UNDERSTANDING
ACUTE MYELOID LEUKAEMIA

WE ARE MACMILLAN. CANCER SUPPORT
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About this booklet

This booklet is about a type of leukaemia called acute myeloid leukaemia (AML). We hope it answers some of your questions and helps you deal with some of the feelings you may have.

We can’t advise you about the best treatment for you. This information can only come from your own doctor, who knows your full medical history.

In this booklet, we’ve included comments from people who have had leukaemia, which you may find helpful (some names have been changed). Some are from members of our Online Community (macmillan.org.uk/community), while others are from healthtalkonline.org

This booklet is for adults with AML. Our cancer support specialists can send you different information about AML in children, and general information about children’s cancers.

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

Turn to pages 73–84 for some helpful books, useful addresses and websites, and page 85 to write down any notes or questions for your doctor or nurse. 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.
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 myeloid (AML)
- chronic myeloid (CML)
- acute lymphoblastic (ALL)
- chronic lymphocytic (CLL).

Each type of leukaemia has its own characteristics and treatment. We have separate booklets about these different leukaemias, which we can send you.
The blood

To help you understand AML and its treatment, it’s useful to know a bit about your blood, how it’s made and what it does.

Blood is made up of blood cells, which float in a liquid called plasma. Blood cells are made in the bone marrow. This is a spongy material that’s found in the middle of our bones, particularly in our pelvis and backbone (spine). Normally, millions of new blood cells are made every day to replace old and worn-out blood cells.

All our blood cells are made from cells called stem cells. There are two types of stem cell:

- **lymphoid stem cells**, which make white blood cells called lymphocytes

- **myeloid stem cells**, which make all the other types of blood cells: red blood cells, platelets, and white blood cells called granulocytes.

In the bone marrow, the stem cells divide and grow to form fully developed (mature) red blood cells, platelets and white blood cells.

To begin with, new blood cells are immature. They don’t look like red blood cells, platelets or white blood cells, and they can’t yet do the jobs they’re supposed to do. These immature cells are called blast cells. Usually, blast cells stay in the bone marrow until they have matured into red blood cells, platelets or white blood cells.
These 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 blood to 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.

<table>
<thead>
<tr>
<th>Type of blood cell</th>
<th>Levels found in a healthy person</th>
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<tr>
<td>Red blood cells (Hb)</td>
<td>13–18g/dl (men) 11.5–16.5g/dl (women)</td>
</tr>
<tr>
<td>Platelets</td>
<td>150–400 x 10⁹/l</td>
</tr>
<tr>
<td>White blood cells (WBC)</td>
<td>4.0–11.0 x 10⁹/l</td>
</tr>
<tr>
<td>Neutrophils</td>
<td>2.0–7.5 x 10⁹/l</td>
</tr>
<tr>
<td>Lymphocytes</td>
<td>1.5–4.5 x 10⁹/l</td>
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These figures can vary from hospital to hospital. Your doctor or nurse will be able to tell you what levels they use. They can also vary slightly between people from different ethnic groups.

The figures might look complicated when they’re written down, but in practice they’re used in a straightforward way. For example, you’ll hear doctors or nurses saying things like ‘your haemoglobin is 14’ or ‘your neutrophils are 4’. Most people with AML soon get used to these figures and what they mean. But remember, you can always ask your medical team for further explanation if you need it.
Acute myeloid leukaemia (AML)

AML is a rare type of cancer. It can affect people at any age but is more common in people over 65. Around 2,500 people are diagnosed with AML each year in the UK.

Normally, blood cells are made in the bone marrow in an orderly and controlled way. In people with AML, this process gets out of control and many abnormal leukaemia cells are made. These immature cells aren’t able to develop into normal functioning blood cells.

In AML, too many early myeloid cells are made. In most types of AML, the leukaemia cells are immature white blood cells. In some less common types of AML, too many immature platelets or immature red blood cells are made.

The immature cells fill up the bone marrow, taking up space that’s needed to make normal blood cells. Some leukaemia cells ‘spill over’ into the blood and circulate around the body in the bloodstream. These leukaemia cells don’t mature, so don’t work properly. This leads to an increased risk of infection, as well as symptoms such as anaemia and bruising caused by fewer healthy red blood cells and platelets being made.
Causes and risk factors

The exact causes of AML are unknown and in most cases it’s unclear why leukaemia has developed. Research into possible causes is going on all the time. Like other cancers, AML isn’t infectious and can’t be passed on to other people.

There are a number of factors that may increase a person’s risk of developing AML. Having a particular risk factor doesn’t mean you will definitely get AML, and people without any known risk factors can still develop it. The known risk factors of AML are explained here.

**Exposure to radiation**

People exposed to high levels of radiation, such as nuclear industry accidents, have a higher risk of developing leukaemia than people who have not been exposed. However, very few people in the UK will be exposed to radiation levels high enough to increase their risk.

**Smoking**

Smoking increases the risk of developing AML. It’s thought this may be due to the concentrated levels of benzene in cigarette smoke.

**Exposure to benzene**

In very rare cases, AML may occur after long-term exposure to benzene (and possibly other solvents) used in industry.
Cancer treatments

Rarely, some anti-cancer treatments such as chemotherapy or radiotherapy can cause leukaemia to develop some years later. The risk increases when certain types of chemotherapy drugs are combined with radiotherapy. When leukaemia develops because of previous anti-cancer treatment, this is called secondary leukaemia or treatment-related leukaemia.

Blood disorders

People with certain blood disorders, such as myelodysplasia or myeloproliferative disorders have an increased risk of developing AML.

Genetic disorders

People with certain genetic disorders, including Down’s syndrome and Fanconi’s anaemia, have an increased risk of developing leukaemia.
Symptoms

Most symptoms of AML are due to the effects of the leukaemia cells in the bone marrow, which leave it unable to produce enough normal blood cells.

The main symptoms are:

• looking pale and feeling tired and breathless, which is due to anaemia caused by a lack of red blood cells

• having more infections than usual, because of a lack of healthy white blood cells

• unusual bleeding caused by too few platelets – this may include bruising (bruises may appear without any apparent injury), heavy periods in women, bleeding gums, nosebleeds and blood spots or rashes on the skin (petechiae)

• feeling generally unwell and run down

• having a fever and sweats, which may be due to an infection or the leukaemia itself.

Other less common symptoms may be caused by a build-up of leukaemia cells in a particular area of the body. Your bones might ache, caused by the pressure from a build-up of immature cells in the bone marrow. You might also notice raised, bluish-purple areas under the skin due to leukaemia cells in the skin, or swollen gums caused by leukaemia cells in the gums.
Occasionally, a person has no symptoms and the leukaemia is discovered during a routine blood test.

Symptoms may appear over a few weeks, and people often feel ill quite quickly. If you have any of the symptoms mentioned here, you should have them checked by your doctor – but remember they are common to many illnesses other than leukaemia.

How AML is diagnosed

Usually you will see your family doctor (GP) who will examine you and take a blood test. If the results of the test are abnormal, your GP or a haematologist from the hospital will contact you. A haematologist is a doctor who specialises in treating blood problems. They will arrange for you to be seen quickly at the hospital for further tests and treatment.

At the hospital

Most people with AML are referred to a specialist haematology unit in the hospital. The haematologist will ask about your general health and any previous medical problems you’ve had. They’ll examine you to check if your lymph nodes, spleen or liver are enlarged. You’ll also have more blood samples taken to check the number of different cells in your blood (a full blood count – see page 7) and to look for leukaemia cells.

If the blood test results are abnormal, the haematologist will want to take a sample of your bone marrow. This is an
important test, as it helps the haematologist find out more about the leukaemia and gives them the information they need to plan the best treatment for you.

**Bone marrow sample (biopsy)**

A small sample (biopsy) of bone marrow is taken from the back of your hipbone (pelvis) or occasionally the breast bone (sternum). This is usually done by a doctor or specialist nurse. A doctor who specialises in cells (a pathologist) or a haematologist will look at the sample under a microscope to identify the type of leukaemia. They will also count the number of immature blood cells (blasts) in the sample and carry out other tests on the sample to help confirm the diagnosis.

Before the bone marrow sample is taken, you’ll be given a local anaesthetic injection to numb the area. A thin needle is then passed through the skin into the bone. A small sample of the bone marrow (bone marrow aspirate) is drawn into a syringe to be looked at later under a microscope. The procedure can be done on the ward or in the outpatients department, and takes about 15–20 minutes.

It can be uncomfortable when the marrow is drawn into the syringe, but this should only last for a very short time. You may be offered a short-acting sedative to reduce any pain or discomfort during the test.

Sometimes a small core of marrow is needed (trephine biopsy), and this procedure takes a few minutes longer. A special type of needle, which is a bit thicker than the one used to take an aspirate sample, is passed through the skin and bone into the bone marrow. The doctor will push the biopsy needle in and gently turn it back and forth. When the needle is withdrawn, it will contain a 1–2cm core of bone marrow.
You may feel bruised after having a sample of bone marrow taken, and have an ache for a few days. This can be eased with mild painkillers.

**Other tests**

Your doctor may arrange for you to have other tests to check that your lungs, liver, kidneys and heart are healthy. These can include a chest x-ray, further blood tests, an electrocardiogram (ECG) and an echocardiogram.

**Classifying AML**

AML can be divided (or classified) into different sub-types. This is important as different types of AML are treated in different ways. Your doctors need to know which type you have to help them plan the most appropriate treatment for you.

Your bone marrow sample will be tested to find out which type of AML you have. Different types of AML are associated with particular genetic changes. So the following tests can help doctors decide on the best treatment and predict how well the leukaemia may respond to it:

- **Immunophenotyping** This involves testing the leukaemia cells with antibodies to look for specific proteins on their surface. It helps doctors identify what type of cell has become abnormal.

- **Cytogenetics** This is the study of chromosomes. Almost all the cells in our bodies contain chromosomes,
which are made up of genes. The genes control all the activities of the cell. With leukaemia, there are often changes in the structure of the chromosomes in the leukaemia cells, but not in the normal cells. A cytogenetic test on the bone marrow sample looks for these changes.

- **FISH (fluorescence in situ hybridisation)** This test is used to look for specific changes in the chromosomes that can’t be seen with cytogenetic testing.

- **PCR (polymerase chain reaction)** This is a very sensitive test that can identify chromosome changes that are too small to see under a microscope. PCR testing may also be done after treatment to check how well it has worked (see page 52).

**WHO and FAB classification of AML**

In the UK, doctors usually classify AML according to the World Health Organisation (WHO) system and the French American British (FAB) system.

The WHO system classifies AML according to the type of cell that has become abnormal and whether:

- there are particular chromosomal changes (cytogenetics)

- there are abnormal changes in more than one type of blood cell

- the leukaemia has developed from a previous blood disorder called myelodysplasia

- the leukaemia is related to previous cancer treatment (treatment-related AML) – see page 12.
The WHO system is important as it’s useful for planning treatment and predicting response.

The FAB system looks at the appearance of the leukaemia cells under a microscope (morphology). Each type of AML is named according to the cell type and given a number from M0–M7. Doctors may classify AML with the FAB system while waiting for the results of other tests.

**Treatment overview**

Treatment for AML aims to destroy the leukaemia cells and allow the bone marrow to work normally again. When there is no sign of the leukaemia and the bone marrow is working normally this is called **remission**. For some people with AML, the remission lasts indefinitely and the person is said to be cured.

Chemotherapy (see pages 25–36) is the main treatment used. Research has shown that certain types of chemotherapy drugs can be very effective in treating AML. These drugs are usually given in combination. In some situations, high-dose treatment and a stem cell or bone marrow transplant are used to improve the chances of curing the leukaemia (see pages 38–40).

**Planning your treatment**

Your treatment will be planned by a team of specialists who will meet to discuss and agree on the plan of treatment they feel is best for you.
This multidisciplinary team normally includes:

• one or more **haematologists**

• **specialist nurses**, who give information and support

• **pathologists**, who advise on the type and extent of the leukaemia

• a **clinical oncologist**, who specialises in radiotherapy and chemotherapy.

The team may also include other healthcare staff, such as social workers, dietitians, counsellors and physiotherapists.

The team will plan your treatment by taking into account a number of factors including your general health, and the type of abnormal genes that are present in the leukaemia cells. They will explain the plan to you and answer any questions you have.

**AML clinical trials**

Most people who are under 60 with AML will be asked if they would like to take part in the AML-17 trial. This trial is comparing the effectiveness of the current treatments used for AML and how many courses of treatment are needed. People aged 60 and over may be invited to take part if they are fit enough for intensive chemotherapy, but there are other trials specifically for older patients.

Other trials looking into the use of newer drugs to treat AML are underway. See pages 48–49 for further information about research trials.
Acute promyelocytic leukaemia
People who have a type of AML called acute promyelocytic leukaemia (APL) are usually treated with a drug called ATRA (All Trans-Retinoic Acid). It is a specialised form of vitamin A and is also known as tretinoin (Vesanoid®).

ATRA is given for up to three months alongside chemotherapy treatment. It makes the leukaemia cells mature, and so can reduce leukaemia symptoms very quickly. See page 42 for more information about ATRA.

People with APL can also enter the AML-17 trial. It’s aimed at people younger than 60, however, older people who are fit enough for intensive treatment may be invited to take part.

Fertility

Treatment for AML may cause temporary or permanent infertility. Before treatment starts, your doctor will discuss this with you, along with some of the things that can be done to preserve your fertility. Fertility is discussed on pages 45–46.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will 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.
Advantages and disadvantages of treatment

The possible advantages of treatment vary depending on each individual situation.

Most people under 60 with AML are offered intensive chemotherapy. This involves spending long periods of time in hospital – often several weeks – and can cause side effects. Most of these side effects are temporary and can usually be controlled with medicines. However some, such as effects on fertility, may be permanent. For some people, intensive chemotherapy will cure the leukaemia, but others may not respond to the treatment. This means that some people may experience the difficult side effects of treatment without any of the benefits.

Some people over 60 will have intensive chemotherapy to try to cure the leukaemia. However, not everyone will be fit enough to go through this, and some people may choose not to have it. Instead, they may have lower doses of chemotherapy to control the leukaemia cells in the bone marrow rather than try to get rid of them completely. This treatment can often be given as an outpatient, so less time is spent in hospital. The chances of the disease going into remission are lower with this treatment.

For people that do have treatment, sometimes the leukaemia doesn’t respond well or the treatment controlling it stops being effective. In these situations, you can still be given supportive (palliative) care to help control your symptoms.

Your haematologist is the best person to discuss your situation with. In some hospitals, specialist nurses are available to talk over all the possible benefits and side effects of treatment.
Second opinion

Your multidisciplinary team 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. Have a list of questions ready, so that you can make sure your concerns are covered during the discussion.
Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. It works by disrupting the way leukaemia cells grow and divide. As the drugs circulate in the blood they can reach leukaemia cells wherever they are in the body.

Chemotherapy is usually given as several sessions (cycles) of treatment. Each cycle lasts 5–10 days and is followed by a rest period of 3–4 weeks. The rest period allows your body to recover from the side effects of the treatment. Most people have three or four cycles of chemotherapy. The complete course of treatment can last about six months.

**Induction chemotherapy**

The main aim of treatment for AML is to try to cure it. The first step is to achieve a remission. Remission is when the abnormal, immature cells – or blasts – can no longer be detected in your blood or bone marrow, and normal bone marrow has developed again.

The treatment given is called *induction chemotherapy*. Most people have two cycles of induction chemotherapy. You may be able to go home between treatments if you are well enough.

The possible side effects of the treatment are discussed on pages 32–36.
The most commonly used induction chemotherapy drugs are:

- cytarabine (Ara C, cytosine arabinoside)
- daunorubicin
- mitoxantrone
- etoposide (VP-16, Etopophos®, Vepesid®)
- idarubicin (Zavedos®)
- fludarabine (Fludara®).

You may have some of these drugs if you choose to take part in the AML-17 trial (see page 20). One of the things the trial is trying to find out is whether giving a monoclonal antibody called gemtuzumab (Mylotarg®) with chemotherapy is better than chemotherapy alone. See pages 43–44 for information about gemtuzumab.

If the induction chemotherapy doesn’t destroy all of the leukaemia cells, you’ll be given further cycles of chemotherapy that aims to get the leukaemia into remission.

**Consolidation chemotherapy**

When you are in remission there may still be a small number of abnormal cells in your body, even if doctors can no longer detect any signs of the leukaemia. To reduce the risk of the leukaemia coming back, you’ll be given further cycles of chemotherapy. This is known as **consolidation chemotherapy**.
The most commonly used drugs for consolidation chemotherapy are:

- cytarabine
- etoposide
- amsacrine (Amsidine®)
- mitoxantrone.

**High-dose chemotherapy treatment**

For some people, high-dose chemotherapy with a stem cell or bone marrow transplant may be helpful. The doctors will consider whether chemotherapy alone is likely to cure the leukaemia or whether a transplant is needed. They will take into account the results of the cytogenetics tests (see pages 16–17) and your response to induction chemotherapy.

If there’s a high risk that your leukaemia will come back after chemotherapy, your doctor may suggest that you have high-dose chemotherapy, or chemotherapy with radiotherapy, followed by a transplant. The transplant will be carried out using a donor’s stem cells or bone marrow. See pages 38–40 for more information about transplants.

**Low-dose chemotherapy treatment**

This may be the best option for people who aren’t fit enough to have intensive chemotherapy, and for people who choose not to have intensive treatment. The chemotherapy drugs may be given by drip (infusion), by mouth or by injection under the skin (subcutaneous). They can often be given to you as an outpatient.
You may be asked to take part in a trial called LI-1 (less intensive-1). This trial is looking at the use of new drugs to treat people who aren’t fit enough to have standard chemotherapy. Your doctor or specialist nurse will explain more about the trial.

The doctors will monitor you closely to see how well your leukaemia is responding to the chemotherapy. They will plan what further treatment is necessary depending on how the leukaemia responds.

Our booklet *Understanding chemotherapy* discusses the treatment and its side effects in more detail. We can also send you cancer information sheets about individual drugs and their particular side effects.

How chemotherapy is given

Chemotherapy drugs for AML are usually given into a vein (intravenously). This might be by a drip (intravenous infusion) or by injection. Chemotherapy given into a vein goes directly into the bloodstream where it can be carried to all areas of your body. You will usually have your treatment given through a central line, PICC line or implantable port.

Central lines

Most people having treatment for AML will have a central line. A central line is a long, thin hollow tube that is inserted into a vein in your chest. Hickman® and Groshong® lines are both commonly used types of central line.

A central line can be used to give chemotherapy intravenously and to take blood samples, so you won’t need repeated injections or needles put into your vein while you have one.
It is designed to stay in place for many months, throughout all your chemotherapy treatment sessions.

You’ll be given a general or local anaesthetic before the central line is put in. The doctor or chemotherapy nurse will explain the procedure to you. After the line has been put in place, you may have some mild pain or stiffness for a few days. Your doctor can give you painkillers for this.

The nurses can show you how to care for your line to prevent blockages or infection. Before you go home, make sure you’re confident about looking after it. If you have any problems, contact the staff in the chemotherapy clinic or on the ward for advice.

If you’re not comfortable looking after the line yourself, then you can be referred to a district nurse who can help look after the line while you’re at home.
**PICC lines and implantable ports**
Instead of a central line, a PICC line (peripherally inserted central venous catheter) or an implantable port may be used.

A PICC line is a long, thin tube put into a vein near the crook of your arm. An implantable port is a thin, soft plastic tube that’s put into a vein in the chest and has an opening (port) just under the skin of the chest or arm.

Your doctor or chemotherapy nurse will explain the procedure to you. You’ll be given a local anaesthetic before the line is put in.

*We can send you information about central lines, PICC lines and implantable ports.*
Supportive care

During your chemotherapy, you’ll also need treatment for the symptoms caused by a lack of normal blood cells. The reduction in numbers of blood cells may be due to both the leukaemia itself and the chemotherapy.

This treatment includes having a drip (transfusion) of red blood cells and platelets to replace your normal blood cells. You may also need antibiotics to prevent and treat any infections. These can be given through your central line. We can send you more information about blood and platelet transfusions.

Possible side effects of chemotherapy

Risk of infection
While the chemotherapy drugs are acting on the leukaemia cells in your body, they also reduce the number of normal cells in your blood for a while. When the number of white blood cells is low (neutropenia), you’re more likely to get an infection.

Your blood will be tested regularly during your chemotherapy. You’ll probably be given tablets or other medicines to reduce the risk of developing an infection. If you get an infection, you’ll be given medicines to treat it. Most infections are caused by bacteria already in your own body. These don’t normally cause infection, but when your immunity is low, they’re more likely to cause a problem.

If your temperature goes above 38°C (100.4°F) or you suddenly feel ill, even with a normal temperature, contact your haematology team at the hospital straight away.
While you’re having chemotherapy it’s best to avoid coming into contact with someone who may have an infection. This includes keeping away from large groups of people. You may also be told to be careful about what you eat in order to avoid infection from raw, undercooked or contaminated food. The hospital will tell you how to prepare foods and which foods to avoid.

You may be given injections of a drug called G-CSF (granulocyte-colony stimulating factor). This is a type of protein that stimulates the bone marrow to produce more white blood cells. G-CSF may help reduce the length of time that your white blood cell count is low. The injections are given under the skin (subcutaneously).

**Anaemia (low level of red blood cells)**
If the level of red blood cells in your blood is low, you may become anaemic. This can make you feel tired and breathless. Anaemia can be treated with blood transfusions.

**Bruising and bleeding**
Platelets help the blood to clot. In leukaemia, the number of platelets in your blood is lower than normal, and chemotherapy may temporarily reduce the number even more.

This means that you may develop blood spots or rashes on the skin (petechiae), bruise very easily, have nosebleeds, or bleed more heavily than usual from even minor cuts and grazes.

**If you develop any unexplained bruising or bleeding, such as nosebleeds, blood spots, rashes on the skin or bleeding gums, contact the hospital immediately.**
You may need to have a drip (transfusion) of platelets before your chemotherapy begins, and at times during your treatment, to increase the number of platelets in your blood.

**Tiredness (fatigue)**
Feeling tired is a common side effect of chemotherapy, especially towards the end of treatment and for some weeks after it’s over. It’s important to try to pace yourself and get as much rest as you need. Try to balance this with taking some gentle exercise, such as short walks, which will help. If tiredness is making you feel sleepy, don’t drive or operate machinery.

**Sore mouth**
Your mouth may become sore or dry, or you may notice small ulcers during treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Some people find that sucking on ice may be soothing. 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.

If you don’t feel like eating meals, you can supplement your diet with nutritious drinks or soups. A wide range of drinks is available and you can buy them at most chemists. You can ask your doctor to refer you to a dietitian for advice about diet.

**Feeling sick**
Some chemotherapy drugs can make you feel sick (nausea) or possibly be sick (vomit). Your specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs aren’t helping, as there are several different types you can try.
Losing your hair
Some chemotherapy drugs cause all or most of your hair to fall out, which can be very upsetting. There are lots of ways you can cover up hair loss if you choose to. There are a variety of wigs, hats, turbans, scarves or bandanas available.

Hair usually starts to fall out within a few weeks of starting chemotherapy or, very occasionally, within a few days. You might notice your hair comes out more when you brush, comb or wash it, and you may find hair on your pillow in the morning.

You may lose underarm, body and pubic hair as well. Some chemotherapy drugs also make your eyelashes and eyebrows fall out.

Your hair will usually grow back over a few months after you’ve finished treatment. It will be very fine at first and may be a slightly different colour or texture than before.

‘Losing my hair didn’t bother me as much as I thought. You know, I thought I would have been a lot more upset. But I just accepted the fact that this was going to happen. There was nothing I could do about it and it was going to grow again anyway.’

Norma
You’ll probably have a full head of hair after 3–6 months.

You might find it helpful to follow these helpful tips:

• Cutting hair short before chemotherapy starts can stop the weight of long hair pulling on the scalp, which can make hair fall out earlier.

• Wearing a hairnet, soft cap or turban at night stops your hair becoming tangled and helps to collect loose hair.

• Ask your hairdresser to cut and style your wig for you.

Our booklet Coping with hair loss has more information. There’s also a video on our website about Bengu, who had hair loss following treatment for leukaemia. You can watch it at macmillan.org.uk/hairloss

Chemotherapy affects people in different ways. Some people find they feel quite well at times during their treatment, but most find they become tired and have to take things more slowly. Do as much as you feel like doing and try not to overdo it.

Always tell your doctor or nurse about the side effects you have. They can often prescribe medicines to improve them or change any medicines you’re already taking to more effective ones.

We can send you more detailed information about all the side effects mentioned in this section.
High-dose treatment and stem cell transplants

Having high-dose treatment and a stem cell transplant allows you to have much higher doses of chemotherapy than usual. This may help to improve the chances of curing the leukaemia, or prolonging a remission.

High-dose treatment

This involves having very high doses of chemotherapy and sometimes radiotherapy over a few days. High-dose treatment is usually used after initial chemotherapy treatment (see previous section).

As well as destroying any leukaemia cells, the high-dose treatment also destroys the healthy stem cells in the bone marrow. Stem cells are blood cells in the very earliest stage of development. They develop into the different types of blood cell (see page 7).

Transplants

To help you recover from the high-dose treatment, you’ll be given a drip (infusion) of stem cells after it. The stem cells find their way to the bone marrow where they start producing new blood cells.

The stem cells can either be donated by someone else (allogeneic transplant) or you can use your own (autologous transplant). People with AML are more likely to have an allogeneic transplant than an autologous transplant.
Stem cell transplants may benefit a number of people with AML, but they may not be suitable for everyone. If your specialist thinks high-dose treatment and a stem cell transplant is necessary or an option for you, they will discuss it with you in detail.

**Allogeneic stem cell transplants**
Most people with AML who have high-dose treatment will be given stem cells from a donor. This type of transplant is called an allogeneic stem cell transplant. The donor will usually be a sibling (your brother or sister). Sometimes the donor may not be related but is still a ‘close match’. This is called a matched unrelated donor (MUD) transplant. It’s also sometimes possible to collect donor stem cells from umbilical cord blood. This is blood taken from umbilical cords and stored in a cord blood bank.

Donor stem cells contain healthy immune cells, which attack any leukaemia cells that might still be there.

After you’ve been given the high-dose treatment, the donor stem cells are given to you through a drip (intravenous infusion) using your central line, PICC line or implantable port.

**Autologous stem cell transplant**
A transfusion of your own stem cells can also be done, although this is less commonly used. This is called high-dose treatment with stem cell support, or an autologous stem cell transplant. If you have APL (see page 21) that has come back after treatment, you may have an autologous stem cell transplant.

Before you have high-dose treatment, some of your stem cells will be collected from your blood. You can have this done as an outpatient. The stem cells are then stored and after you’ve had the high-dose treatment, they’re given back to you through a drip using your central line, PICC line or implantable port.
Bone marrow transplants

Bone marrow transplants are similar to stem cell transplants. Instead of taking stem cells from the blood, some of your own or your donor’s bone marrow is collected. The liquid bone marrow contains stem cells that can be given to you in a drip after you’ve had the high-dose treatment.

After a transplant

After any type of transplant, the new stem cells take a few weeks to settle in your bone marrow and produce the blood cells you need. During this time, you’ll have very low immunity. You’ll probably need to stay in hospital and be nursed in a single room for a few weeks. This is done to reduce your risk of infection until your white blood cell count has recovered.

‘My husband had a room to himself, so we took pictures of key family members and blue tacked them to a picture already on the wall. We also stuck all of his cards to the door for him to see.’ Isabel

Stem cell and bone marrow transplants carry some risk, and are always carried out in specialised treatment hospitals. You may have to be treated at a hospital some distance from your home.

Our booklets Understanding donor stem cell (allogeneic) transplants and Understanding high-dose treatment with stem cell support have more detailed information.
Radiotherapy

Radiotherapy treats leukaemia by using high-energy rays to destroy the leukaemia cells, while doing as little harm as possible to normal cells. It’s not often used to treat AML.

However, if you need to have high-dose treatment with a stem cell transplant, you may have a type of radiotherapy called total body irradiation (TBI). This is where radiotherapy is given to the whole body to destroy the bone marrow cells. It’s described in more detail in our booklets about transplants (see previous page).
**ATRA (All Trans-Retinoic Acid)**

ATRA is given alongside chemotherapy to people with a type of AML called acute promyelocytic leukaemia (APL). It works by making the leukaemia cells mature. ATRA is also known as tretinoin (Vesanoid®). It’s available as a capsule that is taken by mouth, with food. It’s based on the natural substance vitamin A and is not a chemotherapy drug. However, it does have some side effects, which can include:

- headaches
- dry skin and mouth
- feeling sick (nausea)
- bone pain
- dry eyes.

**ATRA in pregnancy**

It’s important not to become pregnant or father a child while taking ATRA, as it may harm the developing baby. It’s important to use effective contraception while taking this drug, and for at least a few months afterwards. Your doctor or nurse will discuss this with you.

If you’re already pregnant, ATRA shouldn’t be given if you’re less than 12 weeks pregnant. After 12 weeks, it can be given safely. It’s usually given without chemotherapy, as this is safer for the baby and still effective.
Newer treatments

The following treatments aren’t licensed for use in the UK for AML, and so may not be available unless you’re taking part in a research trial (see pages 48–49). If you take part in a trial, you may be offered one or more of these drugs as part of your treatment.

**Clofarabine (Evoltra®)**

Clofarabine is very similar to another drug commonly used to treat people with AML called fludarabine. It has fewer side effects than fludarabine, so it’s thought it may be more suitable for older people who are less able to have intensive chemotherapy.

Clofarabine is given as a drip (infusion) into a vein and is only available for people with AML as part of research trials. Some people taking part in the AML-17 trial (see page 26) will be given clofarabine. We can send you a cancer information sheet about this drug.

**Gemtuzumab**

Gemtuzumab, also known as Mylotarg®, is given as a drip into a vein.

It’s made up of a combination of a monoclonal antibody and a chemotherapy drug. The monoclonal antibody attaches itself to a protein (CD33) found on the surface of leukaemia cells. In this way, it carries the chemotherapy directly to the leukaemia cells. Because CD33 is found mainly on leukaemia cells,
it’s hoped this drug will target the chemotherapy against leukaemia cells while causing less damage to healthy cells.

Some people taking part in the AML-17 trial will be given gemtuzumab as part of their treatment. We can send you further information about gemtuzumab.

**AC220**

Some people with AML have a change (mutation) in the leukaemia cells called FLT3. This mutation can increase the risk of the leukaemia coming back in the future. AC220 is an experimental new treatment designed to act against cells with this mutation. It’s given by mouth and is being given as part of the LI-1 clinical trial.

**Arsenic trioxide (ATO, Trisenox®)**

Arsenic trioxide is licensed to treat people who have acute promyelocytic leukaemia (APL) that has come back after treatment, or has not gone into remission with treatment. This drug is made from the poison arsenic, but is given at low, safe doses.

Although it’s licensed to treat APL, it’s not yet known how well it might work for other types of AML. Some people taking part in the AML-17 trial will be given arsenic trioxide along with their chemotherapy treatment. It’s given as a drip into a vein and may be given as an outpatient.
Possible long-term effects of treatment

Unfortunately, treatment for AML can sometimes cause long-term effects on the body that may not occur until many years later. Your doctor or nurse will be able to talk to you about your risk of these effects, and offer advice on how to cope with them.

Changes to the way your heart works

Some of the drugs used to treat AML may affect the heart muscle. These drugs are called anthracyclines and include daunorubicin and idarubicin. This doesn’t affect everyone who has these drugs. If it does occur, it’s usually a temporary side effect, but in some people it can lead to long-term heart problems. Your heart function will be carefully monitored during and after treatment, and the drugs you’re given may be altered if any heart problems occur.

Effects on fertility

Some of the drugs used to treat AML can cause temporary or permanent infertility. Your doctor will talk to you about this in more detail before you start your treatment. If you have a partner, you may want them to be with you at this appointment so you can discuss any fears or worries together.

Some drugs have less effect on your fertility than others, and couples have had healthy babies after one partner has been treated for leukaemia. Unfortunately, people who’ve had intensive chemotherapy (with or without radiotherapy), and a stem cell or bone marrow transplant, are likely to be permanently infertile.
It may be possible for men to store sperm before starting treatment, so it can be used later if they want to have a family. Rarely, a woman’s eggs or fertilised eggs (embryos) can be stored before chemotherapy, so that she may have the chance to have a child after treatment. However, as treatment for AML usually needs to start as quickly as possible, there’s not always enough time to store sperm or embryos.

Your doctor knows the details of the treatment you’re having, and is the best person to answer your questions. You can write down any questions you have so that you are clear about your treatment, and the effect it’s likely to have on you, before it starts. Page 85 has space for any notes or questions.

**Coping with infertility**
It can be very difficult to come to terms with the fact that you can no longer have children. Talking about your feelings with your partner, family or a close friend can help to clarify your thoughts and give the people close to you the opportunity to understand how you’re feeling. You might find it easier to talk to someone outside your immediate circle of friends and family. You can talk to your doctor, nurse, a social worker, counsellor, or one of the organisations on pages 73–79.

Our cancer support specialists can give you information about how to contact a counsellor in your area. Call our Macmillan Support Line free on 0808 808 00 00.

**We have booklets for men and women about cancer treatment and fertility, which give more detailed information. We also have a booklet called Relationships, sex and fertility for young people affected by cancer.**
Research – clinical trials

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, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how treatments for leukaemia work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of chemotherapy, radiotherapy or other treatment is better than what is 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. It’s important to bear in mind that some treatments that look promising at first, are often later found not to be as good
as existing treatments or to have side effects that outweigh the benefits.

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.

Our booklet *Understanding cancer research trials (clinical trials)* describes clinical trials in more detail. We can send you a copy.

**Blood and bone marrow samples**

Blood and bone marrow 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 are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them 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, however, be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.

Our website macmillan.org.uk/clinicaltrials also has links to clinical trial databases.
Follow-up

Once your treatment is finished, you’ll have regular check-ups at the hospital. These are likely to continue every 3–6 months for a few years, but will become less frequent as time goes by.

Many people find they get very anxious before their appointments. This is natural and it may help to get support from family, friends or one of the organisations listed on pages 73–79.

If you have any problems, or notice any new symptoms between these times, let your hospital doctor know as soon as possible.

After treatment, you may still have some physical effects to cope with. How quickly things improve will depend on the treatment you’ve had, your age and general health. Some side effects that develop during treatment may take a long time to get better. It’s important to remember that it can take some time for you to fully recover, so try not to expect too much of yourself too soon.

For people whose treatment is over apart from regular check-ups, our booklet Life after cancer treatment gives useful information on how to keep healthy and adjust to life after cancer.
Monitoring minimal residual disease

Sometimes, even though the leukaemia appears to have gone, a small number of leukaemia cells may be left behind after treatment. This is called minimal residual disease (MRD).

It may not be possible to detect any leukaemia cells in your blood or bone marrow samples. However, doctors can now test for genetic changes in the cells that show how successful the treatment has been, and whether it’s possible that the leukaemia may come back (relapse). If there’s a risk of a relapse, your doctors may suggest further treatment, such as high-dose treatment (see pages 38–40).

Your doctors will look for MRD using a test called polymerase chain reaction (PCR) and immunophenotyping. PCR is a very sensitive test that looks for genetic changes in the cells. It can find a single leukaemia cell among a million normal cells (see page 17). Immunophenotyping looks for certain proteins that are made by leukaemia cells (see page 16).

If AML comes back (relapse)

Chemotherapy can cure AML. Sometimes, however, it may relapse, which can be very disappointing and upsetting. If this happens, your specialist will advise you on how best to treat it, and work out the most positive approach for you. Your AML may be resistant to the drugs you had initially, so different drugs or new combinations of different drugs may be needed to give you further remissions.
Your feelings

Most people feel overwhelmed when they are told they have leukaemia, and have many different emotions. These are part of the process you may go through when dealing with your illness. Partners, family members and friends often have similar feelings and may also need support and guidance to help them cope.

Reactions differ from one person to another – there’s no right or wrong way to feel. We describe some of the common emotional effects of cancer here. However, reactions vary and people have different emotions at different times.

Our booklet How are you feeling? discusses the emotions you may have in more detail, and has suggestions for coping with them.

Shock and disbelief

Disbelief is often the immediate reaction when leukaemia is diagnosed. You may feel numb and unable to express any emotion. You may also find that you can only take in a small amount of information, and so you have to keep asking the same questions again and again. This need for repetition is a common reaction to shock. Some people find that their feelings of disbelief make it difficult for them to talk about their illness with family and friends. For others it may be the main topic of conversation as it’s the main thing on their mind.

You may find our booklet Talking about your cancer helpful.
Fear and uncertainty

Leukaemia is a frightening word surrounded by fears and myths. One of the greatest fears people have is whether they will die. Many cancers are curable if found at an early stage. When leukaemia is not curable, current treatments often mean that it can be controlled for some time.

Many people are anxious about whether their treatment will work and have any side effects. It’s best to discuss your treatment and possible outcomes in detail with your doctor. You may find that doctors can’t answer your questions fully, or that their answers sound vague. It’s often impossible for them to say for certain how effective treatment will be. Doctors know roughly how many people may benefit from a certain treatment, but they can’t predict the future for a particular person. Many people find this uncertainty hard to live with, but your fears may be worse than the reality. Finding out about your illness can be reassuring. Discussing what you have found out with your family and friends can also help.

You might find it helpful to talk to other people in your situation. Call our cancer support specialists on 0808 808 00 00 to find out if there’s a support group in your area. Or you can visit our online community at macmillan.org.uk/community to chat any time with people who know what you’re going through. Some people find some form of spiritual support helpful at this time, and you may like to talk to a spiritual or religious adviser.
Denial

Many people cope with their illness by not wanting to know much or talk much about it. If that’s the way you feel, just let your family and friends know that you’d prefer not to talk about your illness, at least for the time being.

Sometimes, however, it’s the other way around. You may find that your family and friends don’t want to talk about your illness. They may appear to ignore the fact that you have leukaemia, perhaps by playing down your worries and symptoms or deliberately changing the subject. If this upsets or hurts you, try telling them. Perhaps start by reassuring them that you know why they’re doing it, but that it will help you if you can talk to them about your illness.

Anger

People often feel very angry about their illness. Anger can also hide other feelings, such as fear or sadness. You may direct your anger at the people closest to you, or at the doctors and nurses caring for you. It’s understandable that you may be very upset by many aspects of your illness, so you don’t need to feel guilty about your angry thoughts or irritable moods. Bear in mind that your family and friends may sometimes think that your anger is directed at them, when it’s really directed at your illness. It may help to tell them this, or perhaps show them this section of the booklet.
Blame and guilt

Sometimes people blame themselves or others for their illness, trying to find reasons to explain why it has happened to them. This may be because we often feel better if we know why something has happened. In most cases it’s impossible to know exactly what has caused the leukaemia. So there’s no reason for you to feel that anyone is to blame.

Resentment

Understandably, you may feel resentful because you have leukaemia while other people are well. These feelings may crop up from time to time during the course of your illness and treatment. It usually helps to discuss these feelings, rather than keeping them to yourself.

Isolation and depression

There may be times when you want to be left alone to work through your thoughts and emotions. This can be hard for your family and friends, who want to share this difficult time with you. It may help them cope if you reassure them that, although you don’t feel like discussing your illness at the moment, you’ll talk to them about it when you’re ready.

Sometimes, depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer, or prescribe an antidepressant drug for you.

We have a video at macmillan.org.uk/depression that you may find helpful.
What you can do

One of the hardest things to cope with can be the feeling that the leukaemia and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You’ll have good and bad days, but if you’re overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you’ve dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding the leukaemia and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.
Who can help?

Many people are available to help you and your family.

**District nurses** work closely with GPs and make regular visits to patients and their families at home if needed.

The **hospital social worker** can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as **Macmillan nurses**. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you’re at a clinic or in hospital.

**Marie Curie nurses** help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There’s also specialist help available to help you cope with the emotional impact of leukaemia and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.
If you are a relative or friend

Some people find it hard to talk about their illness 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. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with leukaemia feeling very 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 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 Hello, and how are you? helpful. It’s based on carers’ experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at macmillan.org.uk/carers
Relationships

The experience of leukaemia may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have an effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who’ve been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse. Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other.

Our booklets Cancer, you and your partner and Sexuality and cancer have more information that may help.

Family and friends

Your family and friends may not always understand if you aren’t feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.

Our booklet Talking about your cancer has more useful tips.
Talking to children

Deciding what to tell your children or grandchildren about your leukaemia 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. There’s also a video on our website that may help, at macmillan.org.uk/talkingtochildren
Financial help and benefits

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

If you’re an employee and unable to work because of illness, you may be able to get **Statutory Sick Pay**. This is paid by your employer for up to 28 weeks of sickness, and if you qualify for it, your employer can’t pay you less.

Before your Statutory Sick Pay ends, check whether you can claim **Employment and Support Allowance**. This benefit gives financial help to people who are unable to work due to illness or disability. It also provides some support to those who can work.

**Disability Living Allowance (DLA)** is for people under 65 who have difficulty walking or looking after themselves (or both). You need to have had these difficulties for at least three months to qualify, and they should be expected to last for the next six months. As part of the Welfare Reform Act 2012, DLA will be replaced by a **Personal Independence Payment** for people of working age from April 2013.

**Attendance Allowance** is for people aged 65 or over who have difficulty looking after themselves. You may qualify if you need help with personal care, such as getting out of bed, having a bath or dressing yourself. You don’t need to have a carer to be eligible, but you must have needed care for at least six months.

If you’re terminally ill, you can apply for DLA or AA under the ‘special rules’. This means your claim will be dealt with quickly and you’ll receive the benefit you applied for at the highest rate.
Help for carers

If you are a carer, you may be entitled to financial help as well. This may include Carer’s Allowance, which is the main state benefit for carers, and Carer’s Credit, which helps carers build up qualifying years for State Pension.

The benefits system can be complicated, so it’s a good idea to talk to an experienced benefits adviser. You can speak to one by calling the Macmillan Support Line on 0808 808 00 00. We’ve just outlined some benefits here, but there may be others available to you.

You can find out more about benefits from Citizens Advice, or by calling the Benefit Enquiry Line on 0800 882 200 (or 0800 220 674 if you live in Northern Ireland). The website gov.uk (nidirect.gov.uk if you live in Northern Ireland) also has useful information.

See our booklet Help with the cost of cancer for more detailed information. Our video at macmillan.org.uk/gettingfinancialhelp may also be useful.

Insurance

After having cancer treatment, it can be more difficult to get certain types of insurance, including life and travel insurance. An independent financial adviser (IFA) can help you assess your financial needs and find the best deal for you. You can find an IFA through one of the organisations listed on pages 76–77.

Our leaflet Getting travel insurance and our booklet Insurance may be helpful.
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, and 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, and 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, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. 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
How we can help you

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
Questions about cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)
www.macmillan.org.uk
Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.
Non-English speaker?
Interpreters are available.

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

Macmillan Support Line
Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. 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, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at macmillan.org.uk/informationcentres
Publications
We provide expert, up-to-date information about different types of cancer, tests and treatments, and about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audiobooks. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at macmillan.org.uk/cancerinformation

Review our information
Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

If you’d like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk

Need out-of-hours support?
You can find a lot of information on our website, macmillan.org.uk
For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to
When you or someone you know has cancer, it can be difficult to talk about how you’re feeling. You can call our cancer support specialists to talk about how you feel and what’s worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you’re going through.
Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person’s life than those who have been affected by it themselves. That’s why we help to bring people with cancer and carers together in their communities and online.

Support groups

You can find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online community

You can also share your experiences, ask questions, get and give support to others in our online community at macmillan.org.uk/community
Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you’ve been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants
Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at macmillan.org.uk/financialsupport

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – macmillan.org.uk/learnzone – which offers a variety of e-learning courses and workshops. There’s also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.
Other useful organisations

Leukaemia support organisations

African Caribbean Leukaemia Trust (ACLT)
Southbridge House, Southbridge Place, Croydon CR0 4HA
Tel 020 8240 4480
Email info@aclt.org
www.aclt.org
Provides practical help, counselling, advice and support to African-Caribbean people with leukaemia and other blood disorders. Hosts bone marrow registration drives throughout the UK and raises awareness of the need for donors from the black community.

Anthony Nolan
2 Heathgate Place, 75–87 Agincourt Road, London NW3 2NU
Tel 0303 303 0303
www.anthonynolan.org.uk
The UK’s largest stem cell and bone marrow register.

British Bone Marrow Registry (BBMR)
Tel 0300 123 23 23
www.nhsbt.nhs.uk/bonemarrow
Holds details of stem cell donors and cord blood donations from England, Scotland, North Wales and Northern Ireland. Also part of an international network, performing searches around the world to find suitable stem cell donors.

Leukaemia CARE
1 Birch Court, Blackpole East, Worcester WR3 8SG
Careline 08088 010 444
Email care@leukaemiacare.org.uk
www.leukaemiacare.org.uk
Provides care and support to people affected by leukaemia, lymphoma or an allied blood disorder. Offers emotional and financial support via its 24-hour helpline. Has a national office for Scotland (see next page).
Understanding acute myeloid leukaemia

**Leukaemia CARE (Scotland)**
Regus Management, Maxim 1, Maxim Office Park, 2 Parklands Way, Eurocentral, Motherwell ML1 4WR
**Tel** 01698 209 073

**Leukaemia and Lymphoma Research**
39–40 Eagle Street, London WC1R 4TH
**Tel** 020 7504 2200 (Mon–Fri, 9am–5pm)
**Email** info@beatingbloodcancers.org.uk
[www.leukaemia-lymphomaresearch.org.uk](http://www.leukaemia-lymphomaresearch.org.uk)

Sponsors research into leukaemia, lymphoma and myeloma. Also provides patient information booklets and leaflets that you can download or order from the website.

**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](http://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
**Tel** 0800 783 3339 (Mon–Fri, 9am–1pm)
**Email** hello@cancerfocusni.org
[www.cancerfocusni.org](http://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 Support Scotland
Calman Cancer Support Centre, 75 Shelley Road, Glasgow G12 0ZE
Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Irish Cancer Society
43–45 Northumberland Road, Dublin 4, Ireland
Tel 1800 200 700 (Mon–Thu, 9am–7pm, Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie
National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses. You can also chat to a nurse online and use the site’s message board.

Maggie’s Centres
1st Floor, One Waterloo Street, Glasgow G2 6AY
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Maggie’s Centres provide information about cancer, benefits advice, and emotional or psychological support.

Tenovus
Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD
Tel 0808 808 1010 (Mon–Sun, 8am–8pm)
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.
Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House, 15 St John’s Business Park, Lutterworth 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

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 (England, Wales, Scotland)
Tel 0800 882 200 (Mon–Fri, 8am–6pm)
Textphone 0800 243 355
Email BEL-CUSTOMER-SERVICES@dwp.gsi.gov.uk
www.gov.uk/benefit-enquiry-line
Provides advice and information for disabled people and carers on the range of benefits available.

Samaritans
Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling FK8 2SA
Tel 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.
Other useful organisations

NI Direct
(Northern Ireland)
Tel 0800 220 674
(Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm)
Textphone 0800 243 787
www.nidirect.gov.uk/money-tax-and-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 the following 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

Directgov
www.gov.uk
Has comprehensive information about social security benefits and public services.

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.
Equipment and advice on living with a disability

British Red Cross
UK Office,  
44 Moorfields,  
London EC2Y 9AL  
Tel 0844 871 11 11  
Email information@redcross.org.uk
www.redcross.org.uk  
Provides a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK  
12 City Forum,  
250 City Road,  
London EC1V 8AF  
Tel 020 7250 3222  
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org  
Provides information on social security benefits and disability rights.

Disabled Living Foundation (DLF)  
380–384 Harrow Road,  
London W9 2HU  
Tel 0845 130 9177  
(Mon–Fri, 10am–4pm)  
Email helpline@dlf.org.uk  
www.dlf.org.uk  
Provides free, impartial advice about all types of disability equipment and mobility products.

Support for young people

CLIC Sargent  
Horatio House, 77–85 Fulham Palace Road, London W6 8JA  
Tel 0300 330 0803  
www.clicsargent.org.uk  
Provides clinical, practical, financial and emotional support to children with cancer.

Teenage Cancer Trust  
3rd Floor, 93 Newman Street, London W1T 3EZ  
Tel 020 7612 0370  
www.teenagecancertrust.org  
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.
Support for older people

Age UK
Tavis House, 1–6 Tavistock Square, London WC1H 9NA
Tel (England and Wales) 0800 169 6565
Tel (Scotland) 0845 125 9732
Tel (Northern Ireland) 0808 808 7575 (Daily, 8am–7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)
Tel (England) 0844 800 4361
Tel (Scotland) 0141 221 5066
Tel (Wales) 0292 009 0087
Email support@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
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland) 028 9043 9843 (Wed–Thu, 10am–12pm and 2–4pm)
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.

You can search for more organisations on our website macmillan.org.uk, or call our support line on 0808 808 00 00.
Further resources

Related Macmillan information

- Cancer treatment and fertility – information for men
- Cancer treatment and fertility – information for women
- Cancer, you and your partner
- Coping with hair loss
- Hello, and how are you?
- Help with the cost of cancer
- How are you feeling?
- Life after cancer treatment
- Lost for words – how to talk to someone with cancer
- Relationships, sex and fertility for young people affected by cancer
- Sexuality and cancer
- Talking about your cancer
- Talking to children when an adult has cancer
- Understanding cancer research trials (clinical trials)
- Understanding chemotherapy
- Understanding donor stem cell (allogeneic) transplants
- Understanding high-dose treatment with stem cell support
- Work and cancer
- Working while caring for someone with cancer

To order a booklet, visit be.macmillan.org.uk or call 0808 808 00 00.
To order a fact sheet, call 0808 808 00 00.
All of our information is also available online at macmillan.org.uk/cancerinformation.
Helpful books

Adult acute myeloid leukaemia (AML)
Leukaemia and Lymphoma Research, 2011, Free
Explains what AML is and describes its causes, symptoms and how it’s diagnosed and treated. Available from leukaemialymphoma research.org.uk

Bone marrow and stem cell transplantation (BMT) – for children and adults
Leukaemia and Lymphoma Research, 2011, Free
Explains why stem cell transplants are needed, the type of transplant (autologous and allogenic), the transplant itself and the risks associated with it. Available from leukaemialymphoma research.org.uk

Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit be.macmillan.org.uk or call 0808 808 00 00.

Macmillan videos

There are many videos on the Macmillan website featuring real-life stories and information from health professionals.

There’s a video about living with leukaemia at macmillan.org.uk/livingwithleukaemia

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed on the next few pages are
considered by nurses and doctors to contain accurate information and are regularly updated.

**Macmillan Cancer Support**
**www.macmillan.org.uk**
Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate, up-to-date information about cancer and its treatments, including:

- all the information from our 150+ booklets and 360+ cancer information sheets
- videos featuring real-life stories from people affected by cancer and information from medical professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form to send your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

Gives comprehensive information on cancer and treatments.

**www.cancer.org (American Cancer Society)**
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

**www.cancerhelp.org.uk (Cancer Research UK)**
Contains patient information on all types of cancer and has a clinical trials database.
www.healthtalkonline.org
www.youthhealthtalk.org
(site for young people)
Both sites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

www.macmillan.org.uk/cancervoices (Macmillan Cancer Voices)
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.

www.nhs.uk (NHS Choices)
NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make decisions about your health.

www.nhsdirect.nhs.uk (NHS Direct Online)
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhs24.com
(NHS 24 in Scotland)

www.nhsdirect.wales.nhs.uk (NHS Direct Wales)

www.n-i.nhs.uk
(Health and Social Care in Northern Ireland)
The official gateway to health and social care services in Northern Ireland.

www.patient.co.uk
(Patient UK)
Provides people in the UK with good-quality 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.

www.riprap.org.uk (Riprap)
Developed especially for teenagers who have a parent with cancer.
Your notes and questions

You could use this page to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.
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.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist. With thanks to: Professor John Gribben, Professor of Haematology; Dr Anne Parker, Consultant Haematologist; Professor Nigel Russell, Consultant Haematologist; Catherine Wardley, Macmillan Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

Sources

We’ve listed a sample of the sources used in this publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

National Institute for Health and Clinical Excellence (NICE).
Oxford University Press.
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.

**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
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

Valid from    Expiry date

Issue no    Security number

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
Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That’s who we are.

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 supporting you online, any time. The fundraisers who make it all possible.

You don’t have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer? Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm) Alternatively, visit macmillan.org.uk