

# UNDERSTANDING CHRONIC LYMPHOCYtic LEUKAEMIA (CLL)



**My first reaction was shock, followed quickly by a false bravado that masked a severe depression. I've since discovered that this isn't uncommon in people who are newly diagnosed with cancer.**

**Gary, diagnosed with chronic lymphocytic leukaemia (CLL)**



# About this booklet

**This booklet is about chronic lymphocytic leukaemia (CLL). It is for anyone who has been diagnosed with CLL. There is also information for carers, family members and friends.**

The booklet explains the signs and symptoms of CLL, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 107 to 115, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see pages 116 to 117).

## Quotes

In this booklet, we have included quotes from people who have CLL, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). The others are from people who have chosen to share their story with us. This includes Gary, who is on the cover of this booklet. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://www.macmillan.org.uk)

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

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# THE BLOOD AND CLL

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# What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia have abnormal white blood cells in their bone marrow. This usually means their white blood cell count is high. But in a few people with leukaemia, their white blood cell count is low.

There are 4 main types of leukaemia:

- acute lymphoblastic (ALL)
- acute myeloid (AML)
- chronic myeloid (CML)
- chronic lymphocytic (CLL).

Each type of leukaemia is different. We have separate information about these different leukaemias (see page 102).

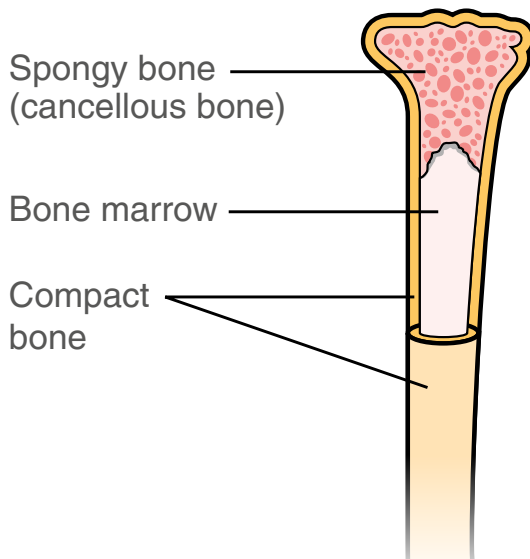


# The blood and bone marrow

To help you understand CLL and its treatment, it is useful to know more about your blood, how it is made and what it does.

Blood is made up of blood cells, which move around in a liquid called plasma. Blood cells are made in the bone marrow. The bone marrow is a spongy material in the middle of our bones. Most blood cells are made in the hip bones (pelvis), backbone (spine) and breastbone (sternum). The bone marrow usually makes billions of new blood cells every day to replace old and worn-out blood cells.

## Bone marrow



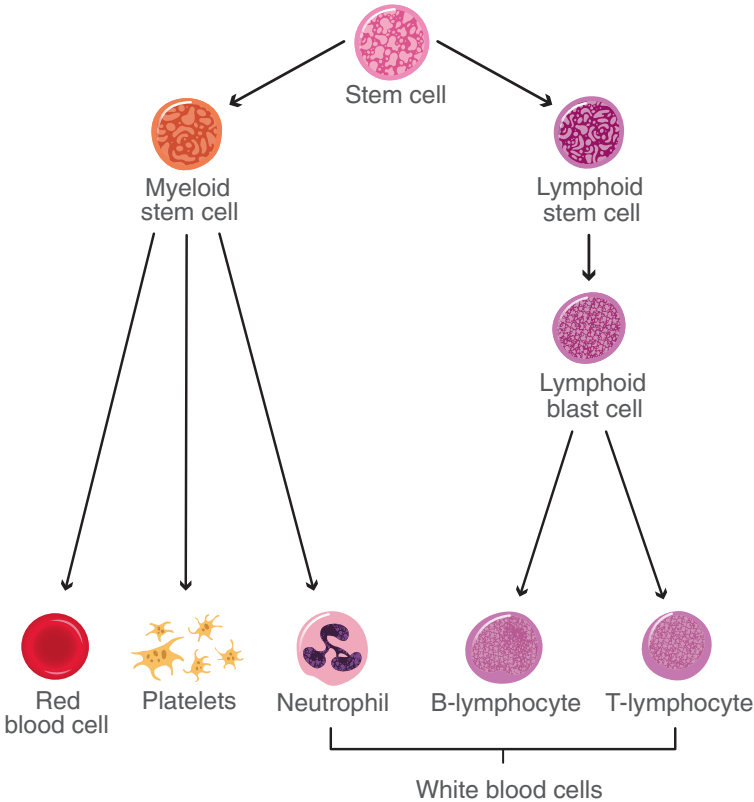
All blood cells are made from blood stem cells. These are blood cells at the earliest stage of their development.

There are 2 types of blood stem cell:

- Lymphoid stem cells make a type of white blood cell called lymphocytes.
- Myeloid stem cells make all the other types of blood cell. These include red blood cells, platelets, and other types of white blood cells, such as neutrophils.

Blood stem cells in the bone marrow divide and grow to make new blood cells. The new, developing blood cells are called blast cells. They do not look like fully developed cells and they cannot do the jobs that fully developed cells do. Usually, blast cells stay in the bone marrow until they have developed into red blood cells, platelets or white blood cells.

# Blood cell division



When they are fully developed, the cells are released into the blood to carry out different functions:

- Red blood cells contain haemoglobin (Hb). This carries oxygen from the lungs to all parts of the body.
- Platelets help the blood to clot and prevent bleeding and bruising.
- White blood cells fight and prevent infection. There are different types of white blood cell. The 2 most important types are neutrophils and lymphocytes.

The levels of these cells in your blood are measured in a blood test called a full blood count (FBC). These numbers are a guide to the levels usually found in a healthy adult.

Types of blood cell	Levels found in a healthy person
Red blood cells (measured in haemoglobin Hb levels)	130 to 180g/l in men 115 to 165g/l in women
Platelets	150 to 400 x 10 <sup>9</sup> /l
White blood cells (WBC)	4.0 to 11.0 x 10 <sup>9</sup> /l
Neutrophils	2.0 to 7.5 x 10 <sup>9</sup> /l
Lymphocytes	1.5 to 4.5 x 10 <sup>9</sup> /l

These numbers can differ slightly between hospitals. Your doctor or nurse can tell you the normal ranges they use. The levels can also vary slightly between people from different ethnic groups.

The numbers might look complicated when they are written down, but doctors and nurses talk about them in a way that is easy to understand. For example, they may say things like, 'Your haemoglobin (Hb) is 140,' or, 'Your neutrophils are 4'.

Most people with CLL quickly get used to these numbers and what they mean. But if you do not understand, you can always ask your healthcare team to explain in more detail.

Your doctors will look at how your blood test results change over time. This helps them know if you need treatment, and what treatment you should have.

# Lymphocytes and the lymphatic system

## Lymphocytes

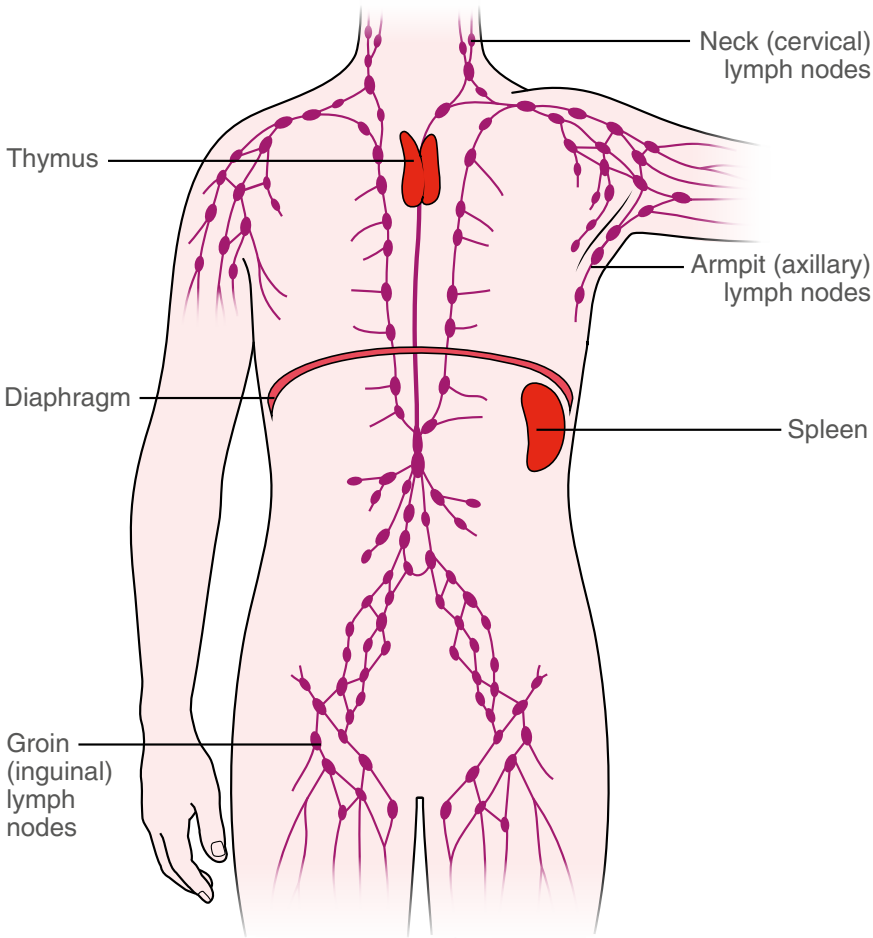
Lymphocytes are a type of white blood cell. They move around the body in the blood and the lymphatic system. Lymphocytes are an important part of the body's defence. They fight against germs such as bacteria, fungal infections and viruses. They do this by:

- killing germs directly
- making special proteins called antibodies that stick to germs and make it easier for other white blood cells to find and kill them
- remembering and recognising germs – lymphocytes can live for a very long time, so they can quickly fight any infection you have had before.

## The lymphatic system

The lymphatic system is part of the immune system. It helps to protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

# The lymphatic system



Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

There are lymph nodes in the neck, armpits, groin and the chest and tummy (abdomen). Doctors can feel these when they do a physical examination of these parts of the body.





# Chronic lymphocytic leukaemia (CLL)

Chronic lymphocytic leukaemia (CLL) is the most common type of leukaemia. About 3,800 people in the UK are diagnosed with CLL each year. It is more common in older people.

CLL is a cancer of the white blood cells, which develop from B lymphocytes. In people with CLL, the bone marrow makes too many abnormal white blood cells, called lymphocytes. These cells look normal under a microscope. But they are not fully developed (immature) and do not work properly.

Over time, these abnormal lymphocytes build up in the lymphatic system (see pages 12 to 14) and may cause large, swollen lymph nodes. The abnormal lymphocytes can also build up in the bone marrow. This leaves less space for normal white blood cells, red blood cells and platelets to develop.

CLL usually develops very slowly, which is why it is called a chronic leukaemia. Many people with CLL do not need treatment for months or years. If you have symptoms, you may need treatment sooner.

In many people with CLL, the leukaemia cells are mainly in the bloodstream and the bone marrow (see pages 7 to 11). If the leukaemia cells are mainly in the lymph nodes, the disease is called small lymphocytic lymphoma (SLL). CLL and SLL are now considered to be the same disease and are treated in the same way.

# Causes and risk factors

We do not know what causes CLL, but research is going on to find out more about it. Certain things called risk factors can increase the risk of developing it.

## Age

The risk of developing CLL increases with age. Most people diagnosed with CLL are aged over 60. It is rare in people under 40.

## Sex

CLL is more common in men than women.

## Family history

Most people with CLL have no family history of it. But studies show that there is an increased risk of developing CLL if you have a close relative who has it. A close relative is a parent, sibling, or child. If anyone else in your family has CLL, it is important to tell your specialist.

Most people who have a relative with CLL will never develop it themselves. CLL is not infectious and cannot be passed on to other people.

## Ethnicity

CLL is most common in people of European origin.

# Signs and symptoms of CLL

CLL develops slowly and many people have no symptoms in the early stages. It is often discovered by chance after a routine blood test .

The symptoms of CLL can include the following:

- Feeling very tired (fatigued), becoming breathless easily and getting headaches regularly. This is caused by a lack of red blood cells (anaemia).
- Having frequent infections. This is caused by a lack of healthy white blood cells. Infections may be more severe and take longer to get better.
- Swollen lymph nodes in the neck, armpits or groin. This is caused by a build-up of CLL cells. It is usually painless.
- Bruising and bleeding easily. This may happen if there are not enough platelets in the blood. You may have nosebleeds that take a long time to stop (more than 10 minutes). You may get big bruises in unexpected places.
- A tender lump in the tummy along with a lack of appetite. A lump in the upper left-hand side may be caused by an enlarged spleen.
- Sweating a lot at night.
- Weight loss.
- A high temperature (fever) without any obvious cause.

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# How CLL is diagnosed

CLL is often diagnosed after a routine blood test and you may have had no symptoms at all.

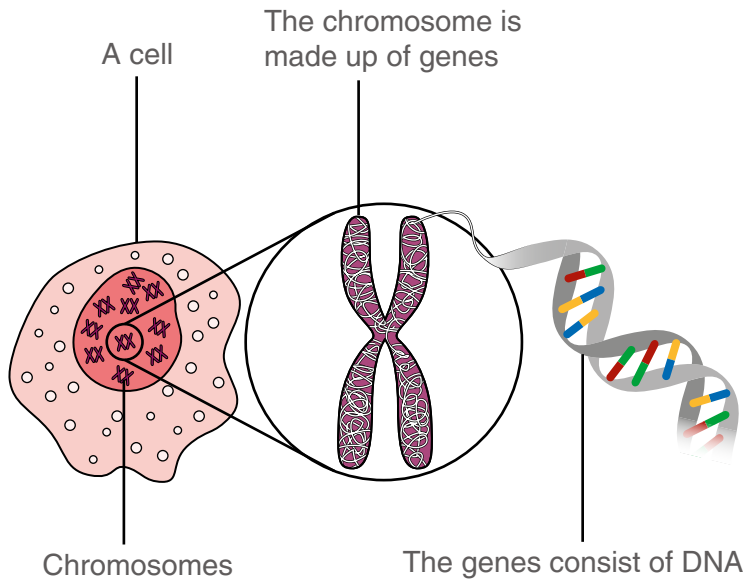
If you do have symptoms, your GP will examine you and do a blood test. If they think you have CLL, they will refer you to a doctor who specialises in diagnosing and treating blood problems. This doctor is called a haematologist.

## Understanding CLL cell changes

To help you understand some of the tests used to diagnose CLL, it is useful to know more about cells.

The organs and tissues of our body are made up of cells. Every cell contains all the biological information we inherit from our parents. This information is stored in our genes in the centre (nucleus) of every cell. Genes control what the cell does. They are grouped together in chromosomes.

## Genes and chromosomes



All CLL cells have abnormal gene changes. This is what makes them behave differently from normal blood cells. These gene changes happen when something goes wrong when the body is making new blood cells. The gene changes in CLL cells vary from person to person. This is why CLL can behave differently in different people. The CLL cells will be tested to check for any gene changes.

Abnormal gene changes are not inherited, and they cannot be passed on to your children.

## At the hospital

The haematologist will ask you about any illnesses or health problems you have had. They will examine you to check whether your lymph nodes, spleen or liver are enlarged. They may arrange further tests, such as scans or a biopsy.

They will also do more detailed blood tests to check whether you have CLL cells in your blood. This is called immunophenotyping.

## Types of blood test

The blood tests you may have include:

- immunophenotyping – checks for CLL cells in the blood
- cytogenetic testing – looks at all the chromosomes in the leukaemia cells
- fluorescent in situ hybridisation (FISH) testing – this is an important cytogenetic test that looks for specific changes in genes or chromosomes in the CLL cells
- immunoglobulin testing – checks the levels of antibodies you have in your blood for fighting infection
- direct Coombs test – checks whether CLL cells are making antibodies that can damage your red blood cells.



## Gene testing in CLL

FISH and cytogenetic testing give information about certain gene changes in chromosomes. The results tell your doctors how well certain drugs may work for you, and helps them plan your treatment.

Gene mutation tests check for important changes. For example, they may check if a gene called TP53 is missing or does not work.

TP53 is usually found in a part of chromosome 17 (called 17p). When this part of the chromosome:

- is missing (deleted), doctors call it a p53 deletion
- has changed (mutated), doctors call it a p53 mutation.

Fewer than 10% of people with CLL have a p53 deletion or p53 mutation when they are diagnosed. But it can develop over time and is more common in CLL that comes back after treatment. Because of this, and depending on your situation, these tests may be repeated.

CLL with a p53 deletion or p53 mutation does not usually respond well to standard chemotherapy treatment. Doctors use different types of drugs to treat this type of CLL.



Having a CT scan

# Further tests

## CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website (see page 102).

## Bone marrow biopsy

Bone marrow is spongy material found in your bones. Blood cells are made in the bone marrow.

A biopsy is when a doctor or nurse removes a small piece of tissue or a sample of cells. This is then checked under a microscope. For a bone marrow biopsy, a small sample of bone marrow is usually taken from the back of the hip bone (pelvis). Rarely, the sample is taken from the breastbone (sternum).

You have a bone marrow biopsy at a hospital. If you take medicine to thin the blood, tell the doctor or nurse before the biopsy.

Before the biopsy, your doctor or nurse will give you injections of local anaesthetic to numb the area. Or you may be given gas and air to breathe in through a mouthpiece or mask. This helps reduce any discomfort during the biopsy. You can ask for medicine to help you relax (sedatives).

If you are having the biopsy from your hip, you lie on your side. The doctor or nurse puts a needle into the hip bone. They then draw a small sample of liquid or core of bone marrow into a syringe. It can feel uncomfortable for a few seconds. Some people feel a pain in their leg while the sample is being taken.

After the biopsy, the doctor or nurse will put a dressing over the area to keep it clean. You can remove this after 24 hours.

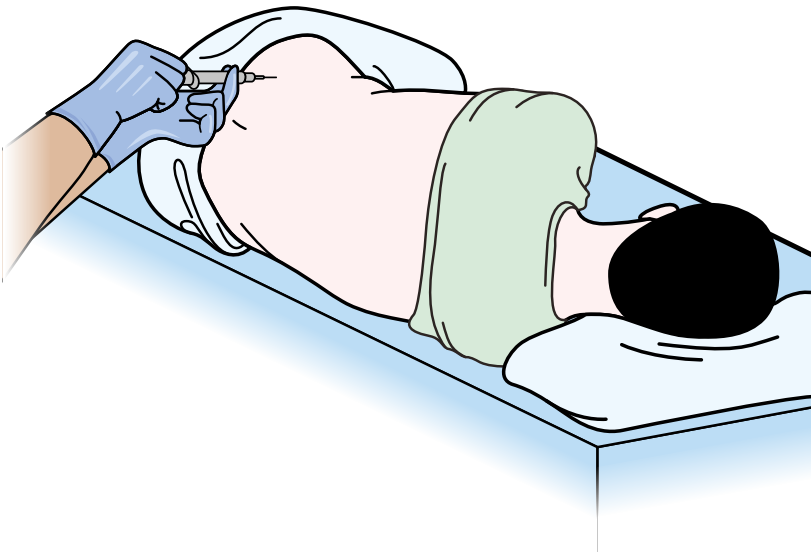
If you had a sedative, you should:

- not drive for 24 hours
- have someone to take you home
- have someone to stay with you overnight.

You may ache or feel bruised. Taking painkillers such as paracetamol can help.

We have more information about having a bone marrow biopsy on our website (see page 102).

A sample of bone marrow being taken from the back of the hip bone





## Lymph node biopsy

You will not usually need a lymph node biopsy. But some people with CLL may have one. People with small lymphocytic leukaemia may also need a lymph node biopsy. Your cancer doctor or specialist nurse can explain whether this is right for your situation.

An enlarged lymph node or a small section of lymph node is removed so it can be looked at under a microscope. You may have this done under a local or general anaesthetic. It is a small operation and most people can go home on the same day. After the operation, you have a small wound with a few stitches. The stitches are usually taken out after 7 to 10 days.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support (see pages 107 to 115). Or you can talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

# Staging

Doctors use staging to find out how much leukaemia there is in the body. This helps them know how advanced the CLL is. There are 2 staging systems commonly used for CLL:

- the Binet system
- the Rai system.

The Binet system is most commonly used in the UK.

## Binet staging system

This looks at the number of white blood cells, red blood cells and platelets in the blood (see pages 7 to 11). It also looks at how many areas of lymph nodes are enlarged. These areas are in the neck, armpits, groin, liver and spleen. If the lymph nodes in both armpits are enlarged, they are only counted as one area.

There are 3 stages in the Binet system:

- Stage A – there are fewer than 3 areas of enlarged lymph nodes.
- Stage B – there are 3 or more areas of enlarged lymph nodes.
- Stage C – there are a reduced number of red blood cells, platelets or both.



# Transformation

In up to about 10% of people with CLL (1 in 10), the leukaemia can change. It can start to grow more quickly and become harder to treat. This is called transformation.

CLL may change into:

- another type of leukaemia called prolymphocytic leukaemia
- a type of lymphoma (cancer of the lymphatic system) called diffuse large B-cell lymphoma (DLBCL) – this transformation is called Richter’s syndrome
- a type of lymphoma called Hodgkin lymphoma – but this is rare.

We have more information about lymphoma in our booklets **Understanding non-Hodgkin lymphoma** and **Understanding Hodgkin lymphoma** (see page 102).

Transformation may cause:

- a sudden swelling of affected lymph nodes, especially in the tummy (abdomen)
- heavy sweats at night
- weight loss
- high temperatures (fever) with no obvious cause.

There may be other reasons for these symptoms. But always tell your doctor if you notice any of them.

Doctors can diagnose transformation of CLL with a bone marrow biopsy, a lymph node biopsy and blood tests.

It is important to remember that transformation is unusual and does not happen for most people with CLL.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research. Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

When I was first diagnosed, I sat there nodding my head, as if I was taking it all in. But all I could hear was “cancer.” It wasn’t until I left that it hit me. It didn’t feel real – I’d just been told this devastating news and for everyone else, life was going on as normal.

Gary, diagnosed  
with CLL



# TREATING CLL

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# Treatment overview

CLL usually develops very slowly, so you may not need treatment for months or years. Some people never need treatment.

Only a small number of people with CLL need to start treatment straight away. Doctors usually wait until there are signs CLL is progressing before suggesting you have treatment. There is no evidence that starting treatment before this helps, and it can cause side effects.

Even if you are not having any treatment, you will see your haematologist or GP regularly for check-ups and blood tests. This is called monitoring (watch and wait) – see pages 44 to 45.

## Treatment aim

The aim of treatment is to reduce the number of CLL cells to as few as possible. This is called remission. It is not usually possible to cure CLL, but it can be well controlled. Most people with CLL have long periods of time when they have a normal life with no symptoms. They may also have a normal life span.

## Types of remission

There are different levels of remission:

- Complete remission (CR) – no CLL cells or enlarged lymph nodes can be found by standard tests and scans.
- Partial remission (PR) – there are still CLL cells in the blood or bone marrow, but their number has reduced, and the lymph nodes are smaller.

Some people who are in complete remission may have what is called minimal residual disease (MRD). This means that there are so few CLL cells remaining that they can only be found with special tests on the blood and bone marrow.

For most people, treatment is very successful at getting the leukaemia into complete or partial remission. This may last for years.

If CLL does not respond well to the first treatment, your doctors can change the treatment. There are many different treatment options available for CLL (see page 39).

When the leukaemia starts to grow again and cause problems, you can have more treatment to put CLL back into remission. This can be done several times.

If treatments to control CLL do not work, or stop working, you can have supportive therapy to manage symptoms (see pages 65 to 69).

## Deciding when to start treatment

### Stages of CLL and treatment

If you have stage A CLL, you do not usually need treatment when you are diagnosed. It develops very slowly and often does not cause any symptoms. Some people with stage A CLL may never need treatment. You usually only start treatment if there are signs the CLL is progressing or you have certain symptoms.

Some people with stage B CLL may not need treatment straight away. This depends on the signs and symptoms you have.

If you have stage C CLL, you usually need treatment soon after being diagnosed.

### Reasons you may need treatment

If you have certain signs and symptoms, your doctors may decide you need treatment. These include:

- very enlarged or fast-growing lymph nodes
- a low level of red blood cells (anaemia) or platelet cells
- heavy, drenching sweats, especially at night
- weight loss
- a high number of white blood cells that is increasing quickly.

Your doctor will check that these symptoms are being caused by the CLL and not something else. This helps them decide whether to start your treatment.

Your doctor will also ask about your general health and check your fitness when planning your treatment. They can explain the benefits and disadvantages of treatment.



Before starting treatment, you will have some blood tests to check for the hepatitis B virus and HIV. These are routine tests before starting treatment for CLL. Your doctor will talk to you about these tests.

## Types of treatment

Most people are treated with a combination of 2 types of treatment. These are:

- chemotherapy (see pages 54 to 60)
- targeted therapy (see pages 46 to 52).

Other treatments that are sometimes used include the following:

- Supportive therapy – you may have this to help control any symptoms caused by CLL, such as infections or anaemia (see pages 65 to 69).
- Donor stem cell transplant – doctors may suggest this treatment if the CLL has not responded to other treatments (see pages 61 to 62), or if it is a type of CLL that is unlikely to respond. It is only suitable for a small number of people. This is because it is an intensive treatment that can have serious side effects.
- Radiotherapy – this is only used in certain situations (see page 63). For example, you may have it if you have enlarged lymph nodes or an enlarged spleen.
- Surgery – this is sometimes used to remove an enlarged spleen (splenectomy).

There are many new treatments being developed to improve the outcomes for people with CLL. You may be invited to take part in a clinical trial of one of these treatments (see pages 71 to 73). Ask your doctor about any clinical trials you could join.

## How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

## Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- One or more haematologists – doctors who diagnose and treat blood cancers and disorders.
- Specialist haematology nurses – who give information and support.
- Radiologists – doctors who look at scans and x-rays to diagnose problems.
- Pharmacists – who gives out medicines and gives advice about taking medicines.

Depending on the type of cancer you have, the MDT may also include:

- a dietitian – someone who gives information and advice about food and food supplements
- a counsellor – someone who is trained to listen to people's problems and help them find ways to cope
- a physiotherapist – someone who gives advice about exercise and mobility
- a psychologist – someone who gives advice about managing feelings and behaviours.

## Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

## **Giving your permission (consent)**

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

## Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website (see page 102).

# Monitoring (watch and wait)

Monitoring is used when you do not need to start treatment straight away. It is also called watch and wait. Your GP or haematologist will check:

- your blood cell count regularly
- if you have any symptoms.

In the first year of being diagnosed, they will usually see you at least once or twice. If you develop symptoms, your haematologist will talk to you about whether you need to start treatment. This may also happen if there are changes to your blood cell count.

Some people may find it hard knowing that they have been diagnosed with leukaemia but are not going to have treatment. Treatments for CLL, such as chemotherapy, can cause side effects and may affect your quality of life. Delaying treatment can avoid side effects. Although CLL cannot be cured, you usually have long periods of time when it does not affect you and you have no symptoms.

It is important to talk to your specialist doctor or nurse. They can help you understand why monitoring may be the best approach for you.

If you are worried about not having treatment, here are some helpful tips from people who have had monitoring:

- Think of your time without treatment as an opportunity to make the most of your quality of life. Use it to do things you enjoy, and to get as fit and healthy as you can.
- Try to focus on the present rather than what might happen in the future.
- Talk about how you feel. You could do this by talking to family and friends, or joining a support group or online forum (see page 105).

Monitoring can be difficult to adjust to at first, but many people find it gets easier with time.

**Now I feel okay and I want to show that people living with cancer can live their lives and celebrate what they achieve.**

**Matt, diagnosed with CLL**

# Targeted therapies

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy. Each type targets something in or around the cancer cell that is helping it grow and survive. Because these drugs only target the cancer cells, they have less effect on healthy cells than other treatments.

There are different types of targeted therapy. They all act in different ways and have different side effects. They are often given with chemotherapy. To decide which treatments may be suitable for you, your haematologist will look at:

- the stage of the leukaemia
- your test results
- your general health
- your gene tests, and whether you have a p53 mutation (see page 23).

## B-cell receptor (BCR) inhibitors

BCR inhibitors are a type of targeted therapy. They work by targeting proteins on the surface of cancer cells. The B-cell receptor is a protein found on the surface of CLL cells. It controls how CLL cells grow. If the B-cell receptor is switched off, the CLL cells die.

BCR inhibitors target the B-cell receptors to stop the cancer growing and dividing.



The drugs that can be used for CLL are:

- ibrutinib (Imbruvica®)
- acalabrutinib.

You take these as tablets or capsules every day. You usually continue taking them for as long as they are working.

## **BCL2 inhibitors**

One of the reasons that CLL cells continue to grow is that they make too much of a protein called BCL2. BCL2 inhibitors work by blocking (inhibiting) this protein. This helps destroy the CLL cells.

Your haematologist may suggest treatment with a BCL2 inhibitor called venetoclax (Venclyxto®). If you have not had previous treatment for CLL, it is given with the monoclonal antibody obinutuzumab. If you have had previous treatment for CLL, you may have venetoclax with a monoclonal antibody called rituximab.

You take venetoclax as tablets. You may have it with other treatments. This drug may only be available in some situations. Your haematologist can tell you if it is suitable for you.

## Monoclonal antibodies

Monoclonal antibodies treat CLL by targeting proteins on white blood cells called B-lymphocytes (B-cells). This makes the B-cells die.

Monoclonal antibodies are usually given with chemotherapy or with other types of targeted therapy. They are usually given as a drip into a vein.

Monoclonal antibody treatments used for CLL include:

- rituximab
- obinutuzumab (Gazyvaro®)
- ofatumumab (Arzerra®)
- alemtuzumab – this is only sometimes used to treat CLL.

## How monoclonal antibodies are given

Monoclonal antibodies are usually given into a vein as a drip (infusion). You can have them as an outpatient. You may be asked to stay in hospital overnight for your first treatment.

You may have a reaction during the infusion. A reaction is more likely with the first infusion, so it is given slowly over a few hours. Reactions are usually milder after the first infusion. You are also given medicines before each infusion to help prevent or reduce any reaction.

Symptoms of a reaction can include:

- a high temperature
- shivering and shaking
- a rash
- low blood pressure
- feeling sick (nausea).

If you have any of these symptoms or feel unwell during or soon after an infusion, tell your nurse or doctor straight away.

Alemtuzumab can also be given as an injection under the skin (subcutaneously). In this case, it is less likely to cause a reaction. But it may cause some redness, swelling or soreness around the area where it is injected. This usually goes away after 1 to 2 weeks.

## Side effects of targeted therapies

Different targeted therapies can have different side effects. Your doctor, nurse or pharmacist will explain the possible side effects of the specific drugs you are having before you start treatment. We have information about most drugs on our website (see page 102).

Your nurse will give you phone numbers for the hospital. If you feel unwell or need advice, you can call them at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

## Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

## Diarrhoea

This treatment may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

## Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

## Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

## Tumour lysis syndrome (TLS)

Rarely, this treatment may cause the cancer cells to break down very quickly. This releases uric acid into the blood. Uric acid is a waste product. The kidneys usually get rid of uric acid, but may not be able cope with large amounts. This can cause chemical imbalances in the blood that affect the kidneys and the heart. This is called tumour lysis syndrome (TLS).

TLS tends to happen in the first week or two of starting treatment. Your doctor may give you drugs to reduce the risk of TLS. They may also ask you to drink more fluids on the day of your treatment. Your doctor or nurse will explain more about this.



# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. These drugs affect with the way leukaemia cells grow and divide.

## How chemotherapy is given

You can have the drugs as tablets (oral chemotherapy) or into a vein (intravenously). The chemotherapy moves around the body through the blood. It can reach leukaemia cells all over the body.

You may have either a single chemotherapy drug or a combination of different drugs given together. Chemotherapy is usually given with a targeted therapy (see pages 46 to 52). This is called chemo-immunotherapy.

You usually have chemotherapy as several cycles of treatment. Each treatment is followed by a rest period. This lets your body recover from any side effects. The treatment and the rest period together make up a cycle of treatment.

The chemotherapy drugs most often used to treat CLL are:

- fludarabine
- cyclophosphamide
- chlorambucil
- bendamustine.

We have more information about these drugs on our website (see page 102).



Fludarabine and cyclophosphamide are usually given together with a targeted therapy called rituximab. This combination is called FCR or RFC. The chemotherapy drugs can be given into a vein or as tablets.

Chlorambucil is given as tablets. It is often given along with a targeted therapy.

Bendamustine is given into a vein. It is usually given with rituximab. This treatment is called BR.

There are lots of different drugs available to treat CLL. Your doctors may use other drugs and combinations of drugs. They will tell you what treatment they think is best for your situation.

You can usually have chemotherapy for CLL as an outpatient.

## Side effects of chemotherapy

We have listed some of the most common side effects of chemotherapy. Different chemotherapy drugs have different side effects. Your doctor, nurse or pharmacist will give you more information about the chemotherapy you are having.

Your nurse will give you phone numbers for the hospital. If you feel unwell or need advice, you can call them at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

## Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

**It is important to follow any specific advice your cancer treatment team gives you.**

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

## Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

## Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

## Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

## Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

## Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

## Hair loss

Some chemotherapy drugs may cause hair loss. You may notice your hair thinning. Some people may have total hair loss, including eyelashes and eyebrows, but this is not common. It depends on what chemotherapy drugs you have. Your doctor or nurse can tell you what to expect.

If you do have hair loss, your hair should start to grow back about 3 to 6 months after you finish treatment. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

We have more information about this in our booklet **Coping with hair loss** (see page 102).

## Sex

If you have sex during a course of chemotherapy, you should use barrier protection such as a condom or dental dam. This will protect your partner if any of the drug is in your semen or vaginal fluid.

## Fertility

Some of the drugs used to treat CLL may cause infertility (being unable to get pregnant or make someone pregnant). This may be temporary or permanent.

If you have high-dose chemotherapy, or radiotherapy before a stem cell or bone marrow transplant, you are likely to become permanently infertile.

If you think you may want to have children in the future, talk to your doctors about this before starting chemotherapy. They can tell you whether your fertility is likely to be affected.

Men may be able to have sperm stored before they start treatment (sperm banking). Sometimes women may be able to have eggs collected and frozen.

It is important to speak to your medical team about this before your treatment starts. If you have a partner, you may want them to be there during these discussions. Together, you can then make an informed decision about your options.

# Stem cell transplant

Stem cells are early blood cells that are inside the bone marrow (see pages 7 to 11). They make all the red blood cells, white blood cells and platelets in the blood.

A stem cell transplant is a very intensive treatment and is not often used to treat CLL. It is only usually used to treat CLL when other treatments are not suitable, or have not worked.

Having a stem cell transplant may result in a long period of remission. But only a small number of people with CLL will have one. It can cause very serious side effects and there are many other effective treatment options available. Your doctor will tell you if it might be suitable for you.

People who have a stem cell transplant to treat CLL usually have a type called a donor stem cell transplant (allogeneic). We have more information about stem cell transplants on our website (see page 102).

## Donor stem cell transplant

For this treatment, you are given stem cells from someone else. This person is called a donor. Having a donor means your doctor can give you a higher dose of treatment than usual. This is because the donor's stem cells will give you a new immune system, which can fight the CLL cells.

The transplant usually uses stem cells from a brother or sister who is genetically similar to you (a match). Ideally this is from a fully matched brother or sister, but in some cases half-matched brothers, sisters, parents, children or other family members may be suitable. If you do not have a brother or sister who can donate stem cells, another donor may be found who has stem cells that genetically match you. This is called a volunteer unrelated donor.

Before you are given donor stem cells, you have intensive chemotherapy. Sometimes radiotherapy is also used. This destroys any remaining leukaemia cells and prepares your immune system for the donor stem cells.

Stem cell transplants are only done in specialist cancer treatment centres. We have more information about stem cell transplants, including how to prepare for treatment, and possible side effects.



# Radiotherapy

Radiotherapy uses high-energy x-rays to destroy leukaemia cells, while doing as little harm as possible to normal cells. Radiotherapy is not often used to treat CLL. This is because radiotherapy usually only targets specific areas in the body.

Radiotherapy is sometimes used to target a specific area of the body where CLL cells have built up. For example, it might be used to treat the spleen or a group of enlarged lymph nodes.

You have radiotherapy in the hospital radiotherapy department. You have it as an outpatient. Treatment is usually given daily, from Monday to Friday with a rest at the weekend. You may have it over 1 or 2 weeks. Each session may last a few minutes and does not hurt.

CLL is very sensitive to radiotherapy. If just one area of your body is being treated, you only need a low dose. This means that side effects are not common. Your doctor, nurse or radiographer will tell you about the treatment plan and the possible side effects of the radiotherapy.

Radiotherapy is also sometimes given before a stem cell transplant (see pages 61 to 62). This is called total body irradiation (TBI).



# Supportive therapy

Supportive therapies are treatments that help control any symptoms caused by CLL or its treatment.

## Infections

People with CLL are more at risk of getting infections. This is because both CLL and the treatments used affect the immune system.

You can usually be treated for infections as an outpatient. But some infections can be life-threatening. If you get one of these, you will need to stay in hospital for treatment. It is important to contact your doctor or specialist nurse straight away for advice if you develop:

- a cough
- a sore throat
- a fever or your temperature goes over 37.5°C (99.5°F)
- any other sign of infection.

Your doctor may prescribe antibiotics, anti-viral drugs or anti-fungal drugs to help prevent or treat any infections during your treatment.

## Shingles

People with CLL are at a higher risk of developing an infection called shingles. This is an infection of a nerve and the area of skin around it. It is caused by the same virus that causes chickenpox. Anyone who has had chickenpox may develop shingles.

The virus usually affects one nerve in one area of the body. The most common areas to be affected are one side of the chest, or one side of the tummy (abdomen). A nerve in the face can also be affected, but this is less common.

The first symptom is often a tingling or burning feeling in the affected area. This is followed by pain and a red rash. This develops 2 to 3 days later.

Contact your GP or the hospital straight away if you:

- think you have shingles
- come into contact with someone who has shingles or chickenpox.

Effective treatment can prevent or limit the infection. Shingles usually gets better within 2 to 5 weeks.

People aged over 70 are routinely offered a vaccine against shingles. But it is not suitable for people with CLL, because it is a live vaccine. Your haematologist can give you more information about vaccines that are suitable for you.

## Vaccinations

Your doctor may advise you to have vaccinations against illnesses such as flu and coronavirus. If you live with other people, your doctor may suggest they also have these vaccinations and any other regular vaccinations. Your doctors may also recommend 2 specific vaccines when you are first diagnosed with CLL. These are to protect against:

- pneumonia
- a type of infection called streptococcus.

There are some types of vaccines that you should avoid. These are called live vaccines. They include flu vaccines that are given as a spray up the nose. If you have young children, they should not have this type of flu vaccine as it may affect you too. Ask your doctor or specialist nurse for more advice about this before you have any vaccinations. It is important to get advice from your doctor if you are planning any travel abroad.

## Low levels of antibodies

Many people with CLL have very low levels of infection-fighting antibodies (immunoglobulins) in their blood. This may mean they keep getting infections. Some people who are affected may need regular immunoglobulin treatment. A nurse gives the immunoglobulins:

- as a drip (infusion) into a vein
- as an injection under the skin.

Most people feel fine when they are having an immunoglobulin infusion, but sometimes it can cause a reaction. A reaction is more likely with the first infusion, so it is given more slowly.

## Auto-immune reactions in CLL

CLL can sometimes cause the immune system to attack normal, healthy red blood cells or platelets. If red blood cells are affected, this is called auto-immune haemolytic anaemia (AIHA). If platelets are affected, this is called immune thrombocytopenic purpura (ITP).

If you have AIHA, the number of red blood cells in the blood can fall very quickly. This can cause:

- breathlessness
- tiredness
- a yellowish tinge to the whites of your eyes
- dark-coloured urine (pee).

If you suddenly become very tired or breathless, contact the hospital straight away. You may need to have a blood test, and possibly treatment.

With ITP, the number of platelets in the blood can fall suddenly. This can cause:

- bruising
- areas of tiny, dark, purple-red dots on the shins or arms
- unusual bleeding from the gums
- a nosebleed that takes a long time to stop.

If you have any of these symptoms, contact the hospital straight away for advice.

## Transfusions

If your bone marrow is not making enough red blood cells or platelets, you may need to have a blood or platelet transfusion. You can have this as an outpatient.

If you are treated with fludarabine or bendamustine, you should only be given blood and platelet transfusions that have been treated with radiation (irradiated).

Irradiated transfusions should always be used during and after you have finished your treatment. This lowers the risk of the donated blood cells reacting against your own blood cells. Your hospital team should give you a card to carry, or a MedicAlert ID tag to wear. This is so hospital staff are aware of this if you ever need a blood transfusion in an emergency.

# Steroids

Steroids (sometimes called corticosteroids) are substances that are made naturally in the body. They control different functions in the body, such as the immune system. They also help reduce inflammation. Steroids can also be made as drugs and used as part of your treatment.

The steroids most commonly used to treat CLL include:

- dexamethasone
- methylprednisolone
- prednisolone.

You may have treatment with steroids if the number of red blood cells in the blood falls very quickly, because of a condition called auto-immune haemolytic anaemia (AIHA) – see pages 68 to 69.

Sometimes, people have high-dose steroid treatment called high-dose methylprednisolone (HDMP). With HDMP, you can have the steroids as tablets or as a drip into a vein.

We have more information about steroids on our website (see page 102).



# Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

## Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials on our website (see page 102).

## Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

# Follow-up and monitoring

CLL often progresses very slowly. This means that people with CLL can live with it for a long time. If you do need treatment, it is usually very effective and can keep the leukaemia under control for many years. You will need to have regular check-ups and blood tests. You may attend the hospital for these, or they may be done by your GP.

If you have any problems or notice any new symptoms, tell your doctor as soon as possible. Do not wait until your next appointment.



# LIVING WITH CLL

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# Well-being

You may want to find out more about having a healthier lifestyle. This will help you stay as well as possible. Many people decide to make changes to their lifestyle.

Some examples of having a healthy lifestyle include:

- having a well-balanced diet
- being physically active
- reducing stress
- being involved in your healthcare.

If you are trying to have a healthier lifestyle, focus on making small, manageable changes to the way you live. This will improve your health and well-being, and lower your risk of getting other illnesses and some cancers.

When you plan changes, you need to consider how the side effects of treatment might affect you. Try not to do too much, too soon.

There are many benefits of having a healthy lifestyle. It does not have to be difficult or expensive. You could try going for a daily walk or doing some exercises at home.



## Eat well

Eating well will help you keep your strength, increase your energy levels and improve your well-being. It can also help reduce the risk of new cancers and other diseases, such as heart disease, stroke and diabetes.

A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least 5 portions a day
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic drinks.

You should also try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

We have more information in our booklet **Healthy eating and cancer** (see page 102).

## Stop smoking

If you smoke, choosing to stop will benefit your health. Speak to your doctor or call a stop-smoking helpline for advice on how to stop smoking. They can also tell you where your local stop-smoking service is. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

## Reduce stress

There are different ways of reducing stress. They will vary from person to person. Some people find it relaxing to meditate or pray, or you might decide to take up a new hobby. You could try a complementary therapy, such as aromatherapy or reflexology. We have more information about this in our booklet **Cancer and complementary therapies** (see page 102).

Some people find it helpful to talk about their feelings to reduce stress. Being in contact with other people who have been through a similar experience can help. Other people find it helpful to write a journal or blog.

## Be physically active

Physical activity can improve your sense of well-being and help build up your energy levels. It also reduces the risk of heart disease, strokes, diabetes and bone thinning (osteoporosis). Being active does not mean you have to exercise intensely. You can start gently and build up the amount you do.

We have more information in our booklet **Physical activity and cancer** (see page 102).

## Be involved in your healthcare

This includes taking your medicines as prescribed and always going to your hospital appointments. If you have any problems or notice any new symptoms between appointments that do not go away within a couple of weeks, tell your doctor as soon as possible.

Understanding more about CLL and its treatment can also help you cope. It can help you talk to your doctors and nurses about your treatment, tests and check-ups. It can also help you be involved in making decisions. This can make you feel more confident and give you back a feeling of control.

## Talk to someone or share your experience

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and they can all help you feel less alone.

Self-help or support groups offer you a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone or do not feel able to talk about your feelings with the people around you. Not everyone finds it easy to talk in a group, so it might not be for you. Try going along to see what the group is like before you decide.

We have more information about local support groups at [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)

## Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by leukaemia. You can use these to ask questions and share your experience. You can ask your nurse for advice if you are unsure of which sites might be useful.

Our Online Community is a social networking site where you can talk to people in our chat rooms, blog about your journey, make friends and join support groups. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## Specialist help

It is common to still have difficult feelings when treatment has finished, but most people find these get better as they recover. Some people only experience a few of these feelings and may be able to deal with them easily. Others may have more, and find them harder to cope with. Try to tell your family and friends how you are feeling so that they can support you. Talking about your feelings is not always easy.

Often it is easier to talk to someone who's not directly involved with your illness. You can ask your hospital consultant or GP to refer you to a specialist doctor or counsellor who can help.

Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call them free on **0808 808 00 00**.

# Your feelings

CLL usually develops very slowly. Many people are surprised at how little it affects their lives, particularly when they are first diagnosed. Your doctor may tell you that you do not need treatment for a long time.

If you have early-stage CLL and are not starting treatment straight away, you may find this difficult to understand or cope with. If you feel this way, tell your doctor or nurse how you feel. They can listen to your fears and concerns and answer any questions you have. Talking to other people in a similar situation may also help.

It is common to have many different emotions when you are told you have leukaemia. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to leukaemia. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

## Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

## Fear and uncertainty

You may feel very anxious or frightened about whether treatment will work and what will happen in the future. It is important to remember that most people with CLL live for many years, and many people find it does not affect their daily activities.

But uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. To do this, you may want to find out more about the leukaemia, its treatment and how to manage side effects. It can also help to talk about your feelings. Take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they cannot be sure what will happen to an individual person. They may not be able to answer your questions fully, but they can usually talk through any problems with you and give you some guidance.

**It was difficult because I didn't look sick in the way that people might expect. So they didn't understand what I was going through.**

**Giuseppe, diagnosed with CLL**

## Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

## Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them.

Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.



## Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people affected by cancer on our Online Community. Visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

## If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 102).

# If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

We have more information in our booklet **Talking with someone who has cancer** (see page 102).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our **Looking after someone with cancer** booklet (see page 102).

# Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too.

For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

## Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website [riprap.org.uk](http://riprap.org.uk) offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 102).



# WORK AND FINANCIAL BENEFITS

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# Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

## Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

## Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

## Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.



## Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

## Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

## Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

## Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

## Help for carers

Carer's Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

## Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (see page 102). Our Online Community forum on Travel insurance may also be helpful. Visit **[macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)**

## More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 112). If you are in Northern Ireland, contact Advice NI (see page 111).

Our booklet **Help with the cost of cancer** has lots more information (see page 102).

# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 102). There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 102).

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# About our information

We provide expert, up-to-date information about cancer.  
And all our information is free for everyone.

## Order what you need

You may want to order more booklets or leaflets like this one.  
Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

## Online information

All our information is also available online at [macmillan.org.uk/information-and-support](http://macmillan.org.uk/information-and-support) You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](http://macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.



## The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at [macmillan.org.uk/ourinfo](https://www.macmillan.org.uk/ourinfo)

# Other ways we can help you

**At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.**

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

### Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## Leukaemia support organisations

### Anthony Nolan

Tel 0303 303 0303

[www.anthonynolan.org](http://www.anthonynolan.org)

The UK's largest stem cell and bone marrow register.

### Blood Cancer UK

Tel 0808 208 0888

[www.bloodcancer.org.uk](http://www.bloodcancer.org.uk)

Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information about blood cancers and treatments.

### Chronic Lymphocytic Leukaemia Support Association

Tel 0800 977 4396

[www.cllsupport.org.uk](http://www.cllsupport.org.uk)

A patient-led UK charity. Their mission is to support and empower chronic lymphocytic leukaemia (CLL) patients, their families and their carers through education and access to reliable, relevant and current information.

### Leukaemia Care

Helpline 08088 010 444

[www.leukaemicare.org.uk](http://www.leukaemicare.org.uk)

National blood cancer charity to patients, their families and carers. Has a nurse service on the helpline during the week.

You can book a call-back on the website or email [nurse@leukaemicare.org.uk](mailto:nurse@leukaemicare.org.uk)

## General cancer support organisations

### Cancer Black Care

Tel 020 8961 4151

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

### Cancer Focus Northern Ireland

Helpline 0800 783 3339

[www.cancerfocusni.org](http://www.cancerfocusni.org)

Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK

Helpline 0808 800 4040

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland

Tel 0800 652 4531

[www.cancersupportscotland.org](http://www.cancersupportscotland.org)

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Macmillan Cancer Voices

[www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices)

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

### **Maggie's**

Tel **0300 123 1801**

**[www.maggies.org](http://www.maggies.org)**

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

### **Penny Brohn UK**

Helpline **0303 3000 118**

**[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)**

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### **Tenovus**

Helpline **0808 808 1010**

**[www.tenovuscancercare.org.uk](http://www.tenovuscancercare.org.uk)**

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## **General health information**

### **Health and Social Care in Northern Ireland**

**[www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### **NHS.UK**

**[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website. Has service information for England.

### **NHS 111 Wales**

**111.wales.nhs.uk**

NHS health information site for Wales.

### **NHS Inform**

Helpline **0800 22 44 88**

**www.nhsinform.scot**

NHS health information site for Scotland.

### **Patient UK**

**www.patient.info**

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

## **Counselling**

### **British Association for Counselling and Psychotherapy (BACP)**

Tel **0145 588 3300**

**www.bacp.co.uk**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

### **UK Council for Psychotherapy (UKCP)**

Tel **020 7014 9955**

**www.psychotherapy.org.uk**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.



## Emotional and mental health support

### Mind

Helpline **0300 123 3393**

**[www.mind.org.uk](http://www.mind.org.uk)**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans

Helpline **116 123**

Email **[jo@samaritans.org](mailto:jo@samaritans.org)**

**[www.samaritans.org](http://www.samaritans.org)**

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**

Textphone **028 9031 1092**

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

## **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

### **England**

Helpline **0800 144 8848**  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### **Scotland**

Helpline **0800 028 1456**  
**[www.cas.org.uk](http://www.cas.org.uk)**

### **Wales**

Helpline **0800 702 2020**  
**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

## **GOV.UK**

**[www.gov.uk](http://www.gov.uk)**  
Has information about social security benefits and public services in England, Scotland and Wales.

## **Local councils (England, Scotland and Wales)**

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

## **England**

[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)

## **Scotland**

[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)

## **Wales**

[www.wlga.gov.uk/welsh-local-authority-links](http://www.wlga.gov.uk/welsh-local-authority-links)

## **Macmillan Benefits Advice Service (Northern Ireland)**

Tel 0300 1233 233

## **Money Advice Scotland**

[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)

Use the website to find qualified financial advisers in Scotland.

## **NiDirect**

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Has information about benefits and public services in Northern Ireland.

## **Northern Ireland Housing Executive**

Tel 03448 920 902

[www.nihe.gov.uk](http://www.nihe.gov.uk)

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

## **StepChange Debt Charity**

Tel 0800 138 1111

[www.stepchange.org](http://www.stepchange.org)

Provides free debt advice through phone, email, the website and online through live chats with advisers.

## LGBT-specific support

### LGBT Foundation

Tel **0345 330 3030**

**[www.lgbt.foundation](http://www.lgbt.foundation)**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### Live Through This

**[www.livethroughthis.co.uk](http://www.livethroughthis.co.uk)**

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

## Support for carers

### Carers Trust

Tel **0300 772 9600**

**[www.carers.org](http://www.carers.org)**

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

### Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**

Helpline (Northern Ireland) **028 9043 9843**

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

## Cancer registries

### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

### National Cancer Registration and Analysis Service

Tel 0207 654 8000

[www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)

Tel (Ireland) 0214 318 014

[www.ncri.ie](http://www.ncri.ie) (Ireland)

### Scottish Cancer Registry

[www.ndrs.nhs.uk/cancer-registration-your-rightsand-privacy](http://www.ndrs.nhs.uk/cancer-registration-your-rightsand-privacy)

### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 02920 104278

[phw.nhs.wales/services-and-teams/welsh-cancerintelligence-and-surveillance-unit-wcisu/](http://phw.nhs.wales/services-and-teams/welsh-cancerintelligence-and-surveillance-unit-wcisu/)

### Northern Ireland Cancer Registry

Tel 0289 097 6028

[www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)





## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Dr Anne Parker, Consultant Haematologist.

With thanks to: Helen Knight, CLL Nurse Specialist; Premini Mahendra, Consultant Haemato-Oncologist; Piers Patten, Consultant Haematologist; and Guy Pratt, Consultant Haematologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

## Sources

Below is a sample of the sources used in our CLL information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Schuh A et al. Guideline for the treatment of chronic lymphocytic leukaemia. British Society for Haematology Guidelines. July 2018.

Eichhorst B et al. Chronic lymphocytic leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. ESMO Guidelines Committee. October 2020.



# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

## 5 ways you can help someone with cancer

### **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

### **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

### **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

### **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

### **Give money**

Big or small, every penny helps. To make a one-off donation see over.

**Call us to find out more 0300 1000 200**  
**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

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If you would rather donate online  
go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)



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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

**This booklet is about chronic lymphocytic leukaemia (CLL). It is for anyone who has been diagnosed with CLL. There is also information for carers, family members and friends.**

**The booklet talks about the signs and symptoms of CLL. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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