

Understanding

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# Acute Myeloid Leukaemia

Caring for people with cancer

## Understanding

# Acute Myeloid Leukaemia

This booklet has been written to help you understand more about acute myeloid leukaemia (AML). It has been prepared and checked by haematologists, cancer doctors, nurses and patients. The information is an agreed view on this leukaemia, its diagnosis and treatment and key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information you may need.



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Haematologist	Tel:
Medical oncologist	Tel:
Radiation oncologist	Tel:
Medical social worker	Tel:
Hospital day ward	Tel:
Emergency number	Tel:
Treatment	Review dates



If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services in the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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## Introduction

This booklet has been written to help you understand more about acute myeloid leukaemia (AML) in adults. It describes what it is and how it is diagnosed and treated. The booklet is divided into four parts.

- **Part 1** gives an introduction to leukaemia, including symptoms and diagnosis.
- **Part 2** looks at the different treatments used and possible side-effects.
- **Part 3** discusses how you can cope with your feelings and the emotional effects of having leukaemia.
- **Part 4** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. We cannot advise you about which treatment to choose. This decision can only be made by you and your doctors when all your test results are ready.



### Reading this booklet

Remember you do not need to know everything about AML straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline on Freephone 1800 200 700. It is open Monday–Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre if one is located in your hospital. See page 58 for more about Daffodil Centres.



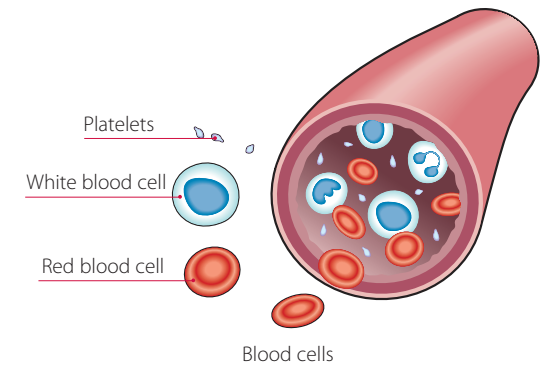
National Cancer Helpline Freephone 1800 200 700

## About AML

### What is bone marrow?

All types of blood cells are made by your bone marrow. This is the soft spongy tissue that fills the centre of your long bones. For example, your hips and breastbone. All blood cells come from a cell known as a stem cell. As these stem cells mature they develop into red blood cells, white blood cells and platelets.

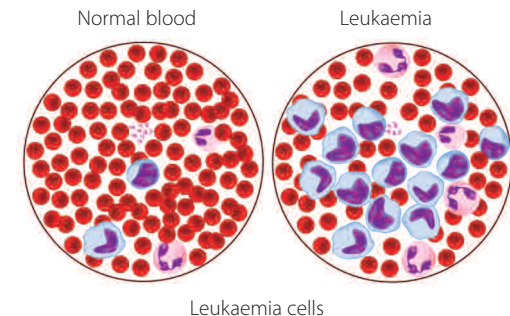
- **Red blood** cells carry oxygen to all the cells in your body.
- **White blood** cells fight infection.
- **Platelets** help to clot your blood.



Once these blood cells are made, they leave your bone marrow and enter your bloodstream. White blood cells have a short life span and only live for a few days. Normally, all the blood cells are made and replaced by your bone marrow when needed.

### What is leukaemia?

Leukaemia is a cancer of your white blood cells. Sometimes it is simply called blood cancer. When the stem cells in your bone marrow do not mature, they cannot make normal blood cells. This leads to a higher risk of infection, bleeding and anaemia.



Leukaemia can be either acute or chronic. This refers to how quickly the leukaemia will grow if left untreated. Acute means the leukaemia develops very quickly over days and weeks. It also needs to be treated right away. Chronic, on the other hand, happens slowly, usually over months or years.

There are different types of leukaemia depending on which type of cell is affected. For example, myeloid or lymphoid.

### Acute myeloid leukaemia

The type of stem cell that matures into the various blood cells is also called a myeloid cell. This is why the leukaemia is called acute myeloid leukaemia. These immature myeloid cells fill up your bone marrow and prevent normal blood cells from growing. It causes many immature cells known as blasts to be made.

For information on chronic myeloid leukaemia, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

### How common is acute myeloid leukaemia?

Leukaemia in general is about the tenth most common cancer in Ireland. AML is a rare disease. About 110 people are diagnosed with it in Ireland each year. It is more common in men than in women.



### To sum up

- All your blood cells are made in your bone marrow.
- Leukaemia is a cancer of your white blood cells.
- When the stem cells in your bone marrow do not mature, they cannot make normal blood cells.
- This can lead to infection, bleeding and anaemia.
- Acute leukaemia develops very quickly over days and weeks.
- Myeloid cells are stem cells that develop into white blood cells, red blood cells and platelets.

## What causes AML?

The exact cause of AML is unknown. Even so, research continues to look for possible causes. But there are certain things called risk factors that can increase your chance of getting the disease. These include:

- **Age:** AML occurs mainly in people over the age of 65.
- **Gender:** It is more common in men than women.
- **Smoking:** Benzene and other solvents in cigarettes can increase your risk.
- **Radiation:** Exposure to high doses of radiation like in nuclear accidents can increase your risk.
- **Exposure to gases and chemicals:** Radon gas, benzene and other chemicals found in industry can increase your risk of AML.
- **Previous cancer treatments:** If you have been treated with chemotherapy or radiotherapy before, it can increase your risk.
- **Genetic disorders:** These include Down syndrome and Fanconi anaemia.
- **Blood disorders:** These include Fanconi anaemia, myelodysplastic syndromes (MDS) and myeloproliferative disorders.

Like other cancers, AML is not infectious and cannot be passed on to other people.

## What are the symptoms of AML?

The symptoms of AML can be vague at first and appear like flu. Sometimes you can have no symptoms and the disease is found during a routine blood test. Symptoms include:

- Tiredness (fatigue)
- Bleeding in your urine or stools
- Unexplained bruising
- Tiny red spots on your skin
- Loss of appetite
- Weight loss
- High temperatures or fevers
- Recurrent infections
- Anaemia
- Shortness of breath
- Aching bones and joints
- Swollen gums

The fever and infections happen due to fewer white blood cells. Shortness of breath and weakness happen because fewer red blood cells cause anaemia. Fewer platelets cause bleeding and bruising. The aching bones and joints are caused by too many abnormal cells in your bone marrow.

## How is AML diagnosed?

Sometimes AML can be suspected during a routine blood test. Your GP may suspect leukaemia after he or she has examined you and noted your symptoms. If a blood test is abnormal, your GP will refer you to a haematologist at the hospital. This is a doctor who specialises in blood and bone marrow diseases. He or she can examine the blood sample in more detail and make the diagnosis of leukaemia.

The haematologist will then get more details of your medical history and arrange further tests. These tests will find out exactly what kind of leukaemia you have. They include:

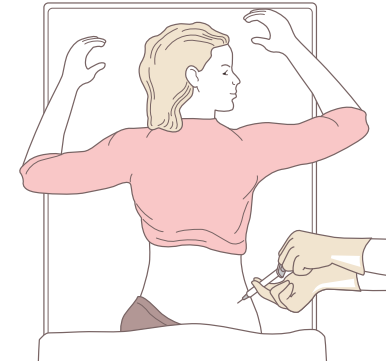
- Physical exam
- Full blood count
- Bone marrow tests
- Chromosome studies (cytogenetics)
- Immunophenotyping
- Blood-clotting tests

**Physical exam:** You will be given a full physical exam. It is important for the doctor to check your general health and also for any signs of disease or infection. This includes checking for anything that seems unusual. He or she will also note any previous illnesses, treatment and your lifestyle. You might have a chest X-ray to check your general health. Bloods may be taken to check how well your liver and kidneys are working too.

**Full blood count:** A full blood count (FBC) will be taken. This finds out the levels of the different types of blood cells in your blood. Your blood will also be examined under a microscope, as leukaemia cells can sometimes be seen and the diagnosis confirmed. This is done by the haematologist.

**Bone marrow tests:** These tests can confirm if you have AML. They involve taking a tiny sample of your bone and bone marrow and looking at them under a microscope. The sample is taken from the

inside of your bone, usually the hipbone. When a sample of bone marrow cells is taken, it is called an aspirate. When a tiny piece of bone or solid marrow is taken, it is a trephine biopsy. Both can be done at the same time.



Bone marrow biopsy

Before the test you will be given a local anaesthetic to numb the area.

After that, a needle is passed through your skin into your bone marrow. A tiny sample of the bone and bone marrow is then taken. You will feel some discomfort during it but it usually takes just 20–30 minutes to do.

A small plaster is put on the area, which might feel tender and sore for a few days afterwards. You can take a mild painkiller for a day or two if needed. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding.

**Chromosomes studies (cytogenetics):** Chromosome tests can find out the number and shape of the chromosomes in your blood cells. Chromosomes are made up of genes that control the activities of cells. The tests can be done on either your blood and/or bone marrow samples. These chromosomes are then compared to normal cells. With AML, there may be some genetic changes in the leukaemia cells. Knowing about these changes will help your doctor to decide on the best treatment for you.

**Immunophenotyping:** Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the leukaemia cells. This test is used to diagnose a subtype of AML. The result can affect what type of treatment you have.

**Blood-clotting tests:** Some types of AML, like acute promyelocytic leukaemia, can cause blood-clotting problems. Your doctor may decide to do a blood test to check how well your blood clots.

## Waiting for results

Usually with AML it is diagnosed quickly so you will not be waiting long for your test results. Your blood and bone marrow samples will be checked by both haematologists and pathologists to find out which type of leukaemia you have. Once all the tests are done, your haematologist will decide what type of treatment you should have.

If you feel anxious before treatment begins, do share your worries with a family member or close friend. You can also call the National Cancer Helpline on 1800 200 700 and speak to one of our specially trained nurses or a patient volunteer. You can also visit a Daffodil Centre.



### To sum up

- The cause of AML is unknown. Certain facts like age, smoking, exposure to radiation, radon gas, chemicals or chemotherapy drugs can increase your risk of getting it. Also, some genetic disorders or blood disorders may be responsible.
- Some symptoms of AML are feeling weak, shortness of breath, fever, infections, bruising or blood in urine or stools.
- AML is diagnosed by a physical exam, blood tests and bone marrow tests.

## What are the types of AML?

There are many types of AML. It can be classified into various subtypes. The most commonly used system is the French-American-British (FAB) one. In this system, there are eight subtypes of AML, classified as M0 to M7. The numbers refer to how the leukaemia cells look under the microscope. It does not refer to how severe the disease is. This system helps your doctor to decide the best treatment for you. Some treatments are only used for certain types of AML.

## FAB classification

M0	acute myeloid leukaemia with little myeloid differentiation
M1	acute myeloid leukaemia without maturation
M2	acute myeloid leukaemia with maturation
M3	acute promyelocytic leukaemia (APL)
M4	acute myelomonocytic leukaemia
M5	acute monocytic/monoblastic leukaemia
M6	acute erythroleukaemia
M7	acute megakaryoblastic leukaemia

## WHO classification

The World Health Organisation (WHO) also classifies AML. It divides it into groups by the type of abnormal myeloid cell and if:

1	If there are genetic changes in the cells
2	If the leukaemia developed from a blood disorder
3	If the leukaemia developed after chemotherapy or radiation
4	If it does not fall into the first three groups
5	If more than one type of blood cell has abnormal changes

Acute promyelocytic leukaemia (APL) is usually treated differently to other forms of AML. It is not discussed in this booklet. Call 1800 200 700 for more information or visit a Daffodil Centre.



### To sum up

- AML is a cancer of the immature myeloid cells.
- There are many types of AML.
- It can be classified by the FAB system or the WHO system.





## Treatment and side-effects

### How is AML treated?

Treatment for AML in Ireland is based on guidelines agreed by specialists and on the results of research worldwide. Some of the following treatments may be used together in AML:

- Chemotherapy
- Supportive care
- Stem cell transplant

**Chemotherapy:** Chemotherapy is the main treatment for AML. It is given to destroy all the leukaemia cells and to make space in your bone marrow for healthy cells to grow again. After chemotherapy, most patients with AML go into remission. This means there are no signs of AML in your blood and bone marrow. Usually chemotherapy greatly decreases the risk of leukaemia coming back. Nowadays, more and more people are being cured of AML. See page 15 for more information on chemotherapy.

»»» Chemotherapy is the main treatment for AML.

**Stem cell transplant:** A stem cell transplant may be carried out after treatment. The transplant will help to create healthy bone marrow that will in turn make healthy stem cells and normal blood cells. This will reduce the chance of AML coming back. See page 29 for more about transplants.

**Supportive care:** This care involves treating your symptoms. For example, anaemia, infections or clotting problems can be treated. If your leukaemia is at an advanced stage, the treatment may only be able to control it. It can ease your symptoms and give you a better quality of life. See page 31 for more details.

**Radiotherapy:** Radiotherapy is rarely used to treat leukaemia cells. But it can be used if AML cells form solid masses in your brain and spinal cord. These are called chloromas and are very rare. It can also prepare your bone marrow before a transplant. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil



Centre. Ask for a free copy of the booklet, *Understanding Radiotherapy*, or download one from [www.cancer.ie](http://www.cancer.ie)

### Where will I be treated?

AML is a rare disease. As a result, it needs to be treated by specialist doctors (haematologists) in a recognised cancer centre. This means that you may have to travel to a different hospital for treatment.

### Who decides on the treatment?

Your doctors and you decide on which treatment is best for you. Before deciding, your doctors will consider such things as:

- Your age
- Your subtype of leukaemia
- Your general health

You may find it reassuring to have a second medical opinion before deciding on treatment. Your doctor can refer you to another specialist for a second opinion if you feel it would help.

### Treatment for over 65s

Treatment can vary depending on your age. It also depends on your physical state. If you are older than 65, you might not tolerate full doses of chemotherapy. You may need smaller doses of the drugs instead. As a result, it may be harder to get a remission and a relapse can happen. Some older patients may also be resistant to a number of drugs. You may be advised by your doctor not to have intensive treatment.

Supportive or palliative care may be offered instead. This is where treatment is given to control your symptoms. Your doctor will talk to you and your family about this option if needed.

### Giving consent for treatment

Before you start treatment, your doctor will explain its aims to you. He or she will tell you about the benefits and any side-effects that you can expect.

You may be asked to sign a consent form saying you give permission for treatment to be given. In some cases you may give verbal permission. No medical treatment will be given without your consent. Ask as many questions as you like so that you understand what is involved. Leukaemia is a disease that can be hard to understand, so do ask for more explanations if you are unsure.

The decision to accept chemotherapy or not can be a hard one for some people. You are also free to choose not to have the treatment if you so wish. But you will need to discuss it in detail with your doctors and nurses first so you fully understand your decision. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

### Chemotherapy

Chemotherapy is the main treatment of AML. It uses drugs to destroy the leukaemia cells and bring about remission. This is when there are no signs of leukaemia in your blood or bone marrow.

Treatment should start as soon as possible. Chemotherapy works by killing off all cells that grow rapidly. Because it cannot tell the difference between cancer cells and normal cells, it may cause side-effects such as hair loss or a sore mouth. But normal cells do recover so most of these side-effects only last a short time. Chemotherapy is given in cycles and allows time for the normal cells to recover.



Chemotherapy drip

## What is remission?

Remission is when there are no signs of AML in your body. There are very few leukaemia cells left in your blood or bone marrow. The number of AML patients who enter remission, stay in remission for years or are cured has greatly increased over the past 25 years. If your remission lasts indefinitely, you are said to be cured.

Sometimes after receiving chemotherapy the leukaemia cells are still present in your bone marrow. This is called refractory disease but can still be treated. There is a chance that AML will come back (relapse). If this happens, treatment may be given with more chemotherapy, other drugs or a stem cell transplant.

## Where do I go for chemotherapy?

Chemotherapy is usually given in hospitals. More than likely you will have to travel to a cancer centre for treatment. When you start treatment, you may need to spend a number of weeks in hospital. If you are well enough and the doctors are satisfied with your blood results, you will be allowed home before the next cycle begins.

## How long will I need chemotherapy?

Chemotherapy is given in cycles. A cycle includes a course and a rest period. Each course or block lasts 5–10 days, followed by a rest period of 3 or 4 weeks. The number of courses or cycles you have will depend on how your leukaemia responds to treatment. It may take four or five courses altogether.

## What are the stages of treatment?

Treatment for AML is divided into two stages: induction and consolidation.

**Induction:** This is the first step in your leukaemia treatment. Induction usually involves two cycles of a combination of chemotherapy drugs. The aim is to get your leukaemia into remission.

For some types of AML other drugs may be given. These drugs are part of your treatment but are not chemotherapy drugs. For example, all-trans retinoic acid. When the induction is over, a bone marrow test will be done to check if the leukaemia has gone into remission.

**Consolidation:** After the first cycle, you are offered more treatment if you are in remission. A further two or three cycles may be given. This is to make sure that any remaining leukaemia cells are destroyed and prevent the leukaemia from coming back. Cells that remain after treatment can be so tiny that they cannot be found in blood or bone marrow tests.

>>> There are two stages of treatment: induction and consolidation.

## How is chemotherapy given?

Before chemotherapy starts, you will be given medication such as allopurinol or rasburicase to help your kidneys get rid of uric acid. Uric acid can build up when a lot of leukaemia cells are killed during chemotherapy. Without this medication, uric acid may cause gout or kidney stones, and can interfere with the flow of urine.

During the treatment cycles, many different chemotherapy drugs are used. There are a few ways to give these drugs:

- By injection into a vein or by a drip infusion
- By injection into the fluid around your spinal cord (intrathecal)
- By mouth in the form of capsules or tablets

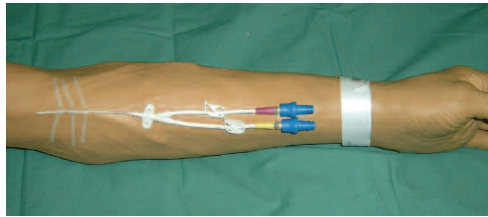
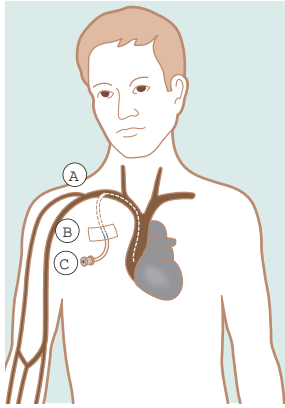
### Drips and central lines

Most chemotherapy for AML is given into a vein. Once in your bloodstream, the chemotherapy drugs can travel around your body. There are also a few ways to give the drugs directly into the vein.

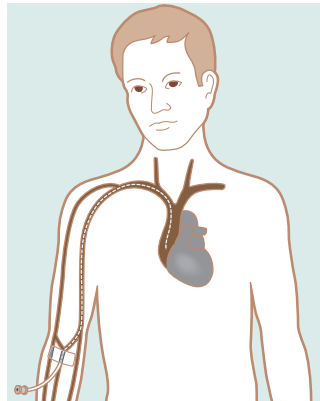
- **Cannula:** This is a fine tube put into a vein in your arm or on the back of your hand.
- **Central line:** This is a thin flexible tube tunnelled through the skin in your chest and put into a large vein near your heart.
- **PICC line** (peripherally inserted central catheter): This is a thin flexible tube put into a vein in your arm and tunnelled through your upper arm and chest until the tube lies in a vein near your heart.

## Central line

- A** The central line is placed in a large vein here
- B** The line is threaded under your skin
- C** The line reaches the surface of your skin here



PICC line: The tube is tunneled through the vein until it is near your heart



Chemotherapy will be given over a long period of time, so it is better and less painful if you have a central line in. It may be called a Hickman or Groshong line. Drugs, antibiotics, and blood and platelet transfusions can go directly into your bloodstream through the central line. Blood samples can easily be taken from the line too. This avoids you having repeated blood tests using a vein in your arm. The line can stay in for months if it does not become infected or blocked.

**>>> Most chemotherapy for AML is given into a vein.**

### Caring for central lines

It is important to take good care of your central or PICC line. You may experience some problems, such as:

- Blockage
- Infection
- Tube falling out

**Blockage:** A blockage can be due to blood clotting where the tube enters your vein, like in a wound. The line may need to be flushed with the drug heparin once a week to prevent clotting.

**Infection:** An infection can cause redness, pain or discharge around the tube, or swelling of one arm. Let the hospital know at once as you may need antibiotics.

**Tube falling out:** In general it is hard for a line to fall out, as your skin will grow around it. If it does fall out, do not panic. Contact the hospital straight away. Before you go home, your nurse will show you how to care for your line and help prevent these complications. You will be told who to contact if you have problems during the day or at night. Keep all the parts of the line, if it falls out, and bring them to the hospital, as it may be repaired.

### Injection into spinal cord

Chemotherapy is sometimes given into the fluid around your brain and spinal cord. This is done using a lumbar puncture. For this treatment, you lie on your side and hold onto your knees. Before placing a small needle into the spine in your lower back, your doctor will give you an injection to numb the area. A small amount of spinal fluid will then be drawn off and the drug injected into your spine. This allows the drug to travel to your brain.

When chemotherapy is given into the spinal cord, you may get some headaches and dizziness or blurred vision. Tell your doctor or nurse if you get any of these symptoms. You must lie flat for 1–4 hours after the lumbar puncture to prevent these symptoms.

### By mouth

Many drugs given for AML can be taken in tablet form. These may include steroids, antibiotics and chemotherapy. It can help if you eat or drink something before taking certain tablets. Your doctor or nurse will advise you about this. If you would like more details on how chemotherapy is given, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet *Understanding Chemotherapy* or download one from [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

## What drugs are used?

There is a range of drugs used in the treatment of AML. It all depends on your subtype of AML, your age and general health. Your doctor will decide which drugs are best for you. Some drugs can be given alone or in combination. Drugs include cytarabine, daunorubicin, fludarabine, idarubicin, cyclophosphamide, mitoxantrone, etoposide, clofarabine.

ATRA is a drug used for acute promyelocytic leukaemia, as is arsenic trioxide. It may be given in clinical trials. See page 30 for more details.

Do ask your doctor or nurse for more information about these drugs.

See the Irish Cancer Society website for more information:

[www.cancer.ie/cancer-information/treatments/chemotherapy/drugs](http://www.cancer.ie/cancer-information/treatments/chemotherapy/drugs)

## What are the side-effects?

The side-effects of chemotherapy vary from person to person and depend on the type of drugs used. Your doctors and nurses will let you know what kind of side-effects to expect. Always tell them if the side-effects of treatment are making you unwell.

Chemotherapy usually affects the parts of your body where normal cells divide and grow quickly. This includes your bone marrow, mouth, digestive system, skin and hair. The side-effects may include:

- Bone marrow effects: anaemia, bleeding, infection
- Tiredness and fatigue
- Nausea and vomiting
- Loss of appetite
- Mouth or taste problems
- Diarrhoea
- Constipation
- Hair loss
- Skin and nail changes
- Changes in hearing
- Nerve changes
- Changes in nervous system: anxiety, headaches, dizziness
- Bladder or kidney changes
- Infertility
- Aching joints

**Bone marrow side-effects:** Because AML is a disease of the bone marrow, chemotherapy treatment is aimed at this area. Side-effects are likely to occur 10–14 days after chemotherapy. Your blood count will be checked regularly to help watch your condition. After each treatment, your blood count will return to normal. But sometimes this may take longer than expected. As a result, your next cycle of treatment may be delayed to allow your bone marrow to recover.

**Anaemia:** If the number of red blood cells in your blood is low, you may become tired and weak. Because the amount of oxygen being carried around your body is less, you may also become breathless. These are all symptoms of anaemia. You might also feel dizzy and light-headed and your muscles and joints can ache. Once the chemotherapy is over, the tiredness will ease off gradually. But you may still feel tired for a year or more afterwards. A blood transfusion can be given if your red blood cells are low. This will help you to feel more energetic and less breathless.

**Bleeding and bruising:** Bruising is caused by a reduced number or platelets. This is called thrombocytopenia. Platelets help to make your blood clot and stop bleeding when you hurt yourself. You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes. Bleeding may develop under your skin, usually as blood spots on your legs, feet, trunk and arms. This is known as petechiae. Bleeding gums is also a common sign of low platelets. In women, periods can be heavier and longer than usual during the first few cycles. Do let your nurse or doctor know at once if you have any bleeding or bruising. You may need a platelet transfusion to help reduce it. Also, use a soft toothbrush such as a child's toothbrush and an electric razor when shaving.

**Infection:** Infection is caused by having fewer white blood cells. This is also called neutropenia and means that your body's immune system cannot fight infections. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you ill. If your temperature goes above 37.5°C (99.5°F) at home, or if you suddenly feel shivery or unwell, contact your doctor or the hospital immediately. You may need to be admitted to hospital to receive antibiotics into a vein. Do check with your nurse about how to take your temperature or when you should contact them if you have a high temperature.

»»» If you feel shivery or unwell, or have a high temperature of 37.5°C or higher, contact the hospital straight away.

You will be more at risk of picking up infections. Avoid crowds and close contact, such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the toilet. Be careful about what you eat given the risk of infection from raw, undercooked or contaminated food. Talk to your doctor or nurse, who will give you more advice.

To reduce the risk of infection growth factors may be used. These drugs encourage the growth of white blood cells. They are helpful if the number of white cells is low after chemotherapy. The two most commonly used ones are called G-CSF and GM-CSF.



### Tips & Hints – anaemia, infection, bleeding



- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid close contact, such as hugging or kissing, with people who have colds, flu's and other infections, especially chickenpox, shingles or measles.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Take care to avoid injury. Use an electric razor when shaving. Wear thick rubber gloves when gardening to protect yourself from cuts.
- Contact the hospital immediately if you have a temperature of 37.5°C (99.5°F) or higher at home, shortness of breath or bleeding that cannot be stopped.

**Tiredness and fatigue:** Many people feel tired during chemotherapy, especially the later months of treatment. Ongoing tiredness is called fatigue. It is a common symptom of cancer as well as due to chemotherapy. It is often described as an overwhelming tiredness not relieved by rest. You may also find it hard to concentrate or make decisions. It can also be caused by the worry of having leukaemia and the added stress of treatment. Overall, you can feel very frustrated if you feel tired all the time.

Even so, there are ways to improve it. For many people, treatment can help to relieve symptoms, allowing you to get back to your normal

routine. If you are feeling very worried and find it hard to sleep at night, tell your doctor or nurse, who may be able to help. Also, talk to your family or close friends about your concerns. The tiredness will ease off gradually once the chemotherapy is over. A booklet on fatigue is available called *Coping with Fatigue*. If you would like more information or a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. See page 34 for more about fatigue.

**Nausea and vomiting:** Some chemotherapy drugs might make you feel sick (nausea) or vomit. You will be given anti-sickness drugs along with your chemotherapy to help you. These drugs are called anti-emetics. Your doctor will also prescribe injections or tablets for you to take regularly. If you feel sick, flat fizzy drinks may help or nibbling on dry biscuits and toast.

**Loss of appetite:** Some chemotherapy drugs can reduce your appetite for a while. If you do not feel like eating during treatment, you could replace some meals with special food supplements. Do get early advice from a dietitian. A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting your appetite. For a free copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

**Mouth or taste problems:** Some drugs can cause a dry, sore mouth that can lead to mouth ulcers. This can happen about 5 to 10 days after the drugs are given. It will gradually clear up but your doctor can prescribe mouthwashes to help in the meantime. If your white cell count is low, the ulcers may become infected. Cleaning your teeth regularly and gently with a soft toothbrush will help to keep your mouth clean. There are special mouthwashes that you can use too. If your mouth is very sore, there are gels, creams or pastes available to reduce the soreness. Do ask your nurse for advice.

Your sense of taste may also change during treatment. Food may taste more salty, bitter or metallic. Normal taste will come back once the treatment is over. It is worth trying various types of food and seeing which ones taste better. Call the National Cancer Helpline on 1800 200 700 for a copy of the booklet *Diet and Cancer* or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)



**Diarrhoea:** Some chemotherapy drugs can affect the lining of your gut and may cause diarrhoea for a few days. Passing watery bowel motions more than three times a day is known as diarrhoea. You may also have cramping and/or abdominal pain. If this happens, drink lots of clear fluids (1½ to 2 litres a day) to replace the fluid you are losing. You must tell your doctor or nurse if you have diarrhoea for more than 24 hours. There are medicines that can stop this side-effect of treatment. Again, it might help to talk to a dietitian who can offer advice and support at this time.

>>> Drink 1½ to 2 litres of fluid a day if you have diarrhoea or constipation.

**Constipation:** Chemotherapy may slow down your bowels and your regular bowel habit may change. You may have difficulty passing a bowel motion. This is known as constipation. If this happens, let your doctor or nurse know as soon as possible. You may need to drink more clear fluids and take a laxative. In some cases, your doctor may have to adjust your treatment.

**Hair loss:** Chemotherapy can cause temporary hair loss. This usually happens about 3 weeks after the start of treatment. You may lose all your body hair, including your eyelashes and eyebrows. But this can vary from person to person. You may experience tingling or sensitivity of your scalp just before your hair starts to fall out. This may last a day or so. But your hair will grow back once you have stopped treatment.

It is natural to feel upset, angry or embarrassed at the thought of losing your hair. Don't be afraid to talk to your nurse or medical social worker about your feelings. They will help you to find ways to cope with your hair loss. You can get a wig or hairpiece when this happens, or you may prefer to wear a hat, bandana



or scarf. Talk to your medical social worker or nurse if you would like a wig or hairpiece. Arrange this before your hair starts to fall out, so that you can get a good colour match to your own hair.

In some cases, it is possible to get financial assistance towards the cost of a wig or hairpiece. Ask your medical social worker or nurse for more information. If you have a medical card, you are entitled to 1-2 free or subsidised new hairpieces every year. If you have private health insurance you are also covered for the cost of a hairpiece. For more information, especially on wig suppliers, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the free factsheet called *Hair Loss and Cancer Treatment*. You can also download a copy from [www.cancer.ie](http://www.cancer.ie)

### >>> Tips & Hints – hair care



- If the drugs are likely to cause hair loss, it can help to have your hair cut short before treatment. The weight of long hair pulls on your scalp and may make your hair fall out faster.
- Use gentle hair products.
- Do not perm your hair during chemotherapy, or for 3 months afterwards.
- If you colour your hair, use a mild vegetable-based colourant. Ask your chemotherapy nurse or hairdresser for advice.
- Try not to brush or comb your hair too roughly – use a soft or baby brush.
- Avoid using hair dryers, curling tongs and curlers. Pat your hair gently after washing it.
- Use a gentle, unperfumed moisturiser on your scalp if it becomes dry, flaky or itchy. Natural oils such as almond oil or olive oil are suitable.
- If you are likely to lose your hair, ask your doctor or nurse about wigs early on, so that the wig will be as close a match to your normal hair.
- You may like to wear a hat, bandana or scarf when you go out. There are also turbans which can be worn in the house.

**Skin and nail changes:** Some drugs can affect your skin. It may become dry, itchy, slightly discoloured or darker. It may be made worse by swimming, especially if there is chlorine in the water. Report any rashes to your doctor, who can prescribe something to help. In general, your skin will improve once treatment is over.

The drugs may also make your skin more sensitive to sunlight, during and after treatment. It is best to stay out of the sun during the hottest part of the day. This is normally between 11am and 3pm. You can protect your skin from the sun by wearing a hat, covering your skin with loose clothing, and using a sun cream with a high protection factor.

Your nails may grow more slowly and white lines appear. Sometimes the shape or colour of your nails may change too. They might become darker or paler. Your nails may also become more brittle and flaky. False nails or nail varnish can disguise white lines. These nail changes usually fade once treatment is over.

**Changes in hearing:** Some drugs make you unable to hear high-pitched sounds. They can also cause a continuous sound in your ears called tinnitus. These buzzing or ringing sounds can be very distressing. Let your doctor know if there is any change in your hearing.

**Numbness or tingling in hands and feet:** Some drugs used to treat cancer can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. You may have trouble picking up small objects or buttoning up a shirt or jacket. If it becomes severe, it can damage your nerves permanently. This side-effect is almost always temporary and goes away after treatment stops. But it may take several months for the numbness to fully go away. Tell your doctor or nurse if this happens, as some changes may need to be made to your treatment.

**Changes in nervous system:** Some drugs can cause headaches and anxiety or make you feel restless and dizzy. Or you might find it hard to sleep or concentrate or have short-term memory loss. If you have any of these side-effects, let your doctor or nurse know, as medication can often ease them. It can help to talk to a close relative or friend about your feelings too. If this is not possible, ask your doctor to refer you to a counsellor or a psychologist.

**Bladder or kidney changes:** Some drugs may irritate your bladder and cause problems with your kidneys. For this reason, you must drink plenty of fluids. If you notice any pain, discomfort or blood on

passing urine, tell your doctor at once. You may receive a red-coloured drug, called doxorubicin, which can turn urine red for 1–2 days after receiving it. This is harmless and nothing to worry about.

**Infertility:** You may not be able to conceive or father a child due to chemotherapy drugs. For this reason, men should consider sperm banking and women discuss their options with their doctor. This should be done before treatment starts. However, do use contraception during treatment as the drugs may harm your baby if you become pregnant. See page 36 for more details on infertility.

**Aching joints:** You may get joint pains if you are given growth factors such as G-CSF or GM-CSF. These drugs can encourage the growth of white blood cells within your bone marrow. This may cause joint pains. Talk to your doctor or nurse if you experience this kind of pain.

### Other side-effects

Sometimes with leukaemia it can be very hard to tell if your symptoms are part of your illness or a side-effect of treatment. These symptoms can vary from time to time and be mild or severe. If you have symptoms not listed above, do let your doctor or nurse know. There are ways to help make your life easier and more comfortable.

For more information, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet *Understanding Chemotherapy* or download it from [www.cancer.ie](http://www.cancer.ie)



### To sum up

- Chemotherapy is a treatment using drugs to kill leukaemia cells.
- The drugs can be given directly into a vein as an injection or through an infusion (drip) or in tablet form.
- The side-effects vary depending on the drugs used.
- Most side-effects are well controlled with medication.



## Stem cell transplant

If your leukaemia returns (relapses) or the first treatment fails, you may be suitable for a stem cell transplant. The aim of the transplant is to create healthy bone marrow that will make healthy stem cells and in turn normal blood cells. Stem cells are immature cells that develop into various blood cells – red blood cells, white blood cells and platelets.

Stem cell transplants may not be suitable for everyone. Depending on your age, general health, donor availability, type of AML and risk of recurrence, your doctor may decide to opt for a transplant. He or she will first discuss it with you in detail. The type of transplant usually given is an allogeneic transplant.

### Allogeneic transplant

In an allogeneic transplant, healthy stem cells are taken from another person whose tissue DNA is the same or almost the same type as yours. This means the donor is HLA compatible with you. The donor can be your brother or sister, or even a person not related to you. Your own bone marrow is first destroyed with high doses of chemotherapy with or without radiotherapy. The healthy stem cells from the donor are then given to you through a central line. They will replace your bone marrow that was destroyed and help you recover from the high dose treatment.

There are various stages when having a stem cell transplant. Your doctor and nurse will explain each stage as it happens. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



### To sum up

- A stem cell transplant can be given if the leukaemia returns or if the first treatment has failed.
- By taking stem cells from a donor and giving them to you after the high dose treatment, your bone marrow can be rescued and allowed to make new blood cells.





## Research – what is a clinical trial?



Research into new ways of treating leukaemia goes on all the time. Some studies look at new anti-cancer treatments, while others look at new ways to stop or slow the growth of leukaemia cells. The best times to give chemotherapy, biological therapy or a stem cell transplant are also being studied. Doctors are also looking at the use of high-dose treatments in groups of patients who, in the past, were not thought to be suitable for this type of treatment.

If a drug or treatment looks of benefit, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and which leukaemias can be treated. If early studies suggest that a new drug may be both safe and effective, more trials are carried out. These aim to:

- Reduce the number of patients who relapse.
- Improve how patients with relapsed AML are managed.
- Lessen the side-effects of treatment.

### Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about AML. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use. You will also be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your blood or bone marrow cells. For a factsheet called *Cancer and Clinical Trials*, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## Supportive care

During your treatment, supportive care will also be given. This means that any symptoms of AML or the effects of chemotherapy will be treated. For example, if you are anaemic, you may get a blood transfusion. Or if you have any bleeding problems, you may get a transfusion of platelets. If you develop any serious infections, you may need antibiotics quickly. If you have any other symptom it can be relieved as well. If your AML is at an advanced stage there are many things that can be done to make you comfortable.

Throughout your treatment, you will have blood tests regularly to check your blood count. Bone marrow tests will also be done regularly to check for leukaemia cells. Your doctors will let you know all these results. Depending on the results of these tests, your doctor may need to make changes to your treatment.

## What if the leukaemia relapses?

Sometimes the leukaemia cells return after being treated. This is called a relapse. The leukaemia cells can be found in either your blood, bone marrow, brain or spinal fluid. A relapse can happen even after you respond well to treatment. Your doctor can decide if you have a low, moderate or high risk of relapsing. This is based on your white cell count at diagnosis and your response to your first treatment.

You can relapse after:

- Being in remission
- While still receiving treatment or soon after finishing treatment
- Months or years after your treatment

If a relapse happens, your doctor will advise you about more treatment.

**While on treatment:** The reason you relapse while on treatment may be because the disease has become resistant to the drugs being used. This is known as refractory disease. In this case, other drugs that work well in leukaemia will be given to you. A stem cell transplant might also be considered as a treatment for some patients.

**After treatment:** It is not fully known why patients relapse after finishing treatment. A relapse can happen even after a good response to treatment. If you do relapse, you might receive the same chemotherapy drugs you were first treated with, as you responded well to them. More treatment may or may not include a stem cell transplant.

Your doctor might invite you to take part in a clinical trial if your leukaemia relapses or is refractory. See page 30 for more details.

## What follow-up do I need?

Once treatment is over and you are in remission, you will still need to visit your doctor at the outpatient clinic regularly. These check-ups are called follow-up. They will include having regular blood tests. You might have other tests as well depending on your hospital.

At first, these visits will be quite often but will become less frequent the longer you are well and free from disease. During the first year you may be checked every 1–2 months. After 5 years you will have yearly check-ups. Sometimes you may need to go to hospital if you get an infection, as your immune system takes time to recover.

If you are between check-ups and you have a symptom or problem that worries you, let your doctor know. Make an appointment to see him or her as soon as possible.

### Getting back to normal

There is life after treatment and no doubt you will be keen for things to get back to normal as quickly as possible.

**Tiredness:** It can take at least a year for you to get over the effects of treatment. You may still feel tired and lacking in energy. You may not feel ready to lead as active a life as you did before treatment. It is better not to fight these feelings but to allow your body the time it needs to recover.

**Work and activities:** You may have problems to solve or decisions to make which you deferred because of treatment. These issues may

include changing jobs, getting back to work or study and if you can have children or not. If you stopped working during treatment, you can start to go back to your job. But you might want to take it slowly at first by working part-time or reduced hours. You can also resume other activities such as sport, hobbies and other pastimes.

**Taking care of your health:** Watch out for any signs of infection or other problems. It is best to get the flu vaccine each winter and the pneumonia vaccine every 5 years. Also, take good care of your mouth, teeth or dentures, as they can be a source of infection. If you develop any bowel problems, contact your doctor as soon as possible. Eat a healthy diet and drink alcohol in moderation.

**Holidays and insurance:** You may decide to go on a holiday once your treatment is over. Check with your doctor first about any special precautions to take or vaccinations you may need. It is best to have travel insurance too. Some insurance companies now provide cover for cancer patients. Contact the National Cancer Helpline on 1800 200 700 for more details.

**Smoking:** It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example, it can reduce how well chemotherapy or radiotherapy works. It can also make their side-effects worse. Sometimes it may cause rarer side-effects such as breathing and heart problems. This is because radiotherapy can make body organs like the lungs more sensitive to tobacco smoke.

Like many others, you may find giving up smoking hard. But with the right information and support you can do it. If you would like advice or support on quitting, call the National Smokers' Quitline on CallSave 1850 201 203. It is open Monday to Saturday from 8am to 10pm.

If you would like further personal support locally, the helpline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see [www.quit.ie](http://www.quit.ie). Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.



## How can I cope with fatigue?

Fatigue is a common symptom of leukaemia and is described as an overwhelming tiredness. Often it is not relieved by rest. You may find it hard to concentrate or make decisions. Fatigue may also be caused by anxiety when a diagnosis of cancer is made and the added stress caused by treatment. It can also be a side-effect of treatment or due to anaemia, or having to travel long distances for treatment.



### Tips & Hints – fatigue



- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing, etc.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Use relaxation techniques to get to sleep like gentle exercise, relaxation CDs, etc.

National Cancer Helpline Freefone 1800 200 700

## Other ways that can help

- **Side-effects to expect:** For many patients treatment may help by relieving symptoms such as fever and feeling unwell, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.
- **Sleep:** If you are feeling worried and find it hard to sleep at night tell your doctor or nurse. They may be able to help. Try talking to your close family or friends about your concerns too. If you find this hard, ask to see a counsellor. He or she will help you to find ways to cope.
- **Physical exercise:** If your illness allows you to take part in physical exercise, try to do some regularly. For example, 30 minutes of exercise 2–3 times a week might be a realistic goal and will boost your morale when you achieve it.
- **Losing weight:** You may notice that you have lost weight. This may be due to the leukaemia or the treatment you are getting. Sometimes when you are feeling weak and tired you may lose interest in your food. Ask for help in preparing your meals. It can help to eat your favourite foods too. Take plenty of clear fluids such as water and fruit juice.
- **Ask for help:** Get others to help you around the house, with travelling to hospital, with the children or with shopping.
- **Working:** Whether you work or not during treatment depends on the kind of work you do and how you are feeling. That said, the treatment will be intensive so it is best not to work full-time for about a year.
- **Studying:** If you are in full-time education, think about putting your studies on hold until your treatment is over. Use the extra free time to do something that you especially enjoy.

A useful booklet called *Coping with Fatigue* is available free of charge. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## Will treatment affect my sex life?

It is unlikely that treatment will affect your sex life. Having sex often depends on how you feel. So coming to terms with the fact that you have leukaemia can take a while. Your emotions are likely to be turned upside down. You may find it hard to relax when you have a lot on your mind too. You may also be feeling tired from the leukaemia itself, the effects of treatment or travelling to the hospital. As a result you may lose interest in sex. This is a normal way to feel at this time.

One common fear is that leukaemia can be passed on to your partner during sex. But this is not true. It is perfectly safe for you to resume having sex. There is no set time for this to happen. It varies from person to person and depends on how you feel. It is likely that once your energy levels return to normal so too will your sex drive (libido). If your platelets or white cell counts are low, do ask your nurse for advice. If you have a stem cell transplant, you will need special advice. If you have a supportive partner, you may find that talking about your feelings will help ease your anxiety.

Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If not having sex becomes a problem for you, do seek help. Do not feel guilty or embarrassed to talk to your doctor or nurse about what is troubling you. He or she may refer you for specialist counselling if you think that would help.

### Pregnancy

It can sometimes happen that you are pregnant when diagnosed with AML. If you are pregnant, your haematologist will get the advice of your obstetrician as soon as possible. They will decide if and when it is safe for you to start treatment. You can also discuss what options are open to you at this time.

## Will treatment affect my fertility?

Many couples go on to have healthy babies after one or other partner has been treated for leukaemia. However, some treatments can cause infertility. This infertility may be temporary or permanent. Before you

start treatment your doctor will talk to you about this in more detail. If you have a partner, you may find it helpful to see the doctor together so that you can both talk about your fears and worries.

### For women

**Chemotherapy:** Some chemotherapy drugs can affect your ovaries. This means that your periods may stop during or for a few months after treatment. You may get hot flushes, a dry vagina or other symptoms of the menopause. If it is temporary, your periods may return to normal after a few months. This happens in about a third of women who have short-term infertility brought on by chemotherapy. In general the younger you are, the more likely your regular periods will return and you can still have children.

**Early menopause:** The nearer you are to the menopause the more likely chemotherapy will stop your periods permanently. Most of the effects of the menopause can be prevented or reversed by replacing the hormones your ovaries normally make. But it will not be possible to restore your fertility.

Your doctor may prescribe hormone replacement therapy (HRT) for you. This treatment can be given in different ways. For example, in tablet form, through a device put under your skin or by a slow-release patch worn on your arm or leg. Often a simple lubricant such as KY gel, which can be bought from most pharmacies, can help to ease any discomfort during sex. Talk to your doctor if this is an ongoing problem for you.

**Contraception:** As periods usually stop during treatment you may not know if you are fertile or not. If you are having sex, you must use a reliable method of contraception throughout your treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment.

**Getting pregnant:** Many doctors believe it is better not to get pregnant for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by then the likelihood of the disease coming back is much less. When you have finished treatment there are blood tests that can show if you are fertile or not. Talk to your doctor or nurse if you need more information. They will answer your questions in more detail.

**Freezing your eggs:** If there is a risk that your chemotherapy will cause long-term infertility, you might have the option of freezing your eggs (oocytes) before treatment begins. That said, the process may take several weeks, if not months, so it may not be a realistic option for you. More than likely you will have to start chemotherapy straight away.

The HARI Unit at the National Fertility Centre in the Rotunda Hospital in Dublin provides a service where eggs can be frozen. You must be 18 years or over, be able to give informed consent, and be referred to the HARI Unit by your medical oncologist or haematologist. For this reason, you should discuss this issue with your doctor before your treatment begins.

It is important to remember that you may not be suitable for it. The type of leukaemia, your age, medical history and viral status can affect your suitability. Your doctor will arrange for you to have a blood test to check for any viruses. For example, hepatitis B, hepatitis C, HIV or CMV. This test needs to be repeated 6 months later.

You will also need counselling as part of the service, as it will be a stressful time for you. The procedure itself is not simple. It is still experimental and not without risk. The time factor too is important. Your ovaries will need to be stimulated to make enough eggs before they can be stored. From the moment you are seen by a doctor at the HARI Unit and considered suitable for egg freezing, your treatment will start with your first menstrual period. It is expected that eggs will be collected within 3 weeks. But in many cases it can actually take several weeks. Your own health will take priority over egg freezing. And if this time interval is not available to you, due to the urgency of chemotherapy, egg freezing cannot be pursued.

If the eggs are successfully collected (harvested), they are stored for 10 years or to age 45. But you can make a request in writing to extend this period. The eggs will only be stored while you are alive, so it is important you keep in touch with the HARI Unit every year. Do inform them of any change in your address.

The egg freezing service at the HARI Unit is free for all cancer patients living in Ireland. If you would like to find out more about egg freezing, talk to your doctor or nurse. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

## For men

**Chemotherapy:** Chemotherapy can cause infertility in men. It may be temporary or permanent. Even though doctors know that some chemotherapy drugs may cause infertility it is very difficult to say if and when this will happen. You may be on treatment 2–3 months before your sperm count is reduced.

**Contraception:** If you are having sex, you must use a reliable method of contraception throughout your treatment and for some time afterwards. There is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many doctors believe it is better for your partner not to get pregnant for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by then the chances of the disease coming back are much less.

**Sperm banking:** If tests show that your sperm count is satisfactory it may be possible to store your sperm before treatment. They can then be used at a later date. Sperm banking is done at the HARI Unit at the Rotunda Hospital in Dublin. To do this, you will be asked to give several sperm samples. There will be a couple of days' break between each sample to make sure good samples are got. The sperm will be frozen and stored until needed.

You may worry that the process of banking sperm may cause a delay in starting treatment. This is seldom the case as it can be done while tests are being carried out and the results of tests awaited. If you wish to find out more about sperm banking, talk to your doctor or nurse. He or she will give you more information.

## Thinking about infertility

The prospect of infertility can be a difficult issue to come to terms with. If you are young you may not have thought about having children. You may also want to get started on treatment straight away. At times like this having children or not may not be a priority for you.

However, as many leukaemias can be completely cured, it is most important that you give yourself some time to think about the future.

It may help to talk to a member of your family or a close friend about your concerns. Ask your doctor or nurse for advice on what you should do.

For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can talk to a nurse who will tell you what services are available.



## Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

### Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, biological therapies and hormone therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

### Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Acupuncture
- Aromatherapy
- Gentle massage
- Hypnotherapy
- Meditation
- Music, art and dance therapy
- Nutrition therapy
- Reflexology
- Relaxation
- Shiatsu
- Visualisation
- Yoga

Many people find complementary therapies helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.



## Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition. Most doctors do not believe that such treatments can cure or control cancer.



### If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, do talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from [www.cancer.ie](http://www.cancer.ie)

## Coping and emotions

### How can I cope with my feelings?

There are many reactions when told you have cancer, in this case leukaemia. Reactions can often differ from person to person too. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until the later stages of your illness that your emotions hit hard.

#### Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a copy or visit a Daffodil Centre or download one from [www.cancer.ie](http://www.cancer.ie). Your medical social worker in the hospital is also available to support you.

#### Shock and disbelief

*'It can't be me.' 'Has there been a mistake?' 'Cancer happens to other people, not me.'*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while.



You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot yet believe what is happening to you.

### Fear and uncertainty

*'I'm going to die.'  
'Will it be painful?'  
'Will I become a  
different person?'*

There is no doubt that leukaemia is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. But remember many leukaemias go into remission for long periods.

It can be very difficult to face an uncertain future and feel you are no longer in control. One way to reduce the stress of uncertainty is to make your plans day by day. Letting go of the past and not worrying about the future allows you to live fully in the present.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, finances, job and lifestyle.

Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

### Loss of control

*'I can't cope with  
this.' 'I'll never get  
through it.'*

After a leukaemia diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom.

Because you don't know enough about leukaemia at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

### Sorrow and sadness

*'I used to be so  
healthy.' 'I had so  
many plans.' 'I've let  
my family down.'*

It is natural to feel sad when told you have leukaemia. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your

type of leukaemia, your life may be affected by treatment to varying degrees. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

### Denial

*'I'm fine, really.'  
'I don't have cancer.'*

Sometimes after being told their diagnosis, people deny they have leukaemia. While this may seem unusual, it is a valid way of coping.

As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your leukaemia until you're ready.

### Anger

*'Why me? I always  
took care of my  
health.' 'Why did  
this happen now?'*

It is normal too to be very upset at the diagnosis. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief,

you may feel angry with God for allowing a cancer like leukaemia to

occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

### Resentment

*'How can you talk, you don't have to deal with cancer.' 'How come I'm not getting better?'*

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have.

You may resent your healthy relatives or having to change your lifestyle in some way. On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

➤➤➤ Don't bottle up your feelings – express them.

### Blame and guilt

*'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'*

When diagnosed with a serious illness such as leukaemia, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

### Withdrawal and isolation

*'I just need to be on my own.'*

It is true that a leukaemia diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal to want to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for them, as they will want to share this difficult time with you. They may worry about you needlessly. Do let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre or download it from [www.cancer.ie](http://www.cancer.ie)

### How can my family and friends help?

Your family and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Others may gather up-to-date information on leukaemia to know what you can expect and what you are going through. Others again may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.



## How to talk to someone with cancer



When someone close to you has a cancer like leukaemia it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help

### Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes of many kinds, great or small. Even so, it is best to keep family life as normal as possible. If you have young children, continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives. Every family deals with cancer in its own way.

You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or grandchildren or that you're letting them down. These are all natural feelings to have at this time.

### Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Young children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your leukaemia diagnosis. If this is not possible, then someone else close to your children should break the news. How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent, grandparent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

### Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, young children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for discussing cancer with children. If you would like a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, or download it from [www.cancer.ie](http://www.cancer.ie)

## How can I help myself?

Here is a list of things to help make you feel more involved and in control of your illness.

- Communicate with your family and close friends.
- Live one day at a time.
- Live well by eating well and taking exercise.
- Expect change in your life.
- Keep an open mind.
- Seek information about your leukaemia and treatment.
- Find which way of coping works for you.
- Build a support network.
- Seek professional help if you have low moods or strong emotions.
- Consider spiritual care.
- Express yourself through writing, music, dance or art.

### Journey Journal

It can help to keep a record of your cancer journey, including both physical and emotional aspects. Call the National Cancer Helpline on 1800 200 700 for a copy of *Journey Journal: Keeping Track of Your Cancer Treatment* or visit a Daffodil Centre. In this journal, you can record any of your tests like blood tests, X-rays and scans, as well as treatments, symptoms, side-effects, medications, and your general health. Write down any emotions you are feeling too, especially strong ones. It's a great way to express yourself without holding back.



## Support resources

### Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society



**Medical social worker:** The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

**Haematology nurse specialists:** Some of the major cancer treatment hospitals have haematology/oncology units where there are specially trained nurses. These are called haematology liaison nurses and/or cancer nurse co-ordinators. They can support you and your family from the time of diagnosis and throughout treatment. The nurses along with other members of your medical team work together to meet your needs.

**Psycho-oncology services:** In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

**GP (family doctor):** You may feel comfortable talking to your family doctor (GP) about your leukaemia too. He or she can discuss any of your queries and offer advice and support.



**Community health services:** There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

**Support groups:** Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Cancer support centres are also found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can also download the Irish Cancer Society's *Directory of Cancer Support Services* from [www.cancer.ie](http://www.cancer.ie)

**Irish Cancer Society:** The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance.

Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

>>> Remember that there are many people ready to help you.

## Health cover

Health cover falls into two groups – cover for medical card holders and cover for all other groups. Details of the following are given here:

- Hospital cover
- GP visit card
- Private healthcare cover
- Outpatient cover
- Drugs Payment Scheme (DPS)
- Benefits and allowances
- Medical card

At the end of this section there are also some useful telephone numbers for further help.

## Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

## Outpatient cover

If you go to the outpatients or emergency department of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the emergency department first.

## Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office.

If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre. LoCall 1890 252 919.

## GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre. LoCall 1890 252 919.

## Long-Term Illness Scheme

If you have acute leukaemia and do not have a medical card, you can apply for the Long-Term Illness Scheme. This is run by the HSE. Under the scheme, you get free drugs, medicines, and any medical or surgical appliance needed to treat AML. The scheme does not depend on your income or other circumstances and is separate from the medical card or GP visit card schemes. If you qualify, you will get a long-term illness book. This lists the drugs and medicines for the treatment of AML. You will receive these medicines free of charge through your community pharmacist. Other drugs and medicines not related to your condition must be paid for by yourself.

To apply for the scheme, fill in an application form from your family doctor (GP) or your local health office. Do ask your medical social worker for more advice.

## Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or local pharmacy.

## Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available

through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

## Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave. More information is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

Application forms are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can download the forms from [www.welfare.ie](http://www.welfare.ie) or [www.citizensinformation.ie](http://www.citizensinformation.ie)

**Appliances:** If you have a medical card most appliances are free of charge or subsidised. For example, if you have hair loss due to chemotherapy, you are entitled to 1–2 free or subsidised new hairpieces every year.

## Travel to hospital

If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services, usually for patients with medical cards.

See page 60 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

## Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre

- The medical social worker in the hospital you are attending.

For social welfare queries, contact:

#### Dept of Social Protection – Information Service

Oisín House                      Tel: 1850 662 244      Email: info@welfare.ie  
212–213 Pearse Street      Leaflet line:              Website: www.welfare.ie  
Dublin 2                              1890 202 325

If you have queries about health and social services, contact the HSE office in your area.

**HSE infoline:** 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

**Citizens Information** Tel: 0761 07 4000  
Email: information@citizensinformation.ie  
Website: www.citizensinformation.ie



### If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 60 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurses will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 61 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 67 for more information.

## Irish Cancer Society services

The Irish Cancer Society funds a range of support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

### Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The National Cancer Helpline 1800 200 700 is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter (@IrishCancerSoc)**.

## Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

## Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 62–65 for more details.

## Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance on the phone. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

National Cancer Helpline Freefone 1800 200 700

## Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

## Haematology/oncology liaison nurses

The Society funds some haematology or oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

## Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from [www.cancer.ie](http://www.cancer.ie) or picked up at a Daffodil Centre.





## Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

**Travel2Care:** If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email: [travel2care@irishcancer.ie](mailto:travel2care@irishcancer.ie)

**Financial Aid:** A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

## Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website [www.cancer.ie](http://www.cancer.ie) or a Daffodil Centre.

## Useful organisations

**Irish Cancer Society**  
43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
National Cancer Helpline:  
1800 200 700  
Email: [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

**The Carers Association**  
Market Square  
Tullamore  
Co Offaly  
Tel: 057 932 2920  
Freefone: 1800 240 724  
Email: [info@carersireland.com](mailto:info@carersireland.com)

**Citizens Information**  
Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

**HARI: The National Fertility Centre**  
Rotunda Hospital  
Parnell Square  
Dublin 1  
Tel: 01 807 2732  
Email: [info@hari.ie](mailto:info@hari.ie)  
Website: [www.hari.ie](http://www.hari.ie)

**Irish Oncology and Haematology Social Workers Group**  
Website: [socialworkandcancer.com](http://socialworkandcancer.com)

**Irish Nutrition & Dietetic Institute**  
Ashgrove House  
Kill Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 280 4839  
Email: [info@indi.ie](mailto:info@indi.ie)  
Website: [www.indi.ie](http://www.indi.ie)

**Money Advice and Budgeting Service (MABS)**  
Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 01 812 9350  
Helpline: 0761 07 2000  
Email: [helpline@mabs.ie](mailto:helpline@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

## Health insurers

**AVIVA Health**  
(formerly VIVAS Health)  
PO Box 764  
Togher  
Cork  
Tel: 1850 717 717  
Email: [info@avivahealth.ie](mailto:info@avivahealth.ie)  
Website: [www.avivahealth.ie](http://www.avivahealth.ie)

**GloHealth**  
PO Box 12218  
Dublin 18  
Tel: 1890 781 781  
Email: [findoutmore@glohealth.ie](mailto:findoutmore@glohealth.ie)  
Website: [www.glohealth.ie](http://www.glohealth.ie)

**Laya Healthcare (formerly Quinn)**  
Eastgate Road  
Eastgate Business Park  
Little Island  
Co Cork  
Tel: 021 202 2000  
LoCall: 1890 700 890  
Email: [info@layahealthcare.ie](mailto:info@layahealthcare.ie)  
Website: [www.layahealthcare.ie](http://www.layahealthcare.ie)

**Voluntary Health Insurance (VHI)**  
IDA Business Park  
Purcellsinch  
Dublin Road  
Kilkenny  
CallSave: 1850 44 44 44  
Email: [info@vhi.ie](mailto:info@vhi.ie)  
Website: [www.vhi.ie](http://www.vhi.ie)

## National support groups

**ARC Cancer Support Centres**  
Dublin and Cork (see pages 63 and 64).

**CanTeen Ireland**  
Young Peoples' Cancer Support Group  
Carmichael Centre  
North Brunswick Street  
Dublin 7  
Tel: 01 872 2012  
Freefone: 1800 200 700  
Email: info@canteen.ie  
Website: www.canteen.net

**Lakelands Area Retreat & Cancer Centre**  
Multyfarnham  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
CallSave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

## Connaught support groups & centres

**Athenry Cancer Care**  
Social Service Centre  
New Line  
Athenry  
Co Galway  
Tel: 091 844 319 / 087 412 8080

**Ballinasloe Cancer Support Centre**  
Society Street  
Ballinasloe  
Co Galway  
Tel: 090 964 5574 / 087 945 2300  
Email: ballinasloecancer@yahoo.co.uk

**Cara Iorrais Cancer Support Centre**  
2 Church Street  
Belmullet  
Co Mayo  
Tel: 097 20590  
Email: caraiorrais@gmail.com

**East Galway Cancer Support Centre**  
The Family Centre  
John Dunne Avenue  
Ballinasloe  
Co Galway  
Tel: 087 984 5574 / 087 945 2300  
Website: www.eastgalwaycancersupport.com

**Gort Cancer Support Group**  
The Hawthorn  
Ennis Road  
Gort  
Co Galway  
Tel: 086 312 4220  
Email: gcsupport@eircom.net  
Website: www.gortcs.ie

**Mayo Cancer Support Association**  
Rock Rose House  
32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407  
Email: info@mayocancer  
Website: www.mayocancer.ie

**Roscommon Cancer Support Group**  
Vita House Family Centre  
Abbey Street  
Roscommon  
Tel: 090 662 5898  
Email: vitahouse@eircom.net

**Sligo Cancer Support Centre**  
44 Wine Street  
Sligo  
Tel: 071 917 0399  
Email: scsc@eircom.net  
Website: www.sligocancersupportcentre.ie

**Tuam Cancer Care Centre**  
Cricket Court  
Dunmore Road  
Tuam  
Co Galway  
Tel: 093 28522  
Email: support@tuamcancercare.ie  
Website: www.tuamcancercare.ie

## Leinster support groups & centres

**ARC Cancer Support Centre**  
ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**ARC Cancer Support Centre**  
ARC House  
559 South Circular Road  
Dublin 8  
Tel: 01 707 8880  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**Arklow Cancer Support Group**  
25 Kingshill  
Arklow  
Co Wicklow  
Tel: 085 110 0066  
Email: arklowcancersupport@gmail.com

**Balbriggan Cancer Support Group**  
Unit 23, Balbriggan Business Park  
Balbriggan  
Co Dublin  
Tel: 087 353 2872

**Bray Cancer Support & Information Centre**  
36B Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Email: info@braycancersupport.ie  
Website: www.braycancersupport.ie

**Cara Cancer Support Centre**  
Mullavalley  
Louth Village  
Dundalk  
Co Louth  
Tel: 042 937 4905  
Mobile: 087 395 5335  
Email: info@ccscdundalk.ie  
Website: ccscdundalk.ie

**Cois Nore: Cancer Support Services Kilkenny**  
8 Walkin Street  
Kilkenny  
Tel: 056 775 2222  
Email: coisnorekilkenny@gmail.com  
Website: www.kilkennycancersupport.ie

**Cuisle Centre**  
Cancer Support Group  
Block Road  
Portlaoise  
Co Laois  
Tel: 057 868 1492  
Email: info@cuislecentre  
Website: www.cuislecentre.com

**Dóchas: Offaly Cancer Support**  
Teach Dóchas  
Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: info@dochasoffaly.ie  
Website: www.dochasoffaly.ie

**Éist Cancer Support Centre Carlow**  
The Waterfront  
Mill Lane  
Carlow  
Tel: 059 913 9684  
Mobile: 085 144 0510  
Email: info@eistcarlowcancersupport.ie  
Website: www.eistcarlowcancersupport.ie

**Gary Kelly Support Centre**  
George's Street  
Drogheda  
Co Louth  
Tel: 041 980 5100 / 086 817 2473  
Email: services@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support**  
La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email: info@greystonescancersupport  
Website: www.greystonescancersupport.com

**Haven Cancer Support and Therapy Group**

Haven House, 68 Hazelwood  
Gorey  
Co Wexford  
Tel: 053 942 0707 / 086 250 1452  
Email: info@thehavengroup.ie  
Website: www.thehavengroup.ie

**HOPE Cancer Support Centre**

22 Upper Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: mary@hopesupportcentre.ie  
Website: www.hopesupportcentre.ie

**Lakelands Area Retreat & Cancer Centre**

Ballinalack  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
CallSave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Newbridge Cancer Support Group**

144 Allenview Heights  
Newbridge  
Co Kildare  
Tel: 083 360 9898  
Email:  
newbridgecancerhealinghelp@gmail.com

**Rathdrum Cancer Support Centre**

34 Main Street  
Rathdrum  
Co Wicklow  
Tel: 087 292 8660  
Email: rathcan@gmail.com

**Tallaght Cancer Support Group**

Millbrook Lawns  
Tallaght  
Dublin 24  
Tel: 087 217 6486  
Email: ctallaght@yahoo.ie

**Wicklow Cancer Support Centre**

1 Morton's Lane  
Wicklow  
Tel: 0404 32696  
Email: wicklowcancersupport@gmail.com

**Munster support groups & centres****Cancer Information & Support Centre**

Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 485 163  
Website:  
www.midwesterncancercentre.ie

**CARE Cancer Support Centre**

14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 618 2667  
Email: cancersupport@eircom.net  
Website: www.cancercare.ie

**Cork ARC Cancer Support House**

Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: info@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**Kerry Cancer Support Group**

124 Tralee Town House Apartments  
Maine Street  
Tralee  
Co Kerry  
Tel: 066 719 5560 / 087 230 8734  
Email: kerrycancersupport@eircom.net  
Website: www.kerrycancersupport.com

**Recovery Haven**

5 Haig's Terrace  
Tralee  
Co Kerry  
Tel: 066 719 2122  
Email: recoveryhaven@gmail.com  
Website: www.recoveryhavenkerry.org

**Sláinte an Chláir: Clare Cancer Support**

Tír Mhuire  
Kilnamona  
Ennis  
Co Clare  
Tel: 1850 211 630 / 087 691 2396  
Email: admin@clarecancersupport.com  
Website: www.clarecancersupport.com

**South Eastern Cancer Foundation**

Solas Centre  
7 Sealy Close  
Earlscourt  
Waterford  
Tel: 051 876 629  
Email: infosecf@eircom.net  
Website: www.secf.ie

**Suimhneas Cancer Support Centre**

2 Clonaslee  
Gortland Roe  
Nenagh  
Co Tipperary  
Tel: 067 37403  
Email: suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**

Clongour Road  
Thurles  
Co Tipperary  
Tel: 0504 21197  
Email: suirhaven@gmail.com

**Youghal Cancer Support Group**

161 North Main Street  
Youghal  
Co Cork  
Tel: 024 92353 / 087 273 1121

**Ulster support groups & centres****Cancer Support and Social Club**

Tiernaleague  
Carndonagh  
Co Donegal  
Tel: 086 602 8993 / 087 763 4596

**Coiste Scaoil Saor ó Ailse**

Knockastoler  
Gweedore  
Letterkenny  
Co Donegal  
Tel: 083 121 7857  
Email: coiste.scaoil.saor@icloud.com  
Website: www.scaoilsaor.ie

**Crocus: Monaghan Cancer Support Centre**

The Wellness Centre  
19 The Grange  
Plantation Walk  
Monaghan  
Tel: 087 368 0965

**Cuan Cancer Social Support and Wellness Group**

2nd Floor, Cootehill Credit Union  
22-24 Market Street  
Cootehill  
Co Cavan  
Tel: 086 455 6632

**The Forge Cancer Support Group**

The Forge Family Resource Centre  
Pettigo  
Co Donegal  
Tel: 071 986 1924

**Living Beyond Cancer**

Oncology Day Services  
Letterkenny General Hospital  
Letterkenny  
Co Donegal  
Tel: 074 912 5888 (Bleep 674/734) /  
074 910 4477

For other support groups or centres  
in your area, call 1800 200 700.

**Support groups & centres unaffiliated to Irish Cancer Society****Cancer Care West**

Inis Aoibhinn  
University Hospital Galway  
Costello Road  
Galway  
Tel: 091 545 000  
Email: info@cancercarewest.ie  
Website: www.cancercarewest.ie

**Cúnamh: Bons Secours Cancer Support Group**

Bon Secours Hospital  
College Road  
Cork  
Tel: 021 480 1676  
Website: www.cunamh.ie

**Dundalk Cancer Support Group**

Philipstown  
Hackballscross  
Dundalk  
Co Louth  
Tel: 086 107 4257

**Good and New Cancer Drop In Centre**

Unit 1, Portlink Business Park  
Port Road  
Letterkenny  
Co Donegal  
Tel: 074 911 3437

**Killybegs Cancer Support Group**

Kille  
Kilcar  
Co Donegal  
Tel: 074 973 1292  
Email: riverbankdunne@eircom.net

**Solace: Donegal Cancer Support Centre**

St Joseph's Avenue  
Donegal Town  
Tel: 074 974 0837  
Email: solacedonegal@eircom.net

**Useful contacts outside Republic of Ireland****Action Cancer**

Action Cancer House  
1 Marlborough Park  
Belfast BT9 6XS  
Tel: 028 9080 3344  
Email: info@actioncancer.org  
Website: www.actioncancer.org

**American Cancer Society**

Website: www.cancer.org

**Cancer Focus Northern Ireland**

40-44 Eglantine Avenue  
Belfast BT9 6DX  
Tel: 048 9066 3281  
Email: hello@cancerfocusni.org  
Website: www.cancerfocusni.org

**Cancer Network Buddies**

Website:  
www.cancerbuddiesnetwork.org

**Cancer Research UK**

Tel: 0044 20 7242 0200  
Website: www.cancerhelp.org.uk

**Healthtalkonline**

Website: www.healthtalkonline.org

**Leukaemia & Lymphoma Research (UK)**

Tel: 0044 20 7504 2200  
Email: info@beatingbloodcancers.org.uk  
Website:  
leukaemialymphomaresearch.org.uk

**Leukemia & Lymphoma Society**

Website: www.lls.org

**Leukaemia CARE: Blood and Lymphatic Cancers (UK)**

Tel: 0044 1905 755 977  
Email: care@leukaemiacare.org.uk  
Website: www.leukaemiacare.org.uk

**Macmillan Cancer Support (UK)**

Tel: 0044 20 7840 7840  
Email: cancerline@macmillan.org.uk  
Website: www.macmillan.org.uk

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
77-81 Lisburn Road  
Belfast BT9 7AB  
Tel: 028 9069 9202  
Email: cancerinfo@belfasttrust.hscni.net

**National Cancer Institute (US)**

Website: www.nci.nih.gov

## Helpful books

### Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

**Adult Acute Myeloid Leukaemia**

Leukaemia & Lymphoma Research, 2012  
[Download from website:  
leukaemialymphomaresearch.org.uk]

**Adult Leukemia: A Comprehensive Guide for Patients and Families**

Barbara B. Lackritz  
Patient Centered Guides, 2001  
ISBN 978-0596500016

**The AML Guide: Information for Patients and Caregivers**

Leukemia & Lymphoma Society, 2012  
[Download from www.lls.org]

**Bone Marrow and Blood Stem Cell Transplants: A Guide for Patients and Their Loved Ones**

Susan K Stewart  
BMT Infonet, 2012  
ISBN 978-0964735231

**Cancer Positive: The Role of the Mind in Tackling Cancers**

Dr James Colthurst  
Michael O'Mara Books, 2003  
ISBN 185479860X

**Understanding Leukaemia and Related Cancers**

Tariq Mughal & John Goldman  
Blackwell Science, 1999  
ISBN 0632053461

**101+ Square Meals**

[Budget and nutrition]  
Norah Bourke et al  
MABS/HSE West/Paul Partnership/Limerick  
VEC/Safefood, 1998  
ISBN 187407514X  
[For more details, see www.mabs.ie]

## Helpful DVDs

**Understanding Radiation Therapy: A Patient Pathway**

Call 1800 200 800 for a copy.  
Website: www.cancer.ie

**A Guide to Chemotherapy**

HSE/Mid-Western Cancer Centre/ICS, 2008  
Call 1800 200 700 for a copy.

## What does that word mean?

<b>Allogeneic</b>	The use of another person's tissue. For example, when healthy stem cells are taken from another person for a transplant.
<b>Alopecia</b>	Loss of hair. No hair where you normally have hair.
<b>Anaemia</b>	When there are fewer red blood cells in your blood. This can cause tiredness and shortness of breath.
<b>Autologous</b>	The use of a person's own tissue. For example, when cells are taken from your bone marrow or blood.
<b>Biopsy</b>	Removing a small amount of tissue from your body and looking at it under a microscope to see if leukaemia cells are present.
<b>Blast cell</b>	The immature myeloid cells that fill up your bone marrow and prevent normal blood cells from being made.
<b>Bone marrow</b>	The soft spongy material found in the centre of large bones. It makes red blood cells, white blood cells and platelets.
<b>Bone marrow aspirate or biopsy</b>	When a sample of bone marrow cells or bone is taken and looked at under a microscope.
<b>Cells</b>	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
<b>Chemotherapy</b>	Treatment that uses drugs to cure or control cancer.
<b>Chromosomes</b>	Tiny structures that contain the genetic information of the cells in your body.
<b>Cytogenetics</b>	Tests that look at the chromosomes of leukaemia cells.
<b>Growth factors</b>	Medicines that help increase the number of red cells, white cells or platelets in your blood.

<b>Haematologist</b>	A doctor who specialises in treating patients with abnormal blood or bone marrow.
<b>Immunophenotyping</b>	A test that checks what kind of proteins or markers are found on the surface of leukaemia cells.
<b>Intravenous</b>	Into a vein.
<b>Leukaemia</b>	Cancer of the white blood cells and blood marrow.
<b>Lymphocytes</b>	A type of white blood cell that helps fight infection.
<b>Neutropenia</b>	Fewer white blood cells called neutrophils in your body. As a result, you develop infections easily.
<b>Neutrophils</b>	Important white blood cells that fight infection.
<b>Petechiae</b>	Bleeding under your skin, usually on your legs, feet, trunk and arms, due to a low platelet count.
<b>Platelets</b>	Blood cells responsible for clotting.
<b>Prognosis</b>	The likely outcome or course of a disease.
<b>Red blood cells</b>	Blood cells that carry oxygen to all parts of your body.
<b>Relapse</b>	When the leukaemia returns after treatment.
<b>Remission</b>	When there are no signs of leukaemia in your blood and bone marrow.
<b>Stem cell</b>	The smallest and earliest cells found in bone marrow. They are responsible for making all blood cells.
<b>Thrombocytopenia</b>	When there are fewer platelets in your blood. This can cause you to bleed and bruise easily.
<b>White blood cells</b>	Blood cells that help fight infection. There are five types: neutrophils, eosinophils, basophils, monocytes and lymphocytes.



## Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- What tests need to be done to diagnose leukaemia?
- What type of leukaemia do I have?
- What type of treatment do I need?
- Why is this treatment better for me?
- How successful is this treatment for my leukaemia?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- Would I be suitable for a clinical trial?
- Will the blood cell count return to normal after treatment?
- What side-effects or after-effects will I get?
- Can some of the side-effects be controlled?
- Is there anything I can do to help myself during treatment?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?
- Should I eat special foods?
- How will you know if the leukaemia is in remission?

## Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

## Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

Eileen O'Donovan, Cancer Information Service Nurse

Melanie Strickland, Cancer Nurse Co-ordinator

Liz Higgins, Transplant Co-ordinator

Human Assisted Reproduction Ireland (HARI) Unit

## Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

## Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

## Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, research and education. This includes patient information booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email: **fundraising@irishcancer.ie**

**Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.**

**Tel:** 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

**Irish Cancer Society**

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: [info@irishcancer.ie](mailto:info@irishcancer.ie)

W: [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

