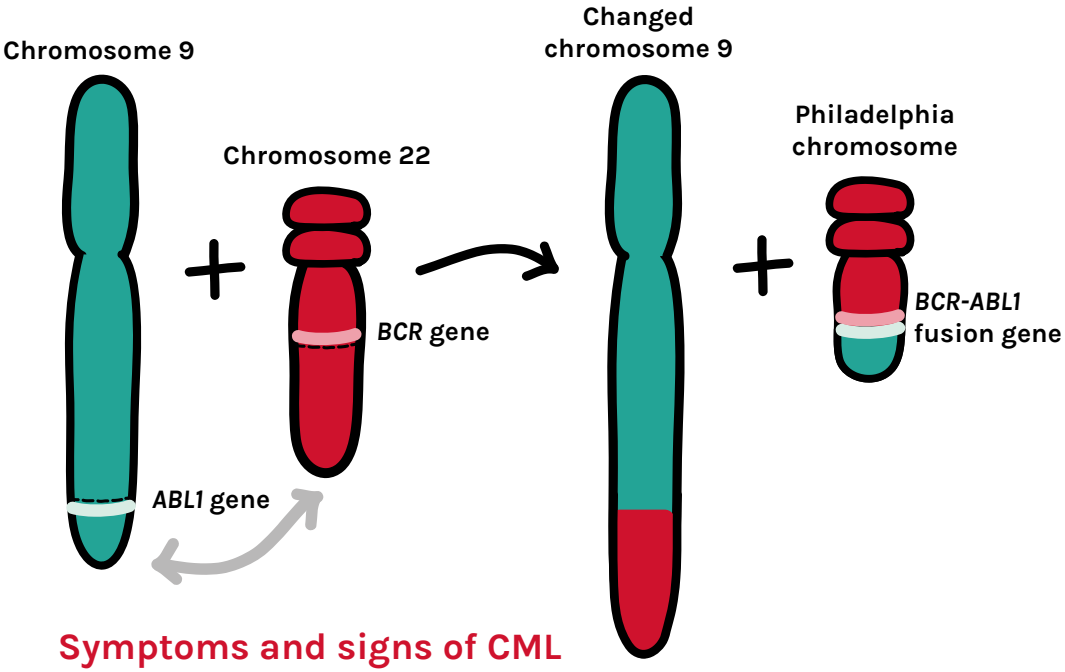


- Genes are made up of DNA. They contain instructions for your cells on how to make proteins needed by your body.
- Chromosomes are long, coiled strands of DNA that sit in the nucleus of each of your cells. Each chromosome contains lots of different genes.
- Humans usually have 23 pairs of chromosomes. They are numbered from 1 to 23.
- Changes to a chromosome or part of its DNA can change the genes that it contains. This can change the proteins your cells make.
- Changes in chromosomes and genes can include:
  - Having an extra chromosome (or bit of a chromosome)
  - Losing a chromosome (or bit of a chromosome)
  - A swap of genetic material between chromosomes or within a chromosome
  - Small differences in the DNA code that can affect how a protein works

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

- About 95 in every 100 people with CML have a genetic change called a **Philadelphia chromosome**. This includes an abnormal piece of genetic code called the *BCR-ABL1* gene. You might also see this written as *BCR::ABL1*.
  - The Philadelphia chromosome forms when genetic material swaps between chromosomes 9 and 22. Scientists write this as t(9;22).
  - The swap makes two genes fuse together to make an abnormal fusion gene called *BCR-ABL1*.
  - The *BCR-ABL1* gene makes an abnormal version of a protein called tyrosine kinase. It is this protein that encourages the overproduction of myeloid cells that happens in people with CML.
- About 5 in every 100 people with CML have a variant of the Philadelphia chromosome.
  - These people still have the *BCR-ABL1* gene, but you can't see the typical Philadelphia chromosome under a microscope.
  - People with a Philadelphia chromosome variant have the same treatment as people with the regular Philadelphia chromosome.
- Some people have extra genetic changes as well as the Philadelphia chromosome or Philadelphia chromosome variant. These can include extra copies of chromosomes, or abnormalities in other chromosomes.
  - Some people have these genetic changes when they are first diagnosed. Some people might develop them later.
  - Having extra genetic changes may increase the chance of your CML progressing faster. Your haematology team will consider this when deciding on the best treatment option for you.

Formation of the Philadelphia chromosome and *BCR-ABL1* fusion gene



Symptoms and signs of CML

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

Between 90 and 95 in every 100 people with CML are diagnosed when they are in the chronic phase. They may have no symptoms or just vague symptoms at the time. In general, people with CML are diagnosed after having a routine blood test for something else.

"Before my diagnosis, I didn't think there was something specifically wrong, and I had only been to the GP for a few minor issues in the months before my diagnosis."

Helen, diagnosed with CML at 59

You may not develop symptoms for years. But if left untreated, you will usually go on to get symptoms such as:

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

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

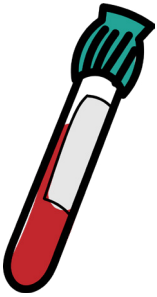
"I had all these symptoms: night sweats, collapsing, weight loss, fatigue... all in isolated incidents so I didn't put it down to anything. But looking back I had every single symptom of CML."

Michael, diagnosed with CML at 29

Diagnosis of CML

Summary

- 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



- You might also have other tests to find out more about how CML is affecting your body.
- It can be difficult waiting for test results. Our Patient Services Team is here for you if you need support. You can email them at support@leukaemiacare.org.uk, message them on WhatsApp at **07500 068065** or call the freephone helpline at **08088 010 444**.

Diagnosis of CML

Your haematology team will diagnose CML based on the results of your:

- Blood tests and bone marrow tests
- Tests looking for genetic changes in your blood or bone marrow samples

"When the doctor told me I had leukaemia, and after reassuring me that I wasn't dying, I felt a profound sense of relief. Yes, I had cancer and that sucked, but at least I knew I wasn't dying. Knowing what you're facing is much less terrifying than facing the unknown, at least to me."

Jo, diagnosed with CML at 34

You might also have other tests to find out more about how CML is affecting your body.

Some of these tests are repeated throughout your treatment period to monitor your response to treatment.

Blood tests

The first test you are likely to have is a full blood count. This will usually be ordered by a non-specialist. It is a routine blood test that measures the number of:

- Red blood cells
- Platelets
- Different types of white blood cells

If you have CML, your full blood count usually shows:

- High numbers of white blood cells. This is due to increased numbers of white blood cells at different stages of development, and leukaemia cells.
- Low numbers of healthy red blood cells. This is due to the bone marrow being too busy making leukaemia cells.
- High or low number of platelets. CML leukaemia stem cells typically make too many cells that develop into platelets, so your platelet count is high. But sometimes, leukaemia cells fill up the bone marrow, so there is no room for platelet-producing cells and the platelet count is low.

A specialist will also look 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.

Based on these results, you will normally need to see a specialist to arrange more complex tests.

You might also have routine 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. It is important to know any other medical problems you have before starting any treatment.

Bone marrow tests

If your haematology team think you might have CML, they will do a bone marrow test in most cases. 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.

To have a bone marrow test:

- You have a local anaesthetic to numb the area where you're having the test. This is usually your hip bone (pelvis).
- Your haematologist then uses a special needle to suck out a sample of liquid bone marrow. This is called a bone marrow aspiration.
- Sometimes they might also need a small sample of harder bone marrow. They use a larger needle for this. It is called a bone marrow trephine biopsy.
- A bone marrow test can be uncomfortable both during and after the procedure. Ask your doctor or nurse what painkillers you can use if you need them.
- You should avoid vigorous exercise for 24 to 48 hours afterwards.

Genetic tests

Your doctors will send your blood or bone marrow samples for tests to find genetic changes in your leukaemia cells. They are looking for changes called the Philadelphia chromosome and the *BCR-ABL1* gene, which are used to diagnose CML.

The genetic tests are done on your blood or bone marrow samples. You might hear your doctor call them PCR tests, cytogenetic tests or molecular tests. In some cases, your haematology team may perform a genetic test called a myeloid gene panel (MGP). This looks for a number of genetic changes linked to myeloid blood disorders such as CML.

The genetic tests can help your haematology team:

- Diagnose CML
  - CML has symptoms and signs that can be similar to other conditions, including other types of leukaemia. Testing for genetic changes in your blood cells helps your haematology team work out whether you have leukaemia or a different condition. If you have leukaemia, it can help them work out the exact type you have.
- Work out how likely your CML is to progress
  - Some gene changes are linked to a higher chance of your CML progressing. Knowing this may help your haematology team decide on the exact treatment to recommend.
- Monitor how well your CML is responding to treatment (page 32)

Your haematology team will talk to you about what your genetic results mean.

Other tests you might have

You might have other tests to get more information about how CML is affecting other parts of your body.

Imaging tests

Some people with CML may have an ultrasound to see how big their spleen is, but this isn't always needed. You might have other imaging tests at diagnosis or during treatment, depending on what symptoms you have.

Lumbar puncture

A small number of people with CML may need a lumbar puncture. This is usually if they have more aggressive (faster-growing) disease, or if they have worrying symptoms.

A lumbar puncture is a test to collect a sample of the fluid that surrounds your brain and spinal cord (called cerebrospinal fluid). This helps find out if you have leukaemia cells in your central nervous system.

- Your haematology team will ask you to lie on your side with your legs pulled up and tucked under the chin. This makes it easier to insert a needle between the bones of your lower spine.
- They will clean the skin of your lower back and inject a local anaesthetic to numb the area.
- They will then put a thin needle between the bones of your lower spine and take a small sample of cerebrospinal fluid. You should not feel any pain, but you might feel some pressure.
- It may be uncomfortable during and afterwards and you might get a headache. Ask your doctor or nurse what painkillers you can use if you need them.

If the test shows you have leukaemia cells in your central nervous system, you will need further treatment straight after diagnosis.

Test results

Your haematologist will diagnose CML if the *BCR-ABL1* gene is present in your blood or bone marrow.

Your haematology team should explain your test results to you. Ask them if you're not sure what the results mean, or if you'd like more information.

Your test results may take a little while, which may 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.

Our Patient Services Team is here for you if you need support while you are waiting for your results. You can email them at support@leukaemiacare.org.uk, message them on WhatsApp at **07500 068065** or call the freephone helpline at **08088 010 444**.

Phases of CML

Your haematologist also uses your test results to work out the phase of your CML. There are two main phases:

Chronic phase

- Most people are in the chronic phase when they are diagnosed. This means that less than 10 to 20 out of every 100 cells in your blood or bone marrow are myeloid blast cells. This is a type of immature blood cell.
- During the chronic phase, you might not have symptoms.
- 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**.

Blast phase

If your CML starts to grow more rapidly, it might enter the blast phase. This means:

- More than 20 to 30 out of every 100 cells in your blood or bone marrow are myeloid blast cells **OR**
- You have clumps of leukaemia cells outside your bone marrow **OR**
- You have increased immature white blood cells called lymphoblasts in your blood or bone marrow. Lymphoblasts are a different type of blast cell.

Around 5 to 10 in every 100 people with CML are in the blast phase when they are diagnosed. People with CML in the blast phase need more intensive treatment.

Treatment of CML

Summary

- There are a lot of treatment options for CML. Most treatments aim to keep your CML under control rather than ‘cure’ it.
- The first treatment for CML is usually a type of targeted therapy called a tyrosine kinase inhibitor (TKI). TKIs are tablets that you take by mouth.
- If your CML is in the blast phase, your haematology team might suggest a TKI alongside chemotherapy. This may be followed by a stem cell transplant using donor cells.
- If your first treatment for CML is not successful, there are many more options to try.

Treatment of CML

There are a lot of treatment options for CML. Most treatments aim to keep your CML under control rather than 'cure' it. Nowadays, most people with CML have a normal life span and a good quality of life.

The first treatment you have is called 'first-line' or 'frontline' treatment. If first-line treatment does not work well or stops working, other treatment options are available. These are called second-line treatments.

> **"My treatment was one pill a day, I didn't have to go through IV chemo, I wasn't likely to lose my hair and the side effects from my medication were minimal."**
>
> **Jo, diagnosed with CML at 34**

Your haematology team will suggest the most suitable treatment for you based on:

- Your personal characteristics
  - Your age
  - Your personal preference
  - Any other medical conditions you have
- The features of your CML
  - Whether your CML is in the chronic phase or the blast phase
  - The risk of your CML progressing to the blast phase
  - The genetic changes in your leukaemia cells
- Previous treatment
  - Whether it's your first-line treatment
  - Any side effects that you have had with other treatments

Tell your haematology team if you think you might want to have children in the future. This could affect the choice of treatment they suggest. Depending on your treatment plan, they may talk to you about options to preserve your fertility.

Before starting your main treatment

If you have high white blood cell counts or troublesome symptoms, your haematology team might start treatment while they wait for all your test results to come back. This is likely to be a course of tablets called hydroxycarbamide (also known as hydroxyurea). This is a type of chemotherapy that helps lower your white blood cell count.

Hydroxycarbamide is given as capsules that you take by mouth once a day. Once your blood counts improve, your haematology team usually reduce the dose before stopping it completely.

We have **separate information about hydroxycarbamide**. Follow the link, search for 'hydroxycarbamide' at **shop.leukaemiacare.org.uk.** or scan the QR code.

Once all your test results are back, your haematology team will work out your long-term treatment plan.

First-line treatment options

The first treatment you have depends on the phase of your CML.

- If your CML is in the chronic phase, the usual first-line treatment is a type of targeted therapy called a TKI.
- If your CML is in the blast phase, your haematology team might suggest a TKI alongside chemotherapy. They might also recommend a stem cell transplant using donor cells.
    - Rarely, people in the blast phase may have leukaemia cells in their central nervous system. If this is the case, your haematology team will give you a course of chemotherapy directly into the fluid surrounding your brain and spinal cord. This is called 'intrathecal chemotherapy'. You have it through a lumbar puncture (page 17).

TKIs

TKIs are a type of targeted therapy. Targeted therapies are drugs designed to block specific proteins in leukaemia cells. This means they kill leukaemia cells with as few effects on healthy cells as possible.

"There are days that I feel so good, I sometimes forget I have CML. The side effects aren't too bad apart from cramps in my hands and sometimes in my toes."

Alma, diagnosed with CML at 51

TKIs block a protein called tyrosine kinase. The *BCR-ABL1* gene found in people with CML makes an abnormal version of a tyrosine kinase. It is this protein that encourages the blood-forming cells in your bone marrow to make too many white blood cells. TKIs are able to block the abnormal tyrosine kinase protein, which is only present in the leukaemia cells.

TKIs are tablets that you take by mouth. They are generally highly effective at keeping CML under control. Each TKI has a different profile and might cause different side effects.

We have separate information on each of the TKIs used to treat CML:

- Imatinib
- Nilotinib
- Dasatinib
- Bosutinib – This is not currently available on the NHS as a first-line treatment for CML. However, it can be used for people who need second-line treatment.
- Ponatinib – This is only used as a first-line treatment for people who have a genetic change in the *BCR-ABL1* gene called the T315I mutation.
- Asciminib – This is not used as a first-line treatment for CML. It might be used for people who have not responded to, or cannot take, other TKIs.

Scan the QR code to order these leaflets in print or visit **shop.leukaemiacare.org.uk** and search the name of the treatment.

To download a digital copy, scan the QR code or visit **bit.ly/LCCMLHub** and find your treatment.

Many people with CML continue taking TKIs unless treatment stops working or they get side effects that are difficult to manage. However, if you've been taking TKIs for at least 5 years and you've responded well, you might be able to either:

- Reduce your dose.
- Stop treatment completely. This is called 'treatment-free remission'.

Your haematology team will talk to you about this if it is an option for you.

Do not stop taking TKIs without discussing it with your haematology team.

We have a separate booklet about treatment-free remission for CML. Scan the QR code to order a hard copy or visit **shop.leukaemiacare.org.uk** and search 'treatment-free remission'.

To download a digital copy, visit **bit.ly/LCCMLHub**.

Stem cell transplant using donor cells

A stem cell transplant using donor cells is called an allogeneic stem cell transplant. It involves having high-dose chemotherapy to kill your own blood-forming stem cells. These are replaced by healthy stem cells from a compatible donor. A stem cell transplant is very intensive. It is only suitable for people who are fit enough to have it.

Your haematology team might suggest a stem cell transplant for you if your CML is in the blast phase. They might also consider it as an option if you've already tried treatment with at least two different TKIs.

Your haematology team should 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 a separate booklet on stem cell transplants. Scan the QR code to order or download the booklet or visit **shop.leukaemiacare.org.uk** and search 'stem cell transplants'.

Chemotherapy

Chemotherapy drugs kill cells that are dividing rapidly. This means they kill cancer cells, but they can also kill healthy cells like blood cells, skin cells, hair cells and the cells lining your gut.

You might be offered chemotherapy if your CML is in the blast phase.

Different chemotherapy medicines may be used to treat blast phase CML. These include hydroxycarbamide, and a combination of chemotherapy medicines called FLAG-Ida.

Your haematology team will tell you what they recommend for you. They will explain what the treatment is, how you have it, and what side effects that you might get.

Macmillan Cancer Support have more information about particular chemotherapy combinations. Scan the QR code or visit **macmillan.org.uk** and either search for your treatment or choose the 'Treatment and drugs A to Z'.

Other treatment options

Depending on your circumstances, your haematology team might suggest other treatments. These include:

- Treatment to remove some of your white blood cells. They might recommend this at diagnosis, or if your white cell count or blast count is very high. It is called leukapheresis.
- A medicine called peginterferon-alfa, although this is very rarely used.

Leukapheresis

Your haematology team might suggest leukapheresis if you have a very high white blood cell that needs to be treated quickly. It may also be an option if you are pregnant.

You have leukapheresis in hospital and go home afterwards. It usually takes a few hours.

- A doctor or nurse puts a thin plastic tube into a vein in both your arms.
- You have blood taken out of one arm.
- The blood passes through a machine called a cell separator. This takes out some of the white blood cells.
- The rest of the blood goes back into your body through the tube in your other arm.

Peginterferon-alfa

Peginterferon-alfa is not often used to treat CML, but it may be an option if you are pregnant. It alters the way your immune system works and helps stop the leukaemia cells growing and multiplying.

You have it as an injection under your skin, usually once a week. Your doctor or nurse can teach you how to do it yourself at home. You could ask them to teach a friend or family member to do it for you if you prefer.

Cancer Research UK have more information about peginterferon-alfa. Scan the QR code or visit **cancerresearchuk.org/** and search 'peginterferon'.

Second-line treatment options

For some people, CML does not respond well to first-line treatment. Sometimes, first-line treatment may stop working, or cause unmanageable side effects. If this happens, you might have to change to a different treatment. There are lots of other options. These include:

- A different TKI. All TKIs work in slightly different ways. If your CML does not respond to one TKI, it might still respond to a different one. Some people try several different TKIs.
- A stem cell transplant if TKIs have not been effective.

If your treatment stops working, your haematology team are likely to check if you have developed any new genetic changes. These could make your leukaemia cells resistant to certain treatments. This can help them work out which treatment to recommend next.

Your haematology team will tell you which option they recommend for you.

We have a separate booklet on second-line and later-line treatments for CML.

Scan the QR code to order a print copy or visit **shop.leukaemiacare.org.uk** and search 'second-line treatments for CML'.

To download a digital copy, scan the QR code or visit **bit.ly/LCCMLHub**

Supportive care

During your treatment and afterwards, you might also need medicine to prevent or treat symptoms or side effects. This is called supportive care. It does not treat the CML itself, but it helps you feel better.

Supportive care might include:

- Medicines called growth factors if your blood counts are too low
- Blood transfusions, although these are rarely needed and can usually be avoided by using growth factors instead
- Anti-sickness medicines
- Anti-diarrhoeal medications

Supportive care is not only limited to the physical impact of your CML. It can also include:

- Psychological support
- Support with exercise or physiotherapy
- Social support
- Spiritual wellbeing such as mindfulness

Your haematology team should talk to you to find out what support they can offer you. Please tell them if you have any symptoms or side effects that you are finding hard to cope with.

Monitoring and follow-up for CML

Summary

- You will have regular tests during your treatment to monitor how well your CML is responding.
- The tests will measure your blood cell counts and the level of the *BCR-ABL1* gene in your white blood cells.
- Your haematology team will use the results of these tests to check your response to treatment.
- You should ask your team for your results to help understand your response.
- Once your CML is treated successfully, you will still have regular blood tests and follow-up appointments. These will check your response, as well as dealing with any complications.
- If you have any serious or worrying symptoms, contact your haematology team. Do not wait for your next appointment.

Monitoring your response to treatment

You will have regular blood tests during your treatment to monitor how well your CML is responding.

The tests will measure:

- Your blood cell counts. This is sometimes called your **haematological response**.
- The level of the *BCR-ABL1* gene in your white blood cells. This is called your **molecular response**.

Most people will not need a repeat bone marrow biopsy during treatment. However, your haematology team may decide this is an important way to assess your condition. This is usually when there are issues with your treatment, or they are worried about progression to faster-growing CML. This is called your **cytogenetic response**.

You might hear your haematology team talk about a haematological response, a molecular response, or a cytogenetic response.

> **"I accept I'll be having blood tests and taking medication for the rest of my life but while this disease is part of my life and always will be, I won't let it define me."**
>
> **Marisa, diagnosed with CML at 18**

Haematological response

This means:

- Your blood cell counts have returned to normal (or abnormalities are only down to treatment)
- Your spleen is not swollen

If your treatment is working well, you should have a haematological response within 1 to 2 months of starting treatment.

A haematological response is not as sensitive as other tests that measure your response to treatment. There might still be low levels of leukaemia cells in your body that can't be seen under a microscope.

Molecular response

You will have regular blood tests during treatment to measure the level of the *BCR-ABL1* gene in your blood. This is a good measure of how much leukaemia is left in your body. It is done using a test called PCR. This test is very sensitive so it can detect extremely low levels of leukaemia in your body. It gives a very accurate measure of your disease status.

"I am taking my TKI, which like all medication comes with its side effects, but it is a small price to pay for something that does such a great job. I am in major molecular response (MMR) and, with fingers crossed, my TKIs continue to work for me and let me live the life I want to live."

Carrie, diagnosed with CML at 36

There are different levels of molecular response:

- **MR1:** Less than 1 in 10 white blood cells (10%) has the *BCR-ABL1* gene. If your treatment is working well, you should reach MR1 within 3 months of starting treatment.
- **MR2:** Less than 1 in 100 white blood cells (1%) has the *BCR-ABL1* gene. If your treatment is working well, you should reach MR2 within 6 months of starting treatment. This is the equivalent of **complete cytogenetic response** on chromosomal tests (page 35), and this is what your team might call it.
- **MR3:** Less than 1 in 1,000 white blood cells (0.1%) has the *BCR-ABL1* gene. This is sometimes called a **major molecular response** (MMR). If your treatment is working well, you should reach MR3 within 12 months of starting treatment.
- **MR4:** Less than 1 in 10,000 white blood cells (0.01%) has the *BCR-ABL1* gene. This is sometimes called a **deep molecular response** (DMR). If you reach and maintain a deep molecular response, you might eventually be able to stop treatment.
- **MR5:** Less than 1 in 100,000 white blood cells (0.001%) has the *BCR-ABL1* gene. This is also called a **deep molecular response** (DMR). If you reach and maintain a deep molecular response, you might eventually be able to stop treatment.
- Levels below MR5 cannot usually be detected. This is called a **complete molecular response**.

If your *BCR-ABL1* levels have dropped, but you haven't quite met the required milestones, you may be in a 'warning' category. You should discuss your options with your haematologist.

Your molecular response can be used to detect any difficulties in treatment early on. They are an essential part of safe monitoring if you can stop treatment (page 26).

Cytogenetic response

This looks at the number of cells in your bone marrow that have the Philadelphia chromosome. It is not as sensitive as molecular response. It is not measured very often, and the cytogenetic response may be worked out from the molecular tests instead.

A complete cytogenetic response means that no bone marrow cells have the Philadelphia chromosome. If your treatment is working well, you should have a complete cytogenetic response within 6 months of starting treatment. This is the equivalent of less than 1 in 100 cells (1%) having the *BCR-ABL1* gene on your molecular tests (MR2).

Follow-up care

Once you have reached a response to treatment, your haematology team will make a follow-up care plan. You will have regular follow-up appointments to check your response, as well as dealing with any complications.

It is important to attend follow-up appointments, either in person or on the phone if you have a telephone appointment. This allows your team to check how well your treatment is working and how you are coping. You are likely to have blood tests every few months, to check your response.

Your follow-up appointments will continue in the long-term. How often you have appointments will depend on:

- Your type of treatment
- Your individual needs - for example, any support you need to manage ongoing side effects

You should report any symptoms or side effects to your haematology team at your follow-up appointments. If you have any serious or worrying symptoms, you do not have to wait for your next appointment. Your haematology team should give you details of who to contact. This may be a Clinical Nurse Specialist (CNS), if one is available in your area.

Follow-up appointments are also a chance to talk to your team about any emotional or mental health concerns you have. It is not unusual for people living with CML to experience challenging emotions that you may need support with. Your team can help you get the support you need.

Some people find it helps to connect with others going through a similar experience. Our buddy scheme offers one-to-one support and the opportunity to speak to someone in a similar situation to you. Email **support@leukaemiacare.org.uk** or call **08088 010 444** to find out more.

You might find it helpful to use an app called 'My CML'. This app was designed by NHS pharmacists. It lets you track your CML symptoms, medicines, test results and appointments.

You can download the My CML app free via the Apple or Google Play app stores, or find out more at **mycml.thetechcompany.co.uk**

Outcomes of CML

Summary

- In general, people with chronic phase CML can expect to live just 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. They depend on lots of different factors. Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.
- Survival figures are only averages. It is not possible to predict for certain what will happen for you.

Outcomes of CML

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

"'If you're going to get cancer, this is a good one to get.' I was told this by both my consultant and nurse specialist. Looking back, I thought, 'What?' But now I realise I am lucky and it's helped me deal with my cancer journey."

Lesley, diagnosed with CML at 54

For people with CML in the blast phase, or progressing into the blast phase, outcomes are less favourable.

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

- 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.

If you are interested in general survival numbers for CML, 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.

5-year survival rates are commonly quoted. 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.

On average:

- Around 90 in every 100 people with CML are still alive 5 years after their diagnosis
- Around 80 in every 100 people with CML who have had a stem cell transplant are still alive 5 years after diagnosis
- Around 10 to 20 in every 100 people with blast phase CML are still alive 5 years later

These overall survival figures are averages for people with CML who are in different phases. It is not possible to predict for certain what will happen for you. Your haematology team will only be able to give you an idea what they expect for you.

Living with CML

Summary

- Having CML can affect your day-to-day life in a number of ways.
- You might experience fatigue. Planning, pacing yourself and saving your energy for things that are important to you can help. You could also ask your haematology team if you may be able to reduce your dose to help with side effects.
- Keep active and eat a healthy, balanced diet if you can to help your fitness in general.
- Being diagnosed with CML can be overwhelming. You may experience a variety of emotions. Contact your GP if you think you may be depressed.
- Having CML can affect your work or finances. You are entitled to reasonable adjustments to help you cope with work. You may be eligible for financial support.
- If you are struggling, don't be afraid to ask for help from friends, family, your haematology team or Leukaemia Care support services.

Living with CML

Being diagnosed with CML can be overwhelming. Symptoms, the effects of treatment, tests and hospital appointments may all have an impact on your day-to-day life. Here, we cover some of the practicalities of living with CML.

> **"Having CML is difficult and life changing, but you can still live your life and enjoy the same things."**
>
> **Carrie, diagnosed with CML at 36**

Telling other people

When you are first diagnosed with CML, 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 is happening which can make you feel under pressure to tell them. Let them know that you need time to process the information yourself before you are ready to talk about it.

> **"Talk about your CML - to your family, friends, medical team, support organisations and other patients. Learn from others so that you can better manage having a chronic disease and your friends and family can better understand what you are going through."**
>
> **Colin, diagnosed with CML at 54**

There will be some people that you want to tell and others that you prefer not to. It is up to you who you tell and how much you tell them.

Managing fatigue and brain fog

Many people with CML experience fatigue. It can be physical: feeling exhausted or lacking the energy to do everyday things. It can also be mental – you may feel mentally drained or have difficulty concentrating. People often call this 'brain fog'.

Fatigue and brain fog can be a side effect of treatment or, more rarely, an effect of the CML itself. It can also be due to the psychological and emotional stress of diagnosis.

Brain fog may leave you not feeling like yourself. This can affect your relationships with friends, family and colleagues. It can also impact your speed of thinking, decision-making and your ability to manage at home.

> **"I consider myself to be living with cancer – I work full time, go on holiday, travel, and dance at weddings. I live my life more or less the same way as I did before. Granted, I take more naps than I used to and I take it easy in the mornings as I can get nauseous, so I've built my routine around that."**
>
> **Jo, diagnosed with CML at 34**

Fatigue is often frustrating as it cannot be treated with medicines. It is common for it to continue after treatment, but it often gets better over time.

There are lots of things you can do to help you cope with fatigue. These include:

- Allowing yourself to rest when you need to
- Making plans and pacing yourself
- Prioritising things that are most important to you
- Keeping to a regular sleep routine
- Accepting help with household tasks
- Taking gentle exercise
- Using lists, notes, apps or a diary to help you remember things

We have more resources to help you cope with fatigue on our website. Scan the QR code to find out more, or search 'fatigue' at **leukaemiacare.org.uk**

Make sure you tell your haematology team if you are experiencing fatigue, either during or after treatment. There may be options to adjust your treatment, including the dose or medication you receive. There are fatigue services to help if it affects you long-term or particularly severely, but waiting lists can be long.

Infection risk

Some people with CML might have a slightly higher risk of getting infections than other people. This may be the case at the beginning of your care, before your CML responds to treatment. If this affects you, ask your haematology team if there are any precautions you should take.

Looking after yourself

It's important to look after yourself well. This can help you feel better physically and emotionally.

If you can, try to eat a well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with your treatment

Some treatments for CML might affect your appetite or have side effects like sickness, constipation, diarrhoea or sore mouth. This can make it difficult to eat a healthy diet. Try to eat what you can. If you're struggling, ask your haematology team for advice.

The NHS website has information and guidance on eating a healthy, balanced diet. Scan the QR code, or go to the 'live well' section at **www.nhs.uk**

Staying active is also important. Exercise can improve your wellbeing, quality of life and physical health. It can also help relieve the stress of your CML and improve side effects. 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're feeling.

If your blood counts are very low, ask your haematology team for any precautions you need to take. These are not usually necessary for people with CML.

Mental health, emotional health, mood and behaviour changes

Being diagnosed with a serious illness can be overwhelming emotionally as well as physically. You may feel a range of emotions like:

- Anger – why has this happened to you
- Guilt – for not being able to do the things you usually do
- Fear – worrying about the future
- Confusion – not understanding the new terminology
- Anxiety and depression – feeling worried, low or hopeless

Sadness and depression

After a diagnosis of CML, you may feel a sense of loss of the person you used to be, and how safe you felt. You might be feeling low, which is a natural effect of your illness, treatment, and recovery. 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, contact your GP. They can help you access the support and treatment 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 or go to the 'mental health' section at **www.nhs.uk**

"I discovered that Leukaemia Care offered a buddy scheme, so I reached out and requested a buddy... The most important thing I learned was that everyone's cancer journey and experience is unique. The fact I've been 'lucky' with my diagnosis and lack of side effects doesn't make me any less deserving of support."

Jo, diagnosed with CML at 34

Talking to others can help. It can be difficult to talk to loved ones so you might need someone independent. This is where Leukaemia Care can help. Alternatively, some people find it helps to connect with others going through a similar experience. Our buddy scheme offers one-to-one support and the opportunity to speak to someone in a similar situation to you.

To find out more, or to get support from our Patient Services team, email **support@leukaemiacare.org.uk** or call our freephone helpline on **08088 010 444**.

Work and money

Juggling work or education with hospital and GP appointments is challenging for anyone.

You may need time off when you're feeling unwell or to attend appointments. If you do not need time off, it is your choice whether to tell your employer about your diagnosis. You are entitled to reasonable adjustments to help you cope with work. You may wish to have an open conversation with your employer about how they can support you.

Your CML may also affect your finances even if you are not working. Being diagnosed with leukaemia comes with extra costs, such as extra heating costs or travel to and from hospital. You should also be able to get free prescriptions as a person with cancer. Your haematology team can provide you with an exemption form.

If you are diagnosed with CML while you are at school or university, you should contact them. They may be able to offer you additional support or defer your attendance for a while if you need it.

We have a range of services that can help you when living with CML, including a welfare service and cost of living hub. Scan the QR code to find out more, or go to **bit.ly/LCSupportForYou**

Home life

A diagnosis of leukaemia is likely to impact your home life. You may need help with shopping, childcare responsibilities, housework or gardening, especially if you are tired and not feeling well.

You might find our **newly diagnosed checklist** helpful. Scan the QR code or follow the link to take you there. Alternatively, you can search 'diagnosed' at **leukaemiacare.org.uk**

Ask for help if you need it, so you can focus on your physical recovery.

Glossary of medical terms

Atypical CML: A blood condition that used to be confused with CML. It is a different condition and needs different treatment. It is now called MDS/MPN with neutrophilia.

***BCR-ABL1* gene:** An abnormal piece of genetic code found in people with CML. It makes an abnormal version of a protein called tyrosine kinase.

Blast phase: When your CML is aggressive or fast-growing.

Blood transfusion: A procedure to give you donated blood through a drip into a vein.

Bone marrow: Spongy tissue in the cavities of bones where blood cells are made.

Cancer: The uncontrolled growth of abnormal cells.

Central nervous system: Your brain and spinal cord.

Cerebrospinal fluid (CSF): The fluid that surrounds your brain and spinal cord.

Chemotherapy: Drugs that kill cancer cells or stop them dividing and multiplying.

Chromosomes: Long, coiled strands of DNA that sit in the nucleus of your cells. Each chromosome contains lots of different genes.

Chronic myeloid leukaemia (CML): A slow-growing type of blood cancer that starts in blood-forming cells in your bone marrow called myeloid stem cells.

Chronic phase: When your CML is slow-growing.

Chronic: Long-term or lasting for a long time.

Cytogenetic response: How well your CML is responding to treatment based on the number of cells in your bone marrow that have the Philadelphia chromosome.

DNA: The genetic code that tells your cells how to grow and behave.

Gene: A section of DNA that tells your cells how to make a particular protein.

Genetic: Relating to genes.

Granulocyte: A type of white blood cell that helps fight infections.

Growth factor: A type of medicine that boosts your blood cell counts.

Haematological response: How well your CML is responding to treatment based on your blood cell counts.

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

Hydroxycarbamide: A chemotherapy medicine that helps lower your white blood cell count.

Intrathecal chemotherapy: Chemotherapy given directly into the fluid surrounding your brain and spinal cord through a needle in your back.

Leukapheresis: A procedure to remove some of your white blood cells.

Lumbar puncture: A test to collect a sample of the fluid that surrounds your brain and spinal cord through a needle in your back.

Molecular response: How well your CML is responding to treatment based on the level of the *BCR-ABL1* gene in your blood. This is a very sensitive measure of how much leukaemia is left in your body.

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

Myeloblast: A type of immature white blood cell.

Myeloid stem cells: Blood-forming cells.

Peginterferon-alfa: Medicine that helps treat leukaemia by altering the way your immune system works.

Philadelphia chromosome: A changed chromosome found in people with CML. It contains an abnormal piece of genetic code called the *BCR-ABL1* fusion gene.

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

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

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

Stem cell transplant: An intensive type of treatment where damaged or destroyed blood-forming cells in your bone marrow are replaced with healthy ones.

Tyrosine kinase inhibitor (TKI): The most common treatment for CML, given as a tablet. TKIs block a protein called tyrosine kinase.

Tyrosine kinase: The protein that is abnormal in people with CML. It encourages the blood-forming cells in your bone marrow to make too many white blood cells.

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

Helpline: 08088 010 444 (Monday to Friday, 9am to 5pm)

WhatsApp: 07500 068065 (Monday to Friday, 9am to 5pm)

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

CML Support

A patient-run UK charity supporting patients with CML.

cmlsupport.org.uk

CML Advocates Network

An interntational network of CML patient organisations.

www.cmladvocates.net

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888

www.bloodcancer.org.uk

Macmillan

Provides free practical, medical and financial support for people facing cancer.

0808 808 0000

www.macmillan.org.uk

Cancer Research UK

Leading charity dedicated to cancer research.

0808 800 4040

www.cancerresearchuk.org

Maggie's Centres

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggiescentres.org

Citizens Advice

Offers 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

If you've been affected by CML, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications team at communications@leukaemiacare.org.uk.

Tell us what you think of this booklet

We aim to provide information that's reliable, up-to-date, and covers what matters to you. We want you to feel supported and able to be involved in decisions about your care. Your feedback helps us improve our information and make sure it meets your needs. Please get in touch to let us know what we can do better. You can also contact us if you'd like a list of the references we used to compile this booklet.

- Email our Information team at information@leukaemiacare.org.uk
- Call our Head Office on **01905 755 977**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG
- Leave us a review if you've ordered a booklet online

If we've helped you - here's how you can give back

Fundraising is at the core of what we do here at Leukaemia Care, and without it we wouldn't be able to provide the support we do.

Fundraising isn't all about running a marathon, and there are plenty of ways to give thanks and show your support.

You could:

- Ask your local shop or workplace to host a collection tin
- Ask your place of work about charity of the year partnerships or grants
- Take on one of our more accessible walking challenges
- Host a quiz night or get your friends together for a catch-up and a meal
- Host a bake sale at work or school, or even a coffee morning with friends
- Share information about the activities we have going on to get friends and family joining in
- Stream online from the comfort of your own home

However, if you can run a marathon or want to do a thrilling skydive, we've got you covered!

Whatever you want to do, we can support you to raise money for Leukaemia Care. Get in touch with the fundraising team by email fundraising@leukaemiacare.org.uk or calling **08088 010 444**.

You can also find out more about how to get involved by scanning the QR code

Plenty of ways to give

There are so many ways you can give in support of those affected by a leukaemia diagnosis, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer your donation straight from your account to ours. Our bank details are:

Sort code: **20-98-61**

Account number: **80823805**

Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at www.leukaemiacare.org.uk/donate or scan the QR code to pay your money in. Remember to include as much information as possible to help us know it's you paying in.

By phone

You can call us to pay by debit or credit card over the phone. Simply call **01905 755977**.

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?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

WhatsApp: **07500 068065**

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum

Version 1
Printed: 03/2024
Review date: 03/2027