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CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING CHRONIC LYMPHOCYTIC LEUKAEMIA



About this booklet

This booklet is about chronic lymphocytic leukaemia (CLL).

We hope it answers some of your questions and helps you cope with some of the feelings you may have.

We can't advise you about your own situation. This can only come from your healthcare team, who know your medical history.

How to use this booklet

We've divided the booklet into parts to help you find the information you need. You can go to any section or chapter in the booklet and start reading from there.

Finding out you have leukaemia can be a very emotional time. There is information on taking care of yourself and getting the support you need on pages 65–69.

We've also included some comments from people who have been affected by leukaemia, which you might find helpful. Some of these quotes are from the website [healthtalk.org](https://www.healthtalk.org) and some are from our online community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). Some names have been changed.

Some quotes are from Gary, who is on the cover of this booklet. He has chosen to share his story with us.

There are useful addresses and websites at the end of this booklet (see pages 89–96). There’s also a page to write any notes or questions you may have for your doctor or nurse (see page 97).

If you’d like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you’re hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

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What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia usually have more white blood cells than normal. These leukaemia cells behave differently from healthy white blood cells.

The four main types of leukaemia are:

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

Each type of leukaemia has its own characteristics and treatment.



We have separate information about these different leukaemias, which we can send you.

The blood

To help you understand CLL and its treatment, it is useful to know a bit about your blood, how it's 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. This is a spongy material in the middle of our bones – particularly in our pelvis, backbone (spine) and breast bone (sternum). Normally, millions of new blood cells are made every day to replace old and worn-out blood cells.

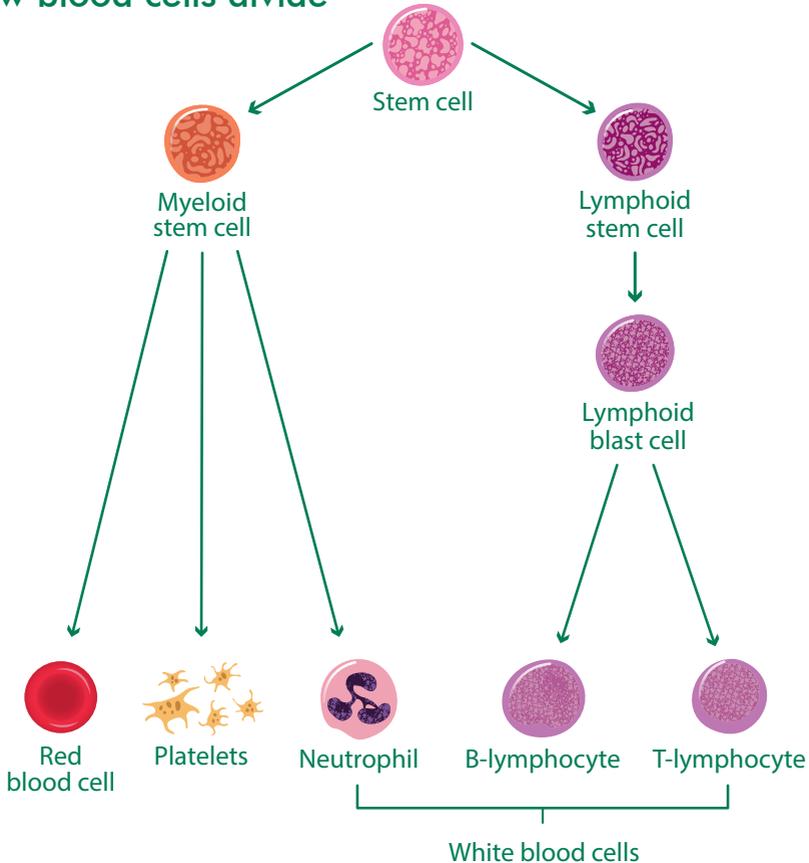
All blood cells are made from blood stem cells.

There are two types of blood stem cell:

- **Lymphoid stem cells**, which make a type of white blood cell called lymphocytes.
- **Myeloid stem cells**, which make all the other types of blood cell: red blood cells, platelets, and white blood cells.

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 don't look like fully developed cells and they can't 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 (see diagram on page 8).

How blood cells divide



The developed cells are then released into your blood to carry out different functions:

- **Red blood cells** contain haemoglobin (Hb), which carries oxygen from your lungs to all the cells in your body.
- **Platelets** are very small cells that help your blood clot and prevent bleeding and bruising.
- **White blood cells** fight and prevent infection. There are several types of white blood cell. The two 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). The figures below are a guide to the levels usually found in a healthy person.

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

These figures can vary slightly between hospitals. Your doctor or nurse will be able to tell you the levels they use. The levels can also vary slightly between people from different ethnic groups.

The figures might look complicated when they're written down, but doctors and nurses use them in a straightforward way. For example, you'll hear them saying things like, 'Your haemoglobin (Hb) is 140,' or, 'Your neutrophils are 4'.

Most people with CLL soon get used to these figures and what they mean. But remember, you can always ask your medical team to explain more if you need to.

Your doctors will look at how your blood test results change over time to decide what, if any, treatment is needed.

Lymphocytes and the lymphatic system

Lymphocytes

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

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

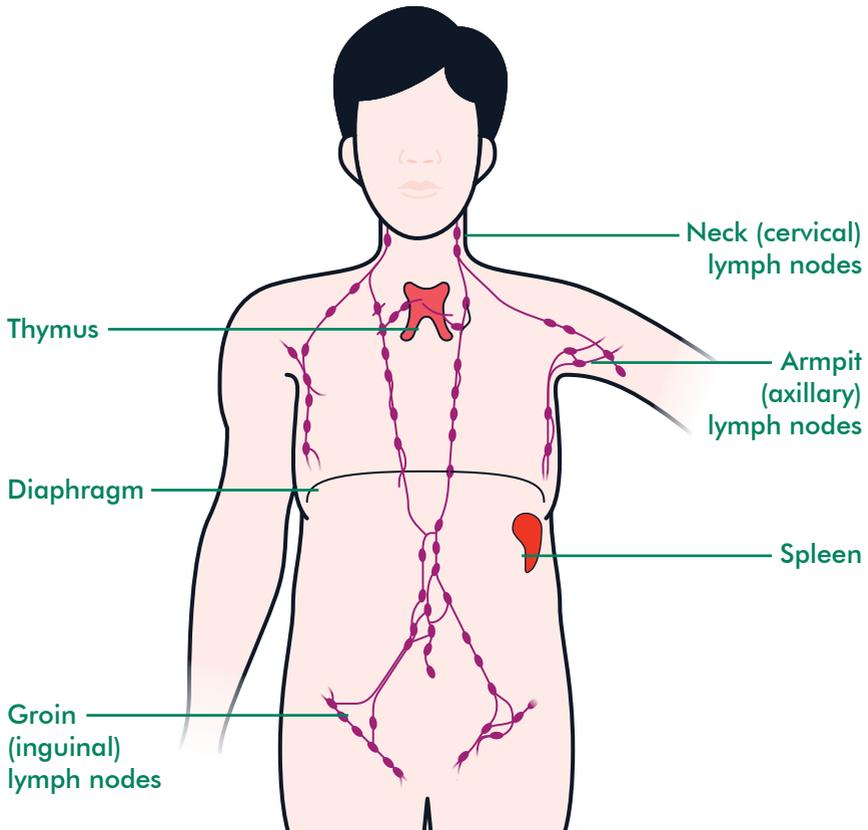
The lymphatic system

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

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

There are groups of lymph nodes in the neck, armpit and groin. There are also lymph nodes in the chest and tummy (abdomen). The bone marrow, spleen and thymus are also part of the lymphatic system.

The lymphatic system



Chronic lymphocytic leukaemia (CLL)

Chronic lymphocytic leukaemia (CLL) is the most common type of leukaemia. It is more common in older people. About 3,200 people in the UK are diagnosed with it each year. CLL usually develops very slowly which is why it's called a chronic leukaemia. Acute leukaemias develop more quickly.

Many people with CLL don't need treatment for months or years. However, if people have symptoms, they may need treatment sooner.

CLL is a cancer of the white blood cells which develop from the lymphoid stem cells (see page 8). In people with CLL, the bone marrow makes too many abnormal white blood cells called lymphocytes (see page 10). When these cells are examined under a microscope, they look normal. But they aren't fully developed (immature) and don't work properly.

Over time, these abnormal lymphocytes build up in the lymphatic system (see pages 10–11) and may cause large, swollen lymph nodes. The abnormal lymphocytes can also build up in the bone marrow (see page 7). This leaves less space for normal white blood cells, red blood cells and platelets to develop.

'My first reaction was of shock, followed quickly by false bravado which masked a severe depression. I've since discovered this isn't uncommon in newly-diagnosed cancer patients.'

Gary



Causes and risk factors

We don't know what causes CLL, but research is going on to find out more. There are a number of factors that can increase the risk of developing it.

Age

The risk of developing CLL increases with age. Most people with CLL are over 60. It's rare in people under 40.

Gender

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 first degree relative (parent, sibling or child) who has it. If anyone else in your family has CLL, it's important to let your specialist know. However, most people who have a relative with CLL will never develop it themselves.

Ethnicity

CLL is most common in people of European origin.



CLL is not infectious and cannot be passed on to other people.

Signs and symptoms

CLL develops slowly and many people have no symptoms in the early stages. It's often discovered by chance when a blood test is taken for another reason. For example, before an operation, or as part of a routine health check.

The symptoms of CLL can include the following:

- Feeling tired (fatigued) or unwell.
- Having frequent infections. This is caused by a lack of healthy white blood cells. Infections may be more severe and take longer to clear.
- Swollen lymph nodes in the neck, armpits or groin. This is caused by a build-up of CLL cells. It's usually painless.
- Breathlessness, tiredness and headaches. This is caused by a lack of red blood cells, called anaemia.
- Bruising and bleeding easily. This may happen if there aren't enough platelets in the blood. You may have nosebleeds that take a long time to stop (more than 10 minutes). You may get large bruises in unexpected places.
- A tender lump in the upper left-hand side of the abdomen. This is caused by an enlarged spleen.
- Severe sweating at night.
- Weight loss.



DIAGNOSING CLL

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How CLL is diagnosed

CLL is often diagnosed following a routine blood test and you may have had no symptoms at all. If you have symptoms, your GP will examine you and arrange a blood test. If they think you may have CLL, they will refer you to a **haematologist** for further tests. A haematologist is a doctor who specialises in diagnosing and treating blood problems.

At the hospital

The haematologist will ask you about any illnesses or health problems you've had. They will examine you to check whether your lymph nodes, spleen or liver are enlarged. You will also have more blood tests. This is to check the number of different cells in your blood (a full blood count – see page 9) and to look for leukaemia cells.

If the blood tests show there are leukaemia cells in your blood, the haematologist will arrange further tests. This is to find out which type of leukaemia you have and what stage it is. The results of these tests will help them plan your treatment.

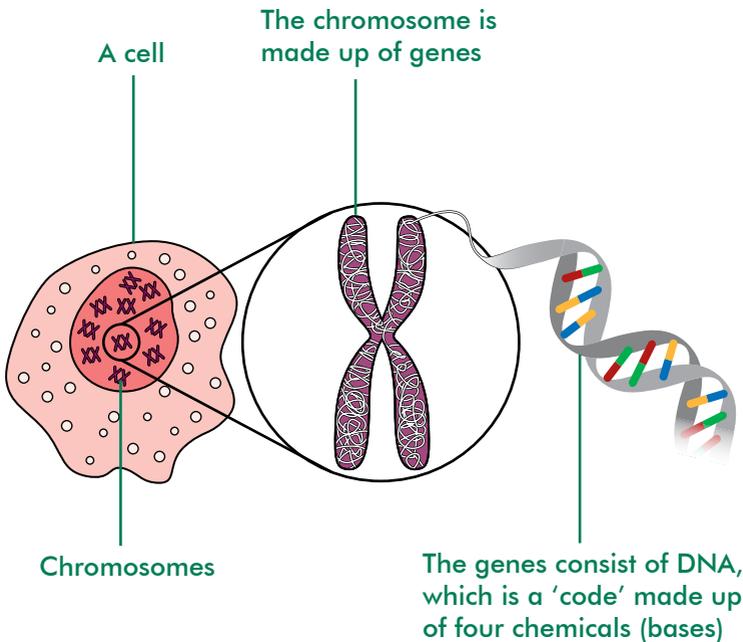
In most people with CLL, the leukaemia cells are mainly in the blood stream and the bone marrow. In some people, the leukaemia cells are mainly in the lymph nodes. In this case, the disease is called **small lymphocytic lymphoma (SLL)**. CLL and SLL are now considered to be the same disease, so you may hear doctors refer to it as CLL/SLL.

Further tests

To help you understand some of the tests used to diagnose CLL, it can be helpful to know a bit 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 are grouped together on **chromosomes** and the genes control what the cell does.

What DNA is made of



Blood tests

The blood tests you may have include:

- **Cytogenetic testing** – this looks at the chromosomes in the leukaemia cells. There are often changes in the chromosomes of CLL cells (see page 24).
- **Fluorescent in situ hybridisation (FISH)** – this is sometimes used to look for any changes in the leukaemia cells. Knowing what these changes are helps doctors understand how the CLL may behave and plan your treatment.
- **Immunophenotyping** – this shows which types of white blood cells are abnormal.
- **Immunoglobulin testing** – this checks the levels of antibodies you have in your blood for fighting infection. CLL cells may also make antibodies that damage your red blood cells.

Chest x-ray

This uses x-rays to take a picture of your chest, to check your lungs and heart. The x-ray will also look at lymph nodes in your chest.

CT (computerised tomography) scan

This is sometimes done to check how many lymph nodes are affected by CLL and to see whether the spleen is enlarged.

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless.

It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection. You'll probably be able to go home as soon as the scan is over.

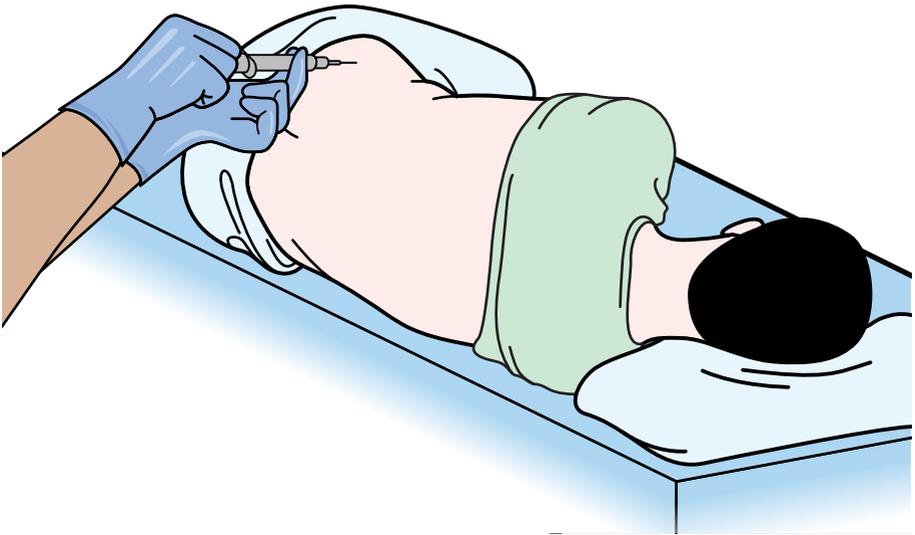


Someone having a CT scan

Bone marrow biopsy

Some people may have this test to check how much CLL is in their bone marrow. A small sample (biopsy) of bone marrow is taken from the hip bone. This is usually done under a local anaesthetic in the outpatient department and takes about 10 minutes. It can feel quite uncomfortable but you can take painkillers if you need to.

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



Lymph node biopsy

This test isn't usually needed, but some people may have an enlarged lymph node removed so it can be examined under a microscope. You may have this done under a local or general anaesthetic. It's a small operation and most people can go home on the same day. After the operation, you'll have a small wound with a few stitches. The stitches are usually taken out after about 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 of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 89–96, can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Cytogenetic testing

CLL can behave very differently in different people. It can often develop slowly over many years – sometimes 20 years or more. However, in some people, CLL develops more quickly.

Cytogenetic tests give information about changes in the chromosomes (see page 19), such as whether a part is missing or 'deleted'. This information helps the doctors plan what treatment you are most likely to benefit from. These are the most common changes:

- Between 30–50% of people (3–5 out of 10) with CLL have a cytogenetic change called **del (13q)**. People with this change alone often have a type of CLL that develops extremely slowly and doesn't need any treatment for many years.
- Less than 10% of people (1 out of 10) have a cytogenetic change called **del (17p)**. This makes the leukaemia more difficult to control. If this is found, a FISH test (fluorescent in situ hybridisation – see page 20) may be done to see if a gene called TP53 is missing.
- About 40–60% of people (4–6 out of 10) either have other cytogenetic changes in their CLL cells, or none at all. The leukaemia often needs treatment, but usually not immediately. It can be controlled for a number of years with treatment.



Staging

Doctors use staging to assess how much leukaemia there is. This helps them know when you may need treatment and which treatment is best for your situation.

There are two staging systems commonly used for CLL – the Binet system and 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. It also looks at how many areas of lymph nodes are enlarged. These areas are in the neck, armpits, groin, liver and spleen (see page 11). If the lymph nodes in both armpits are enlarged, it's only counted as one area.

There are three stages in the Binet system:

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

Transformation

In a small number of people with CLL, the leukaemia can change and start to grow more quickly. This is called **transformation**.

In about 10% of people (1 out of 10), CLL may change into another type of leukaemia called **prolymphocytic leukaemia**. In less than 10% of people, CLL may develop into a type of lymphoma (cancer of the lymphatic system) known as **Richter's syndrome**.

Transformation can be found by a blood test that shows a high number of leukaemia cells.

Sometimes, the first sign of transformation is when a person has more symptoms. These include:

- a high temperature (fever)
- sweats
- weight loss
- a sudden swelling of affected lymph nodes, especially in the tummy (abdomen).

However, there are many other reasons why someone may have these symptoms.

It's important to remember that transformation is unusual and doesn't happen for most people with CLL.



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Treatment overview

Doctors will usually wait until you have symptoms before suggesting treatment. CLL usually develops very slowly, so people often don't need treatment for months or years. Some people will never need it. However, people with symptoms caused by CLL may need treatment straight away.

Even when you're not having any treatment, you'll still see your haematologist or GP regularly. This is usually called **monitoring**, or watch and wait (see page 36).

Aims of treatment

Treatment aims to reduce the number of CLL cells to as few as possible, so you can have a normal life with no symptoms. This is called **remission**.

There are different levels of remission:

- **Complete remission (CR)** – No CLL cells can be found.
- **Minimal residual disease (MRD)** – There are so few CLL cells remaining that they can only be found with special blood tests.
- **Partial remission (PR)** – The number of CLL cells in the blood and bone marrow has reduced and the lymph nodes are smaller, but CLL can still be found.

Treatment is very successful at getting the leukaemia into complete or partial remission in most people. This may last for years. If the leukaemia does start to grow again and begins to cause problems, you can have more treatment. This can be done several times.

If the leukaemia doesn't respond well to the first treatment you have, your doctors can change the treatment.

If there's no change after treatment, if the number of CLL cells increases, or if the lymph nodes get bigger, the CLL is described as **refractory**. This means the leukaemia cells haven't responded to treatment.

If treatment to control CLL is no longer helpful, you can have supportive therapy with medicines and blood transfusions to reduce symptoms (see pages 54–57).

Starting treatment

There are a number of things your doctors will consider when deciding if you need treatment and which treatment might be best for you. These include checking for the following:

- the number of white blood cells
- very enlarged or fast-growing lymph nodes
- low level of red blood cells (anaemia) or platelets
- severe night sweats
- weight loss.

Your doctor will also ask you about your general health and check your fitness when planning your treatment.

Treating stage A

People with stage A CLL (see page 26) don't usually need treatment. Often, stage A CLL doesn't cause any symptoms and it develops very slowly. Starting treatment at this stage doesn't help the CLL and it can cause side effects. Some people with stage A CLL will never need treatment.

It's still important to go to the hospital or GP surgery for regular check-ups and blood tests. This is to monitor the leukaemia. Usually, you'll only need to start treatment if you develop symptoms, or your blood test shows that the CLL is progressing. Your doctor will discuss the benefits and disadvantages of treatment with you.

A common symptom of CLL is tiredness (fatigue). Our booklet **Coping with fatigue** has more information about how to manage this.

Treating stages B and C

If you have stage B or stage C CLL, you may be offered one or more of the following treatments (or a combination of them):

- **Chemotherapy** – This is a common treatment for CLL (see pages 38–44).
- **Targeted therapies** – There are different types of targeted therapies (see pages 46–49). The most common type used to treat CLL is called a monoclonal antibody. These drugs are often given with chemotherapy.
- **Stem cell transplant** – Doctors may suggest this treatment if the CLL hasn't responded to chemotherapy, or if it's a type of CLL that's unlikely to respond to it. It's an intensive treatment, so is usually only suitable for younger people (see pages 50–51).
- **Radiotherapy** – You may have this if you have enlarged lymph nodes or an enlarged spleen (see page 52).
- **Supportive therapy** – This may be given to help control any symptoms caused by CLL, such as infections or anaemia (see pages 54–57).
- **Steroids** – These might be given if your immune system acts against your red blood cells or platelets (see page 58).
- **Surgery** – This is occasionally used to remove an enlarged spleen (splenectomy).
- **Clinical trials** – There are many new treatments being looked at to try to improve the outcome for people with CLL. Ask your doctor about any clinical trials you could join (see pages 59–61).

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

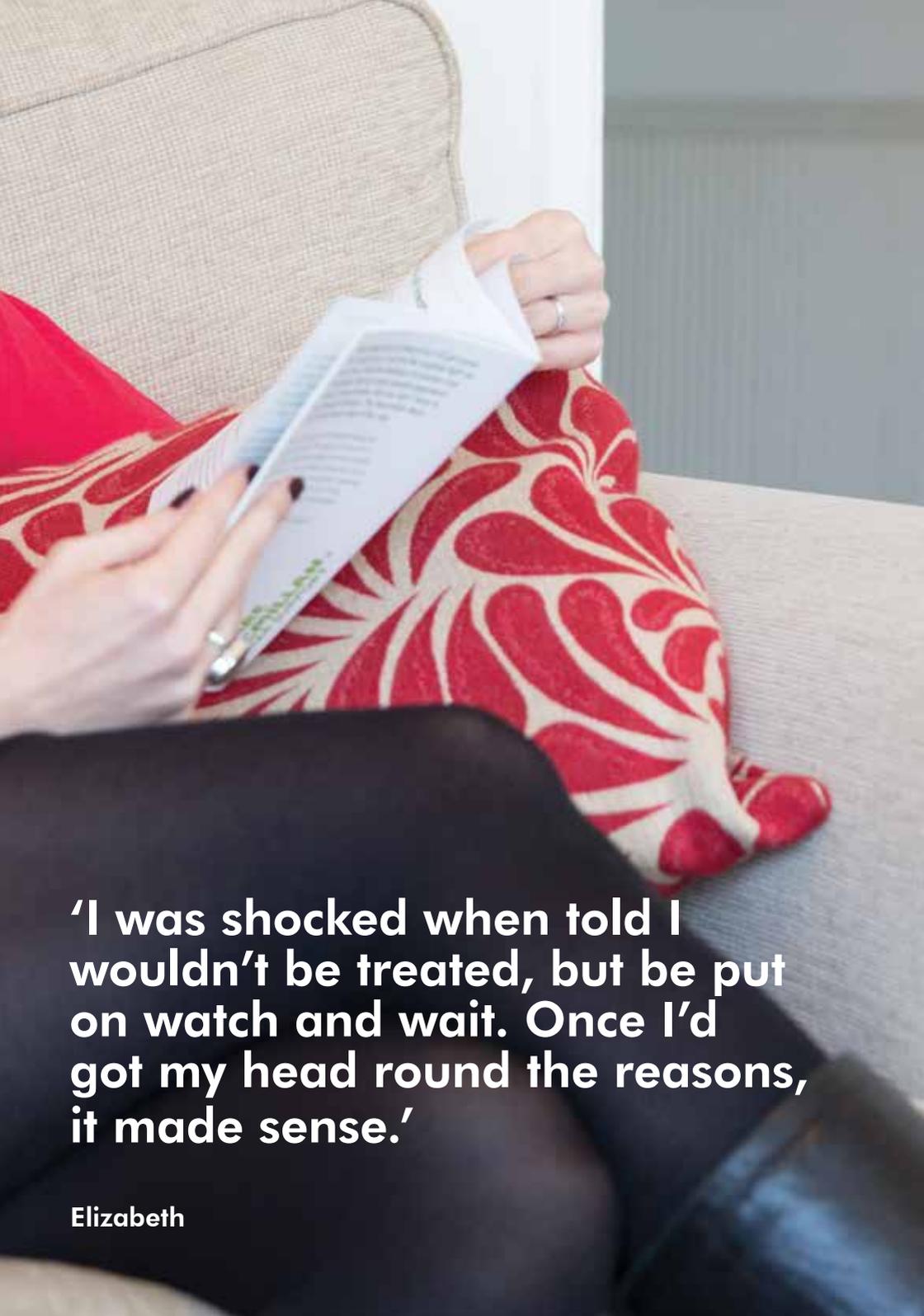
Monitoring (watch and wait)

Your haematologist or GP will check for any swollen lymph glands and arrange blood tests. You're usually seen at least twice within the first year of being diagnosed.

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

- Make sure you understand why monitoring is recommended. If you have any worries, talk to your doctor.
- 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.
- Express your feelings. You could do this by talking to family and friends, or joining a support group or online forum (see page 69).

Although monitoring can be difficult to adjust to at first, many people find it gets easier as time goes on.



'I was shocked when told I wouldn't be treated, but be put on watch and wait. Once I'd got my head round the reasons, it made sense.'

Elizabeth

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. These drugs interfere with the way leukaemia cells grow and divide. The drugs can be given as tablets (oral chemotherapy) or into a vein (intravenously). The chemotherapy travels around your body through your blood. It can reach leukaemia cells all over your body.

You may have either a single chemotherapy drug or a combination of different drugs given together. You can usually have chemotherapy for CLL as an outpatient.

Before starting chemotherapy, you will have your height and weight checked. This is used to work out the right dose for you.

Chemotherapy is usually given as several sessions of treatment. Each treatment is followed by a rest period of a few weeks. This allows your body to recover from any side effects. The treatment and the rest period together, make up a **cycle** of treatment.

The drugs most often used to treat CLL are:

- chlorambucil (Leukeran®)
- fludarabine (Fludara®)
- cyclophosphamide
- bendamustine (Levact®).

Chlorambucil chemotherapy is given as tablets. They can be prescribed in different ways, depending on your needs.

Fludarabine and cyclophosphamide are usually given together (known as FC chemotherapy). The treatment can be given as tablets or into a vein. A monoclonal antibody called rituximab (see page 46) is usually given with FC chemotherapy. This is called FC-R or R-FC treatment.

Bendamustine may be given to people with stage B or stage C CLL (see page 26), who might not be able to have fludarabine. Rituximab is often given with bendamustine.

Sometimes, a combination of the chemotherapy drugs cyclophosphamide, vincristine and doxorubicin are given together. They are given into the vein. Steroid tablets (see page 58) called prednisolone are taken for five days with each cycle of treatment. This treatment is known as CHOP.

Your doctors may use other drugs and combinations of drugs. They will tell you what treatment they recommend for your situation.

We have a booklet called **Understanding chemotherapy** and fact sheets on different chemotherapy drugs, which we can send you.

Side effects

If you're taking a single chemotherapy drug, such as chlorambucil, any side effects you have will usually be mild. Treatment with a combination of two or more chemotherapy drugs may cause more side effects.

Risk of infection

Chemotherapy can reduce the number of white blood cells, which help fight infection. If the number of your white blood cells is low you'll be more prone to infections. A low white blood cell count is called neutropenia.

Always contact the hospital immediately on the 24-hour contact number you've been given and speak to a nurse or doctor if:

- you develop a high temperature, which may be over 37.5°C (99.5°F) or over 38°C (100.4°F) depending on the hospital's policy – follow the advice you have been given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection, such as a cold, sore throat, cough, passing urine frequently (urine infection), or diarrhoea.

If necessary, you'll be given antibiotics to treat any infection. You'll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally, your treatment may need to be delayed if the number of white blood cells is still low.

If you develop an infection, you may need to go into hospital for treatment. If the antibody levels in your blood are very low, you may be given immunoglobulin replacement therapy (see page 56) through a drip into the vein or as an injection under the skin (subcutaneously).

If you're being treated with fludarabine, you may be given drugs to help prevent viral infections as well. You may also need to take antibiotics for up to a year after fludarabine treatment, to help prevent chest infections.

Anaemia (reduced number of red blood cells)

Chemotherapy may reduce the number of red blood cells (haemoglobin) in your blood. A low level of red blood cells is called anaemia, which can make you feel very tired and lethargic. You may also become breathless. Let your doctor know if you get these effects.

Increased bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

If your red blood cells or platelets take a while to recover, you may need a blood transfusion (see page 57) or a platelet transfusion. You can have transfusions as an outpatient.

Anyone treated with fludarabine or bendamustine 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've finished your treatment. This lowers the risk of the donated blood cells reacting against your own. Your hospital team should give you a card to carry or a MedicAlert ID tag to wear, so that hospital staff are aware in case of an emergency.

Feeling sick

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your haematologist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Sore mouth

Your mouth may become sore (or dry), or you may notice small ulcers during treatment. Some people find that sucking on ice may be soothing. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicine to prevent or clear mouth infections.

Tiredness (fatigue)

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect).

If you do have hair loss, your hair should start to grow back within about 3–6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Most drugs used to treat CLL do not cause hair loss.



We have more information about all these side effects. Call our cancer support specialists or visit our website at [macmillan.org.uk](https://www.macmillan.org.uk)

Contraception

Men who may possibly father a child, or women who might become pregnant, should use effective contraception during their course of chemotherapy treatment. This is because the drugs might harm a baby conceived during this time. It is important to carry on using effective contraception after your treatment finishes, for up to a year afterwards. You can discuss this with your doctor or specialist nurse.

A barrier contraception such as a condom should be used during sex within the first 48 hours after chemotherapy, to protect your partner from any of the drug that may be present in semen or vaginal fluid. You can discuss this with your doctor.

Fertility

Some of the drugs used to treat CLL may cause infertility (being unable to become pregnant or to father a child). This may be temporary or permanent.

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

If you have a partner, it's a good idea for both of you to be there during these discussions. You can then make an informed decision about your options.

If you have high-dose chemotherapy or radiotherapy before a stem cell transplant (see pages 50–51) or bone marrow transplant, you are likely to become permanently infertile. Men may be able to have sperm stored before they start treatment (sperm banking) and sometimes women may be able to have eggs collected and frozen. It's important to speak to your medical team about this before your treatment begins.



We have further information about fertility for men and women. You can order our free booklets from [be.macmillan.org.uk](https://www.be.macmillan.org.uk)



Targeted therapies

Targeted therapies are drugs that recognise certain proteins on the surface of cells. In CLL, they are designed to block the growth and destroy the abnormal lymphocytes (see page 12).

There are different types of targeted therapies. They all act in different ways and have different side effects. They are often used in combination with chemotherapy. The ones most commonly used to treat CLL are called monoclonal antibodies.

Monoclonal antibodies

The monoclonal antibodies most commonly used to treat CLL are:

- rituximab (Mabthera®)
- alemtuzumab (Campath®).

Rituximab is often given with the chemotherapy drugs fludarabine and cyclophosphamide, and also with bendamustine.

Alemtuzumab may be given with chemotherapy or on its own. It may be used if your leukaemia has come back after chemotherapy treatment.

You may be able to have targeted therapy treatment as an outpatient or you may be asked to stay in hospital overnight. Rituximab and alemtuzumab can be given by a drip (intravenous infusion).

Most people don't have many side effects. But some people may have a reaction during, or just after, the first infusion. You'll be given your first infusion very slowly to reduce the chance of this happening. You'll also be given medicines to help reduce any reaction you get. Reactions are usually milder with a second infusion and any infusions after that.

Symptoms showing a reaction can include:

- a high temperature
- shakes
- a rash
- low blood pressure
- feeling sick (nausea).

Alemtuzumab can also be given as an injection under the skin (subcutaneously). In this case, it's less likely to cause a reaction. You may notice some redness, swelling or soreness in the area where you had the injection, but this usually goes away after a week or two.

Targeted therapy treatments can lower your resistance to infection. You'll probably be given antibiotics during treatment and for some time afterwards to prevent an infection.



We have more information about rituximab.
Call our support line on 0808 808 00 00.

Newer monoclonal antibodies

At the time of writing, (September 2015) two newer monoclonal antibody treatments, ofatumumab and obinutuzumab, have been recently approved by the National Institute for Health and Care Excellence (NICE). NICE is an independent organisation that assesses which drugs and treatments are available on the NHS in England and Wales.

Ofatumumab or obinutuzumab can be used as a first treatment option for those who are unable to have fludarabine or bendamustine. Ofatumumab or obinutuzumab can be given with the chemotherapy drug chlorambucil. Your haematologist can tell you whether either of these treatments might be helpful in your situation.

Both ofatumumab and obinutuzumab are given through a drip into a vein (intravenously). They can sometimes cause an allergic reaction while they are being given. You will be given medicines to reduce the chance of this happening and be closely monitored during your treatment. You can ask your haematologist to explain more about this.

Other new targeted therapies

B-cell receptor inhibitors

Ibrutinib and Idelalisib are B-cell receptor inhibitors. They target the receptors (proteins) on the surface of the cells and stop the cancer growing and dividing.

These drugs might be used when other treatments are no longer working. They are taken by mouth as tablets. Your haematologist will explain whether these treatments might help you.

Ibrutinib and Idelalisib may only be available in some situations. Your haematologist can tell you if they are suitable for you. If a drug is not available on the NHS, there may be different ways you can access it. Your haematologist can give you advice.

There are other types of targeted drugs being researched and tested in clinical trials (see pages 59–61).

Stem cell transplants

This treatment may be an option for some younger people with CLL. Your doctor will discuss with you if it might be suitable.

Stem cell transplants are only carried out in specialist cancer treatment centres. It allows you to have higher doses of chemotherapy than usual. It's an intensive treatment and side effects can be severe. However, it may result in a long period of remission (see page 30).

Stem cells are found inside our bone marrow. They make all the red blood cells, white blood cells and platelets in the blood (see pages 7–8).

There are two types of stem cell transplant:

- **Autologous transplants** – uses your own stem cells (also known as high-dose treatment with stem cell support).
- **Allogeneic transplants** – when you are given stem cells from someone else (a donor).

Allogeneic transplants

This is most commonly used for people with CLL.

It uses stem cells that are matched from a brother or sister who is genetically similar to you. If you don't 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're given donor stem cells, you'll have intensive chemotherapy and sometimes radiotherapy too. This destroys any remaining leukaemia cells and prepares your immune system for the donor stem cells.

Some types of allogeneic transplant use less chemotherapy and radiotherapy than an autologous transplant, and are known as **reduced intensity transplants**.

Our booklet **Understanding donor (allogeneic) stem cell transplants** has detailed information about this treatment.

Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It's not often used to treat CLL, but is sometimes used if your lymph nodes or spleen are very enlarged.

Radiotherapy is given in the hospital radiotherapy department. Treatment is usually given daily, from Monday to Friday. It is usually given over one or two weeks, with a rest at the weekend. Each session may last a few minutes and is painless. You usually have radiotherapy as an outpatient.

CLL is very sensitive to radiotherapy and usually only very low doses are needed. This means that side effects are very uncommon.

Our booklet **Understanding radiotherapy** gives detailed information about this treatment and its side effects.



RADIOGRAPHER

NHS
SCOTLAND

Supportive therapy

Supportive therapies are treatments that help to control any symptoms caused by CLL or its treatment. This section explains the more common problems that some people with CLL may have, and the treatments that can help.

Infections

People with CLL are more at risk of getting serious infections. This is because both CLL and the treatments used for it, affect the immune system (see page 10).

You can usually be treated for infections as an outpatient. However, more serious infections can be life-threatening. It's important to contact your doctor for advice straight away if you develop a cough, sore throat, fever or any other sign of infection.

Shingles

People with CLL are at a higher risk of developing an infection called shingles. The infection affects a nerve and the area of skin around it. It's caused by the same virus that causes chickenpox. Anyone who has had chickenpox before 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 sensation in the affected area. This is followed by pain and a red rash which develops 2 to 3 days later.

If you think you have shingles, or you have come into contact with someone who has shingles or chickenpox, it's important to contact your GP or the hospital immediately. Effective treatment can prevent or limit the infection. Shingles usually gets better within 2 to 5 weeks.

People over 70 are routinely offered a vaccine against shingles. But if you have CLL, you will need to talk to your haematologist before you have the vaccine. It's not usually safe for people with CLL to have it, because it is a **live vaccine** (see below).

Vaccines

Having CLL can mean your immune system isn't as effective as before, and vaccines may not work very well for you. But most people with CLL are still advised to have a yearly flu vaccine. This is to give them as much protection as possible. Your doctors may also recommend two specific vaccines when you are first diagnosed. These are to protect against pneumonia and a type of infection called streptococcus.

There are some types of vaccines that you should avoid. For example, live vaccines. Live vaccines contain a weak, altered form of the live virus. People with CLL have a weakened immune system, so the vaccine may cause them harm. Your haematologist can tell you which vaccinations are safe and if there are any you should avoid.

Low levels of antibodies

Most people with CLL have very low levels of infection-fighting antibodies (immunoglobulins) in their blood. This can sometimes lead to problems with repeated infections. Some people who are affected may need to be given regular immunoglobulin treatment. The immunoglobulins are given into a vein as a drip (infusion) or as an injection under the skin (subcutaneously).

Most people feel fine when having an immunoglobulin infusion, but sometimes it can cause a reaction similar to that described on page 47. This is most likely to happen with the first infusion. To reduce the chance of a reaction, the first infusion is given slowly.

Autoimmune reactions in CLL

CLL can sometimes cause your immune system to act against normal, healthy red blood cells or platelets. If red blood cells are affected, this is called **autoimmune haemolytic anaemia (AIHA)**. If platelets are affected, this is called **immune thrombocytopenic purpura (ITP)**.

With AIHA, the number of red blood cells falls very quickly. This may cause:

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

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

When the number of platelets suddenly drops, it can cause:

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

Transfusions

If your bone marrow isn't making enough red blood cells or platelets, you may need to have transfusions of blood or platelets. This can be done in the outpatients department. You may need to have blood or platelets that have been irradiated (see page 42).

We have more information about blood and platelet transfusions. Call our cancer support specialists on **0808 808 00 00**.

'They were giving me blood every couple of weeks to sort of boost me. I'd feel like a new man with three pints of blood just running round my veins.'

Ash

Steroids

The steroids most commonly used to treat CLL include:

- dexamethasone
- methylprednisolone
- prednisolone.

You may be given treatment with steroids if your red blood cell count falls very quickly, because of a condition called autoimmune haemolytic anaemia or AIHA (see page 56).

You may also have steroids with chemotherapy treatment, for example as part of CHOP chemotherapy (see page 39). As well as treating CLL, steroids help reduce possible sickness from the chemotherapy.

Occasionally, people will be given high-dose steroid treatment, called high-dose methylprednisolone (HDMP). The steroids can be given as tablets or into a vein as a drip. You may be prescribed antibiotics, anti-viral drugs or anti-fungal drugs to help prevent infection during your treatment.

We have information about steroids. Call us on **0808 808 00 00** or visit our website **macmillan.org.uk**

Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for leukaemia. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of treatment is better than what's already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about leukaemia and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. However, some treatments that look promising at first are later found not to be as good as existing treatments, or have side effects that outweigh the benefits. This is something for you to bear in mind.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into leukaemia. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of leukaemia and its treatment, which will hopefully improve the outlook for future patients.

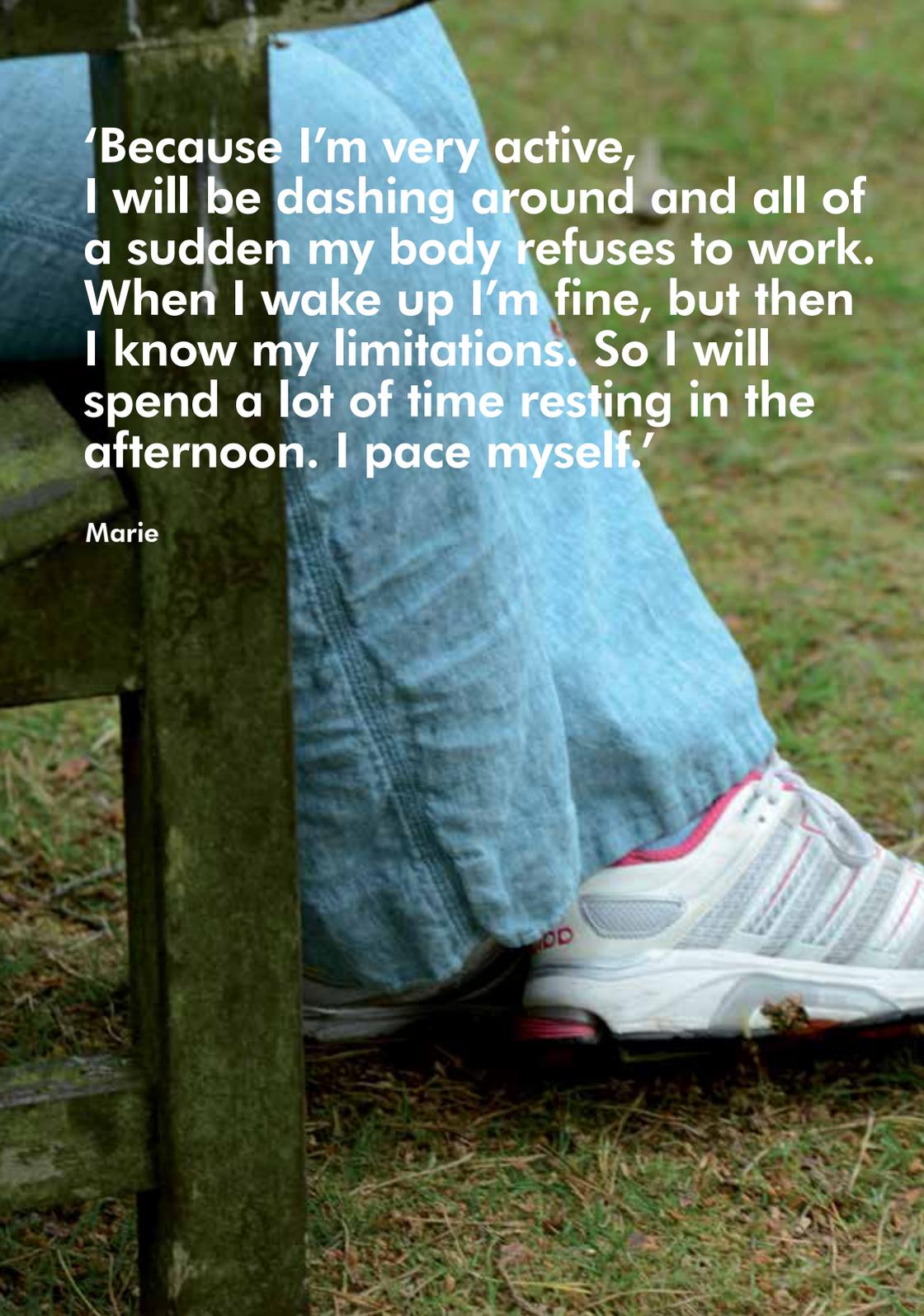
Current research

There are a number of CLL trials happening in the UK. Many of the trials are organised by the National Cancer Research Institute (NCRI) CLL trials sub-group. Some trials are testing new combinations of existing treatments, to find out if this makes them more effective. Other trials are looking for more effective treatments for CLL that is difficult to treat or is no longer responding to standard treatments. Some trials are looking at the possible causes of chronic leukaemia, including genetics.

Your haematologist will know if there are any trials that you might want to take part in.



You may want to read our booklet **Understanding cancer research trials (clinical trials)**. You can order this from [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call one of our cancer support specialists on **0808 808 00 00**.



**'Because I'm very active,
I will be dashing around and all of
a sudden my body refuses to work.
When I wake up I'm fine, but then
I know my limitations. So I will
spend a lot of time resting in the
afternoon. I pace myself.'**

Marie

LIVING WITH CLL

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Follow-up and monitoring

CLL is an illness that you can live with for a long time, as it often progresses very slowly. If treatment is needed, it's usually very effective and can keep the leukaemia under control for many years. You will need to have regular check-ups and blood tests.

If you have any problems or notice any new symptoms that don't go away within a couple of weeks, let your doctor know as soon as possible. You don't need to wait until your next appointment.



Well-being

To help you stay as well as possible, you may want to make changes to your lifestyle and find out more about healthy living. Even if you had a healthy lifestyle before your diagnosis, you may want to focus more on making the most of your health.

You might choose to make just a few changes, or completely change the way you live. Adopting a healthy lifestyle is about making small, achievable changes to the way you live. This will improve your health and sense of well-being, and lower your risk of getting other illnesses and some cancers.

A healthy lifestyle includes having a well-balanced diet, being physically active, reducing stress, and being involved in your healthcare. We've listed some tips over the next few pages. When planning changes, you will need to take any side effects of treatment into account. Try not to do too much, too soon.

Adopting a healthy lifestyle doesn't have to be difficult or expensive. It may feel like it's a lot of hard work and you're denying yourself life's pleasures. But there are many benefits. It's important to do what's right for you.

Eat well and keep to a healthy weight

A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least five 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.

Stop smoking

If you smoke, speak to your doctor or call a stop-smoking helpline for further advice. They can tell you where your local stop-smoking service is.

Reduce stress

There are different ways of reducing stress, and 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.

Some people find it helpful to talk about their feelings or have contact with other people who have been through a similar experience (see page 69). Others find it helpful to write a journal or online blog.

Get physically active

Physical activity can improve your sense of well-being and help build up your energy levels. It reduces the risk of heart disease, strokes, diabetes and bone thinning (osteoporosis). Physical activity doesn't have to be very strenuous. You can start gently and build up the amount you do.

Get 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 your appointments that don't go away within a couple of weeks, let your doctor know as soon as possible.

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



Self-help and support groups

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

Self-help or support groups offer 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 don't 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.

Online support

Many people now 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.

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)

Your feelings

CLL usually develops very slowly and many people are surprised at how little it affects their lives, particularly when they're first diagnosed. Your doctor may tell you that you don't need treatment for a long time, which you may find hard to believe. It can be very difficult to accept that you have leukaemia, especially when nothing seems to be being done. You can tell your doctor or nurse about your feelings so they can explain why it's better for you not to have treatment at your stage of the illness.

It's common to feel overwhelmed by different feelings when you're told that you have leukaemia. Partners, family and friends may also have some of the same feelings. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help. You might have different reactions to the ones we describe here.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have leukaemia. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the leukaemia. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and uncertainty

People can be very anxious or frightened about whether treatment will work and what will happen in the future. Most people with CLL live for many years and many people find their day-to-day activities are unaffected.

However, uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. 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 and to 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 can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about leukaemia and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have leukaemia. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have leukaemia. They may not want to talk about it or they might change the subject. This is usually because they are also finding the leukaemia difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. It can help to let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the leukaemia. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's leukaemia. Over time, several different factors may act together to cause leukaemia. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about leukaemia. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups**. You can also talk to other people going through the same thing on our online community at **macmillan.org.uk/community**.

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.



Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

If you are a relative or friend

Some people find it hard to talk about leukaemia or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with leukaemia, or you might feel you're letting them down if you admit to being afraid. Often by being honest about how you feel can help the person with leukaemia to talk themselves, and to feel less isolated.

Partners, relatives and friends can help by listening carefully to what the person with leukaemia wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with leukaemia 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, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.



Our booklet **Lost for words – how to talk to someone with cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with leukaemia, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with leukaemia at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

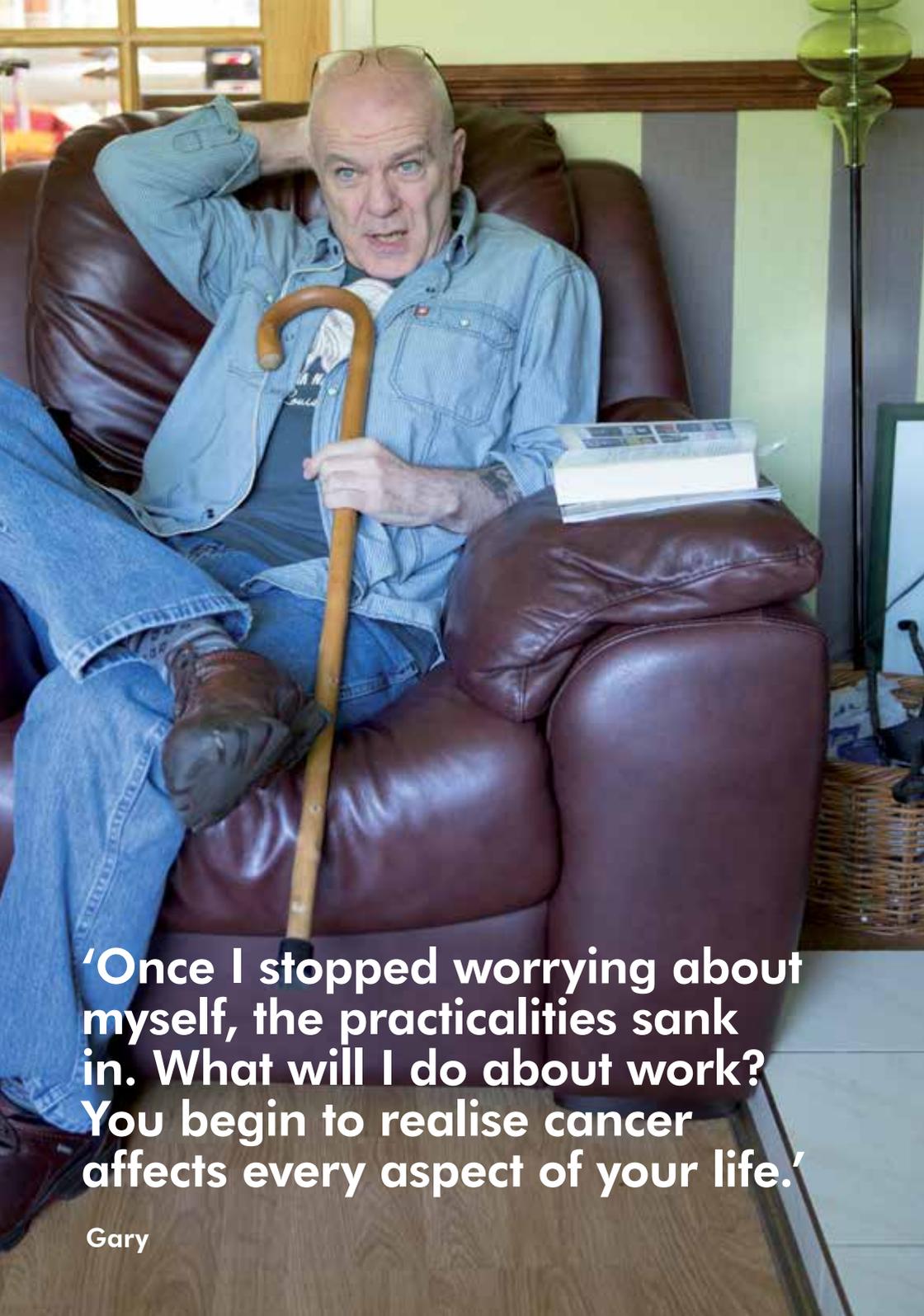
Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website riprap.org.uk which has been developed especially for teenagers who have a parent with cancer.



Our booklet **Talking to children when an adult has cancer** includes discussion about sensitive topics.



'Once I stopped worrying about myself, the practicalities sank in. What will I do about work? You begin to realise cancer affects every aspect of your life.'

Gary

WORK AND FINANCES

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Work 81

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- **contributory** – you can get this if you have made enough national insurance contributions
- **income-related** – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance (DLA)** in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for **Carer's Credit**. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 95) or Citizens Advice (see page 94). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at [macmillan.org.uk/gettingfinancialhelp](https://www.macmillan.org.uk/gettingfinancialhelp) useful.

Insurance

People who have, or have had, leukaemia may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 96.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

Direct payments

If you've been assessed as having a need for social services, you may be entitled to get direct payments from your local authority. This means that you are given payments to organise the services yourself, rather than the local social services organising and paying for them for you. You can get information about direct payments from the Department of Health website at [dh.gov.uk](https://www.dh.gov.uk) or from your local social security office.

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work. This will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from treatment for leukaemia. It may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, leukaemia. Even if a person who had leukaemia in the past has been successfully treated, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their leukaemia diagnosis. The Disability Discrimination Act protects people in Northern Ireland.



Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at macmillan.org.uk/work



YOUR RIGHTS FOR TREATMENT

CANCER

UNDERSTANDING THYROID CANCER (DUCULAR AND PAPILLARY)

SEX AND RELATIONSHIPS

SIDE EFFECTS OF CANCER TREATMENT

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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 leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

There you'll also find videos featuring real-life 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](https://www.macmillan.org.uk/otherformats)

If you'd like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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**

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'd 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** 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's 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](https://www.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](https://www.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.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

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

Financial advice

Our financial guidance team can give you advice 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're 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)



Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Leukaemia support organisations

Bloodwise

39–40 Eagle Street,
London WC1R 4TH

Tel 020 7504 2200

(Mon–Fri, 9am–5pm)

www.bloodwise.org.uk

Dedicated to researching blood cancer and disorders including CLL. Produces patient information on CLL.

CLL Support

Association (CLLSA)

c/o 39–40 Eagle Street,
London WC1R 4TH

Tel 0800 977 4396

Email info@cllsupport.org.uk

www.cllsupport.org.uk

Shares information, empathy, support, education, advice and empowerment with others affected by CLL.

Leukaemia CARE

One Birch Court,
Blackpole East,
Worcester WR3 8SG

Careline 08088 010 444

Email care@leukaemia
care.org.uk

www.leukaemicare.org.uk

Provides care and support to patients, their families and carers whose lives have been affected by leukaemia, lymphoma or an allied blood disorder. Offers emotional support and financial assistance through their network of volunteers and the dedicated 24-hour free helpline.

General cancer support organisations

Cancer Black Care

79 Acton Lane,

London NW10 8UT

Tel 020 8961 4151

Email info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus

Northern Ireland

40–44 Eglantine Avenue,

Belfast BT9 6DX

Helpline 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Angel Building,

407 St John Street,

London EC1V 4AD

Tel 0300 123 1022

www.cancerhelp.org.uk

Has patient information on all types of cancer and has a clinical trials database.

Cancer Support Scotland

The Calman Centre,

75 Shelley Road,

Glasgow G12 0ZE

Tel 0800 652 4531

Email [info@](mailto:info@cancersupportscotland.org)

cancersupportscotland.org

www.cancersupportscotland.org

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

Maggie's Centres

20 St. James Street,
London W6 9RW

Tel 0300 123 1801

Email enquiries@
maggiescentres.org

www.maggiescentres.org

Provides information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care

Chapel Pill Lane,
Pill, Bristol BS20 0HH

Helpline 0845 123 2310
(Mon–Fri, 9.30am–5pm, Wed
6–8pm)

Email
helpline@pennybrohn.org

**www.pennybrohn
cancercare.org**

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Riprap

Maggie's, The Stables,
Western General Hospital,
Crewe Road,
Edinburgh EH4 2XU

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD

Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)

Email info@
tenovuscancercare.org.uk

www.tenovus.org.uk

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

Healthtalk

Email

info@healthtalkonline.org

www.healthtalk.org

www.youthhealthtalk.org

(site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

National Cancer Institute – National Institute of Health – USA

www.cancer.gov

Gives information on cancer and treatments.

NHS Choices

www.nhs.uk

The UK's biggest health information website.

Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

www.nhsinform.co.uk

NHS health information site for Scotland.

Patient UK

www.patient.co.uk

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.

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street,
London SE1 0EH

Tel (England)

0844 800 4361

Tel (Scotland)

0300 123 2008

Tel (Wales)

0292 009 0087

Email info@carers.org

www.carers.org and

www.youngcarers.net

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

(Mon–Fri, 10am–4pm)

Tel (Northern Ireland)

028 9043 9843

Email

advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Counselling and emotional support**British Association for Counselling and Psychotherapy (BACP)**

BACP House,
15 St John's Business Park,
Lutterworth,
Leicestershire LE17 4HB

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

Freepost RSRB-KKBY-CYJK,
Chris, PO Box 9090,
Stirling FK8 2SA

Helpline 08457 90 90 90

Email jo@samaritans.org

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.

UK Council for Psychotherapy (UKCP)

2nd Floor, Edward House,
2 Wakley Street,
London EC1V 7LT

Tel 020 7014 9955

Email info@ukcp.org.uk

www.psychotherapy.org.uk

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

Financial or legal advice and information

Benefit Enquiry Line

Northern Ireland

Helpline 0800 220 674

(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

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.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Civil Legal Advice

Helpline 0345 345 4345

(Mon–Fri, 9am–8pm,
Sat, 9am–12.30pm)

Minicom 0345 609 6677

**[www.gov.uk/
civil-legal-advice](http://www.gov.uk/civil-legal-advice)**

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

Department for Work and Pensions (DWP) Disability Living Allowance Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment Helpline 0345 850 3322
Textphone 0345 601 6677
Carer's Allowance Unit 0345 608 4321
Textphone 0345 604 5312
www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK
www.gov.uk

Has comprehensive information about social security benefits and public services.

The Money Advice Service Helpline 0300 500 5000
 (Mon–Fri, 8am–8pm, Sat, 9am–1pm)
Typetalk 18001 0300 500 5000
www.moneyadvice.service.org.uk

Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

Money Advice Scotland Helpline 0141 572 0237
www.moneyadvice.scotland.org.uk

National Debtline (England, Wales and Scotland)

Tricorn House,
 51–53 Hagley Road,
 Edgbaston,
 Birmingham B16 8TP
Tel 0808 808 4000
 (Mon–Fri, 9am–9pm,
 Sat, 9.30am–1pm)

www.nationaldebtline.org

A national helpline for people with debt problems. The service is free, confidential and independent.

**Personal Finance Society –
'Find an Adviser' service
www.findanadviser.org**

Use the website to find qualified financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk

www.unbiased.co.uk

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.



You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on **0808 808 00 00**.

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 photographs 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 our Senior Medical Editor, Professor Graham Jackson, Consultant Haematologist.

With thanks to: Dr Claire Dearden, Consultant Haematologist; Dr Abraham Jacob, Consultant Haematologist; Dr Mike Leach, Consultant Haematologist; Jo Tomlins, Specialist Haematology Nurse. Thanks also to the people affected by cancer who reviewed this edition.

Sources

We've listed a sample of the sources used in the publication below.

If you'd like further information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk**

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www.bcsghguidelines.com/documents/Interim_statement_CLL_guidelines_version6.pdf (accessed 2015).

Eichhorst B, et al. Chronic lymphocytic leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*. 26 (Supplement 5): v78–v84. 2015. www.annonc.oxfordjournals.org/content/26/suppl_5/v78.full.pdf (accessed 2015).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



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

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Signature _____

Date / / _____

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to macmillan.org.uk/donate

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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CANCER SUPPORT**