

Understanding

Acute Lymphoblastic Leukaemia

Caring for people with cancer

Understanding

Acute Lymphoblastic Leukaemia

This booklet has been written to help you understand more about acute lymphoblastic leukaemia (ALL). 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:
Radiation therapist	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 lymphoblastic leukaemia (ALL) 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 how ALL is treated 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 this 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 ALL 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 62 for more about Daffodil Centres.



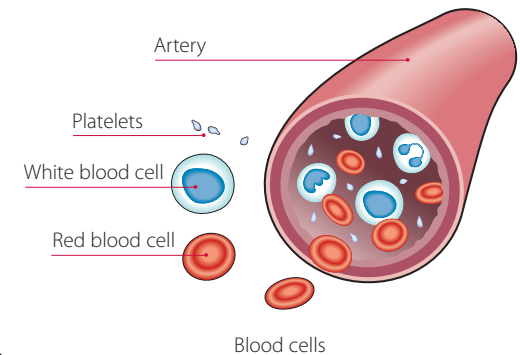
National Cancer Helpline Freephone 1800 200 700

About ALL

What is bone marrow?

To understand leukaemia we first need to talk about bone marrow. All types of blood cells are made by your bone marrow. This is the soft spongy tissue that fills the centre of some of your bones. 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.



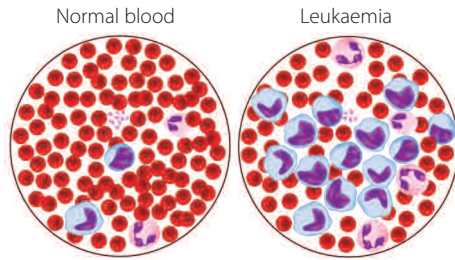
Once these blood cells are made, they leave your bone marrow and enter your bloodstream. White blood cells have a short life span and only live for a few days. Normally, all the blood cells are made and replaced by your bone marrow when needed.

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. 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 lymphoblastic leukaemia

The type of stem cell that matures into white blood cells is called a lymphoid cell or lymphocyte. These immature lymphocytes are known as lymphoblasts or blast cells. They quickly fill up your bone marrow and prevent normal blood cells from growing. This is why the leukaemia is called acute lymphoblastic leukaemia (ALL). It is sometimes called acute lymphoid leukaemia.



Lymphocytes fight infection in different ways in your body. They are further divided into types of cells known as T cells and B cells, depending on how they fight infection. Overall with ALL, the body cannot fight infection very well. Because your bone marrow is crowded with immature white blood cells, it cannot make the right amounts of red blood cells and platelets either. This means that fatigue, shortness of breath, bruising and bleeding can occur. ALL can affect your lymph nodes and enlarge your spleen too.

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

How common is acute lymphoblastic leukaemia?

Leukaemia in general is about the tenth most common cancer in Ireland. ALL is a rare disease. About 64 people are diagnosed with it in Ireland each year. It is more common in children than in adults. When it occurs in adults, it is usually between the ages of 15 and 25. Some adults develop it after the age of 70. It is slightly more common in men than in women.

National Cancer Helpline Freefone 1800 200 700



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.
- Lymphoid cells are stem cells that develop into white blood cells.

What causes ALL?

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

- **Age:** ALL occurs mainly in children and young adults or later in life, after the age of 70.
- **Gender:** It is slightly more common in men than women.
- **Exposure to chemicals and smoking:** These include certain pesticides, benzene and other chemicals found in industry. Tobacco use might also be a risk.
- **Exposure to radiation:** This includes exposure to high doses of radiation in industry or nuclear accidents or to previous radiotherapy.
- **Genetic disorders:** These include Down syndrome and Fanconi anaemia.
- **Genetic mutations:** Many doctors believe ALL is linked to mutations or faults in the genes that make blood cells. But this does not mean you inherit a faulty gene. These chromosome changes occur when the disease develops and are not passed on through your family.
- **Previous medical treatment:** This includes taking previous chemotherapy or radiotherapy or drugs that affect your immune system.
- **Infection:** Some types of infection may lead to ALL. For example, Epstein-Barr virus.

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

What are the symptoms of ALL?

The symptoms of ALL 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
- Feeling weak and unwell
- Shortness of breath
- Bleeding and bruising easily – nosebleeds, bleeding gums, heavy periods
- High temperatures or fevers
- Recurrent infections
- Aching bones and joints
- Enlarged glands
- Painless lumps in your neck, underarm, stomach or groin
- Loss of appetite
- Weight loss
- Enlarged spleen

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 leukaemia cells in your bone marrow.

How is ALL diagnosed?

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 greater detail and make the diagnosis of leukaemia.

Further tests

The haematologist will get more details of your medical history and arrange further tests. Some tests will find out exactly what kind of leukaemia you have, while others will check how many organs are affected or your general health. They include:

- Physical exam
- Full blood count
- Other blood tests
- Chest X-ray
- CT scan
- Ultrasound of spleen
- Bone marrow tests
- Chromosome studies (cytogenetics)
- Immunophenotyping
- Molecular (mutation) analysis
- Lumbar puncture

Physical exam: You will be given a full physical exam. It is important for your doctor to check your general health and also for any signs of disease or infection. This includes checking for anything that seems unusual like swollen glands. He or she will also note any previous illnesses, treatment and your lifestyle.

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.

Other blood tests: Your doctor will also check how well your blood clots. Bloods may be taken to see how well your liver and kidneys are working too.

Chest X-ray: You might have a chest X-ray to check your general health and for any swollen glands.

CT scan: This is a special type of X-ray that looks at the tissues in your chest and tummy. It can tell if any lymph nodes or organs in your body are enlarged. For example, your spleen.

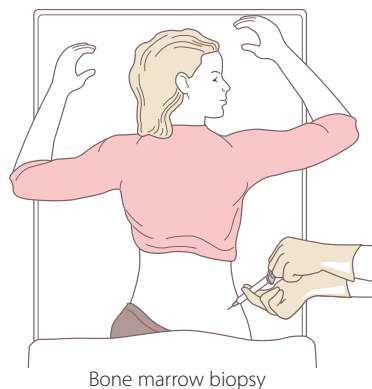
Ultrasound of spleen: This scan uses sound waves to look at your spleen. It only takes a few minutes and does not hurt. Some gel is first put on your tummy, which is then scanned using a device called a probe. It checks if your spleen is enlarged or not.

Bone marrow tests: These tests can confirm if you have ALL. 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.

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

After that, a needle is gently passed through your skin into your bone marrow. A tiny sample of the bone and bone marrow is then taken. The test usually takes about 20–30 minutes and you will feel some discomfort during it.

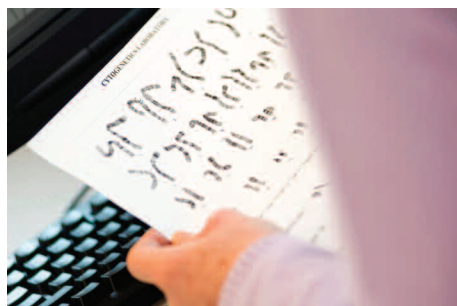
A small plaster is then put on the area. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. The area might feel tender and sore for a few days afterwards. You can take a mild painkiller for a day or two if needed.



Bone marrow biopsy

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 or bone marrow samples. These chromosomes are then compared to normal cells.

Sometimes in ALL, part of one chromosome is moved to another chromosome, and a new one is formed. This is called the Philadelphia chromosome. This chromosome makes a protein that in turn causes an enzyme called tyrosine kinase to make more leukaemia cells in your bone marrow. These chromosome changes occur when the disease develops and are not passed on through your family. They won't affect your children.



Chromosome studies

Molecular (mutation) analysis: In some cases, the leukaemia cells will be tested for specific mutations. Mutations are faults in the genes that store information about your body. These tests will help your doctor to decide on the best treatment for you. If a mutation like BCR-ABL is found, the ALL can be treated using tyrosine kinase inhibitors. This mutation happens if you have the Philadelphia chromosome.

Immunophenotyping: Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the leukaemia cells. The test can see if the abnormal lymphocytes came from either the B cells or T cells. In adults, the most common type of ALL is from the B cells.

Lumbar puncture: This test may be done in certain cases. It involves taking a sample of cerebrospinal fluid (CSF) from your spine to see if leukaemia cells are present. First you will be placed on your side, then the doctor will give you an injection to numb your lower back area. He or she will then put a small needle into your spine. A small amount of fluid will be taken and then sent to the laboratory for analysis. It is important for you to lie flat for at least 4 hours afterwards. This is to prevent any headaches, dizziness or blurred vision occurring.

Waiting for results

It may take a while before all your test results are ready. 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 ALL is unknown. Certain factors like age, gender, smoking, exposure to radiation, chemicals or chemotherapy drugs, genetic disorders, mutations and infection can increase your risk of getting it.
- Some symptoms of ALL are tiredness, shortness of breath, fever, infections, bleeding, bruising, weight loss, and an enlarged spleen.
- ALL can be diagnosed by a physical exam, full blood count, CT scan and ultrasound of your spleen, bone marrow tests, chromosome studies, immunophenotyping, molecular analysis, and lumbar puncture.



Treatment and side-effects

How is ALL treated?

The aim of treatment is to destroy all the leukaemia cells so there is space in your bone marrow for normal cells to grow. Treatment should begin as soon as possible. Before deciding on your treatment, your doctors will take into account:

- Your age
- Your general health
- The type of lymphocyte involved
- If you have the Philadelphia chromosome
- If your leukaemia has been treated before or come back

Treatment for ALL in Ireland is based on guidelines agreed by specialists and on the results of research worldwide. It needs to be treated by specialist doctors (haematologists) in a recognised cancer centre. This may mean you may have to travel to a different hospital for treatment.

Types of treatment

Some of the following treatments may be used in ALL:

- Chemotherapy
- Radiotherapy
- Steroid therapy
- Stem cell transplant
- Biological therapy
- Supportive care

Chemotherapy: Chemotherapy is the first and main treatment for ALL. It is given to destroy all the leukaemia cells and to make space in your bone marrow for healthy cells to grow again. Usually chemotherapy reduces the risk of leukaemia coming back. See page 15 for more details on chemotherapy.

Steroid therapy: Steroids may also be given with chemotherapy and for some time afterwards. Not only do they help to kill the leukaemia cells along with chemotherapy they can help improve your symptoms too.

Biological therapies: Sometimes biological therapies are given to treat ALL. If you are positive for the Philadelphia chromosome, you may be suitable for a type of biological therapy known as a tyrosine kinase inhibitor. It can be used together with chemotherapy or given later if your ALL is no longer responding to it. See page 30 for more details.

Stem cell transplant: Depending on your age, the progress of your disease and the risk of it recurring, you may be suitable for a stem cell transplant. The transplant will help to make healthy bone marrow that will in turn make healthy stem cells and normal blood cells. This will further reduce the chance of ALL coming back. See page 33 for more about transplants.

Radiotherapy: Radiotherapy is rarely used to treat leukaemia. But it can be used if leukaemia cells are found in your head or spine. It can also be given to prepare your bone marrow before a transplant. See page 31 for more details.

Supportive care: This type of care means treating your symptoms. For example, anaemia, infection or clotting problems. If your leukaemia is at an advanced stage, the treatment may only be able to control it. Supportive care can ease your symptoms and give you a better quality of life. See page 36 for more details.

>>> Chemotherapy is the main treatment for ALL.

Deciding on treatment

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 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.

Asking questions: 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. You could use the fill-in page at the back of this booklet for your questions and answers.

Accepting treatment: 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. It may help to talk to your GP as well. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Second opinion: 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. But remember your ALL will need to be treated quickly.

Individual treatment: Sometimes you may find that other people with a diagnosis of ALL are having a different treatment to you. With ALL, no two patients are the same. Because the illness takes different forms, every patient will have different needs.

Chemotherapy

Chemotherapy is a treatment using drugs to destroy the leukaemia cells. The aim is to cause a remission where leukaemia cells are no longer in your blood or bone marrow. The drugs are carried by your bloodstream to nearly every part of your body. Because they do not reach the brain, they can be given into the fluid around your brain and spinal cord using a lumbar puncture.

What is remission?

After chemotherapy, most patients with ALL go into remission. This means there are no signs of the disease in your blood and bone marrow.

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 ALL will come back (relapse) after treatment. If this happens, treatment can be given with more chemotherapy or high-dose chemotherapy.

What's involved in chemotherapy?

Cycles: Chemotherapy is usually given in cycles or courses, where each course lasts a few days. There is usually a rest period between each treatment to allow your body time to recover from any side-effects. The number of courses or cycles of treatment you have will depend on how the leukaemia responds.

Inpatient: When you start treatment you may need to spend many weeks in hospital while your chemotherapy is being given. This is to give your body time to get used to the treatment. It will also allow your doctors to see how you are responding. If you are well enough and your doctors are satisfied with your blood results, you will be allowed home before the next cycle begins. Some of your treatment may be given as an outpatient. This is where you attend a day treatment centre in the hospital.

What are the stages of treatment?

Treatment is usually given in three stages or phases: induction, intensification and maintenance.

Care of kidneys: Before chemotherapy begins, you will be given a drug called allopurinol or rasburicase. These are given to help your kidneys get rid of uric acid. Uric acid collects in your kidneys when a large number of leukaemia cells are killed by chemotherapy. Uric acid may cause gout or kidney stones which may interfere with the flow of urine. You will be encouraged to drink plenty of fluids to protect your kidneys.

»»» Drink plenty of fluids to protect your kidneys.

1 Induction

Induction is the first phase of treatment. It usually involves two courses where you take a number of drugs to destroy as many leukaemia cells as possible. During this phase, chemotherapy may be given into your spinal cord as well. This is called intrathecal therapy. See page 19 for more details.

This stage can last several weeks. Once your blood counts have recovered well enough, a bone marrow biopsy will be repeated.

This can check how well your bone marrow is responding to the treatment and if remission has happened.

2 Intensification

Once remission occurs, more courses of chemotherapy are usually given with a different combination of drugs. This is called the intensification or consolidation period. During this time tests may be done to find a suitable stem cell donor, if you are a young adult. This may affect what treatment is given next. After intensification, you may go on to maintenance therapy. For younger patients, a transplant may be a possibility. See page 33 for more details about transplants.

3 Maintenance

The third phase of treatment is called maintenance. It aims to kill any remaining leukaemia cells. This is far less intensive than the previous phases and treatment is given over a longer period of time. The drugs are mainly given in tablet form but occasionally can be given into your veins. This stage of treatment typically lasts for several months. You will be treated as an outpatient and see your doctor or nurse regularly in the hospital. It is unlikely that you will be admitted to hospital unless you get a relapse or develop an infection.

How long will the entire treatment last?

Depending on how well you respond to treatment and your age and gender, the total length of time for all treatments can be up to 2 or 3 years. In general, you will only need to spend time in hospital during the first two phases. Again depending on your condition, you might need to spend a short time in hospital. The treatment can make you very tired, so it is best not to work full-time for about a year. During this time your doctors will let you know about your progress.

How is chemotherapy given?

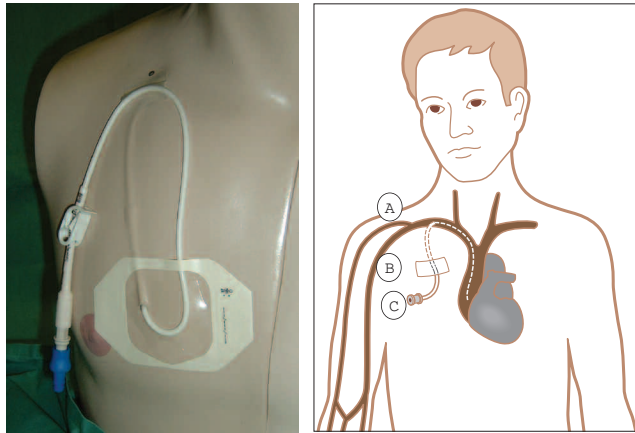
There are many different chemotherapy drugs used during the various cycles. There are a few ways to give them:

- 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 ALL is given into a vein. Once in your bloodstream, the chemotherapy drugs can travel around your body, except to your brain. 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.



Central lines

- 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 (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.

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 ALL 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.

If you would like more information about central lines, a free video is provided by the Irish Cancer Society. Two versions are available: one for females and one for males. A free booklet called *Understanding Chemotherapy* is also available. Contact the National Cancer Helpline on 1800 200 700 for copies of either or visit a Daffodil Centre.

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 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 ALL 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.

Injection into muscle

Some drugs can be given by injection directly into your muscle. The most common one given in this way is asparaginase. Your nurses will give this to you. However, if you are at home, you or a family member will be shown how to do it. Do not worry if this is not possible, as a public health nurse can visit you at home to give you the injection instead.

More information

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

What drugs are used?

There is a wide range of drugs used in the treatment of ALL. Your doctor will decide which drugs are best for you. Some drugs can be given alone or in combination. They include cyclophosphamide, vincristine, daunorubicin, methotrexate, cytarabine and mercaptopurine, among others. Your doctor and nurse will give you more details about the drugs you will receive. See also the Irish Cancer Society website for more information: www.cancer.ie/cancer-information/treatments/chemotherapy/drugs

What are the side-effects?

Side-effects occur because the drugs can affect both leukaemia cells and healthy cells. The side-effects of chemotherapy vary from person to person. Often they depend on the type of drugs used and your own reaction to them. Your doctors and nurses will let you know what kind of side-effects to expect. Always tell them if the treatment is 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 and infection
- Nausea and vomiting
- Loss of appetite
- Mouth or taste problems
- Tiredness and fatigue
- Hair loss
- Skin and nail changes
- Diarrhoea
- Constipation
- Numbness or tingling in hands and feet
- Bladder or kidney changes
- Hearing changes
- Changes in nervous system: anxiety, headaches, dizziness
- Infertility

Bone marrow side-effects: Because ALL is a disease that affects your 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 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 fewer 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. In women, periods can be heavier and longer than usual during the first few cycles. 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. 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.
- Avoid unpasteurised milk, soft cheeses, undercooked meats and poultry, the skin of raw vegetables and fresh fruit.
- Take care to avoid injury. Use an electric razor when shaving. Wear thick rubber gloves when gardening to protect yourself from cuts.
- Do not take aspirin as it can increase your risk of bleeding.
- 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.

Nausea and vomiting: Some 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, replace some meals with special food supplements. Do get advice early 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. Or download it from www.cancer.ie

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 free copy of the booklet *Diet and Cancer* or visit a Daffodil Centre.

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 leukaemia 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 such as nausea, 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 39 for more about fatigue.

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, scarf or bandana. 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



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 changes 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.

Diarrhoea: Some 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 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.

Numbness or tingling in hands and feet: Some drugs 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. For more advice or a copy of our free factsheet on peripheral neuropathy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Bladder or kidney changes: Some drugs like cyclophosphamide 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 drug called daunorubicin or doxorubicin that can turn urine red for 1–2 days afterwards. This is harmless and nothing to worry about.

Hearing changes: Some chemotherapy 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.

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.

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 41 for more details on fertility.

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 free copy of the booklet *Understanding Chemotherapy* or download it from www.cancer.ie



To sum up

- Chemotherapy is a treatment using drugs to destroy leukaemia cells.
- The drugs can be given directly into a vein as an injection or in a drip.
- The drugs may also be given in tablet form or by injection into muscle or directly into the spine.
- The side-effects vary depending on the drugs used.
- Most side-effects are well controlled with medication.

Steroid therapy

Steroids are often used with chemotherapy in the treatment of ALL. These are natural hormones made in your body. But they can kill leukaemia cells while having little effect on normal cells. Examples of the drugs are prednisolone and dexamethasone. These drugs are usually part of the first treatment for ALL and may be continued throughout your treatment. They are usually given in tablet form, but can be given directly into your vein too. It is very important that you continue taking these tablets as stopping them quickly may cause some health problems.

What are the side-effects?

In high doses steroids can have several side-effects. But not everyone will experience the same ones. The more common side-effects include:

- Increased appetite and weight gain
- Increased blood pressure
- Osteoporosis
- Stomach upset
- Increased blood sugar – diabetes
- Fluid retention
- Higher risk of infection, especially thrush
- Sleeplessness
- Mood changes – irritability, anxiety, tearfulness, high spirits

Blood sugars: While receiving steroids or the chemotherapy drug asparaginase, blood tests will be done regularly to check your blood sugar levels. Tell your doctor if you get very thirsty or if you are passing more urine than usual. Your blood sugars usually return to normal once treatment has stopped.

Mood and emotional changes: Occasionally steroids may cause you to have episodes of extreme happiness, sadness and mood swings. These are rare but if they occur, let your doctor know.



Tips & Hints – steroids

- Take steroids in the morning as you may sleep better at night.
- Take steroids with milk or food to prevent stomach upset.
- Talk to the hospital dietitian if you are putting on weight.
- Report any signs of infection to your doctor and nurse – a high temperature, cough, swelling or any inflammation.
- Do not stop taking steroids suddenly or without your doctor's advice.

Biological therapies

Sometimes biological therapies are used in the treatment of ALL. They can kill the leukaemia cells or prevent them from growing by using your body's immune system or by targeting specific cells. There are many different types of biological therapies. They can be used alone or with chemotherapy.

The type used in ALL is called tyrosine kinase inhibitors. The most commonly used drugs are imatinib (Glivec®) and dasatinib (Sprycel®). Within leukaemia cells there is an enzyme called tyrosine kinase that makes the cells grow and divide. Imatinib and dasatinib work by blocking this enzyme, causing the leukaemia cells to die. It is often given to those who have the Philadelphia chromosome. You are likely to receive imatinib at the start of the induction stage and continue to receive it throughout your treatment. It can also be used if the ALL relapses. The drug is taken in tablet form. Dasatinib might be used if you have the Philadelphia chromosome and are an older patient.

Biological therapies are often given as part of clinical trials. See page 35 for more details.

What are the side-effects?

These drugs have some mild side-effects. Sometimes they can cause nausea and diarrhoea, fatigue, leg aches, muscle cramps, skin rashes and swelling of fingers, eyelids, face or lower legs. But these can be treated easily. Your skin may become more sensitive to sunlight when taking the drugs. As a result, you can develop skin rashes, itching, redness or severe sunburn. It is best to use a high protection sunscreen when outdoors. You might be more prone to infection, anaemia and bleeding as well. Avoid taking grapefruit juice with these drugs.



To sum up

- Biological therapies kill or prevent the growth of leukaemia cells by using your immune system or by targeting specific cells.
- The type used in ALL is called tyrosine kinase inhibitors. The most common examples are imatinib (Glivec®) and dasatinib (Sprycel®).
- They are often given to those who have the Philadelphia chromosome.
- Some side-effects include nausea and diarrhoea, fatigue, leg aches, muscle cramps, and skin rashes.

Radiotherapy

Radiotherapy is a treatment where high-energy X-rays are aimed at cancer cells. Sometimes radiotherapy may be used to prevent or to treat leukaemia that is found in your head or spine. The X-rays usually come from a machine called a linear accelerator. This is known as external radiotherapy. The treatment



A linear accelerator

session only lasts a few minutes and does not cause any pain. But you will be asked to lie still while it is being given. External radiotherapy does not make you radioactive. It is quite safe for you to mix with family and friends afterwards.

This type of radiotherapy is different to that given before a bone marrow transplant where radiation is given to the whole body.

Planning your treatment

Before radiotherapy, your doctors and other specialists plan how to deliver it. They work out how to give you the right amount of radiation with the least damage to normal cells. Treatment planning is a very

important part of radiotherapy and it may take a few visits before you are ready to receive treatment.

Each time you go for treatment you will go into a radiotherapy room. The radiation therapist operates the treatment machine. You will be asked to lie or sit in a certain position. When you are ready he or she will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed circuit camera. You can talk through an intercom if you wish.

Side-effects of radiotherapy

Radiotherapy is given directly to the site of the leukaemia cells. As a result, the side-effects that occur are related to the part of your body being treated. When the head or neck are being treated with radiotherapy it is called cranial radiotherapy. The most common side-effects are:

- Headaches
- Skin changes
- Nausea
- Tiredness and fatigue

Headaches: Radiotherapy to the head may cause headaches. But these will stop once treatment finishes. During this time your doctor can prescribe painkillers to ease any headaches.

Skin changes: During radiotherapy the skin in the treated area may become red and sore. A cream can be used to treat this problem. Only use creams recommended by your nurses and radiation therapists at the radiotherapy unit. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

Nausea: You may experience some nausea or vomiting during the first few days after your treatment. Your doctor will prescribe medication to help you. If you feel sick, drinking fizzy drinks or nibbling on dry biscuits and toast can help.

Tiredness and fatigue: With radiotherapy to the head, you may develop severe tiredness and drowsiness (somnolence). This usually occurs about 2 weeks after your treatment begins and may last for a few

weeks. For more information about fatigue, see the booklet called *Coping with Fatigue*. If you would like a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Other side-effects

These or any other side-effects you develop will be watched very carefully during your course of radiotherapy. You will be given information on how to prevent side-effects and medication if you need it. All these side-effects should go away when treatment is over, but do let your doctor know if they continue.

For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Understanding Radiotherapy*, or download one from www.cancer.ie



To sum up

- Radiotherapy may be used if leukaemia cells are found in your head or spinal cord.
- The radiation comes from a machine called a linear accelerator.
- A lot of planning is needed before the treatment happens.
- Some side-effects include headaches, skin changes, nausea and tiredness.

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 make 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



Stem cells

health, donor availability, type of ALL 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 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.

»»» In an allogeneic transplant, healthy stem cells are taken from a donor and given to you.

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.

National Cancer Helpline Freefone 1800 200 700



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, radiotherapy 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 ALL 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 ALL. 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

Supportive care

During your treatment, supportive care will also be given. This means that any symptoms of ALL 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 ALL 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 counts. Bone marrow tests will also be done regularly to check for leukaemia cells. Your doctors will tell you about these results. Depending on the results, they may need to make changes to your treatment.

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 and checking your risk of relapse. Other tests will be arranged as needed.

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.

Chemotherapy can make you more prone to getting other conditions as well. If you are between check-ups and have a symptom or problem that worries you, let your doctor know as soon as possible. Make an appointment to see him or her early.

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. Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

What if the leukaemia relapses?

Sometimes the leukaemia cells do return after being treated. This is called a relapse. With a relapse, ALL can be found in blood, bone marrow, brain, spinal fluid or in testicles. Your doctor will let you know 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:

- While still receiving treatment or soon after finishing treatment
- Months or years after your 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 may also be considered as a treatment. Sometimes biological therapies are used if the ALL comes back.

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 will advise you on the best course of treatment if your leukaemia comes back.

National Cancer Helpline Freefone 1800 200 700

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.

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.
- **Asking 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

Will treatment affect my sex life and fertility?

Sex and sexuality

For some people sex is an important part of their relationships, while it is less so for others. During diagnosis and treatment you may lose the desire for sex. This is normal and there can be many reasons for it. Some aspects of treatment, such as losing your hair or having a central

line in place, may make you feel less sexually attractive. You might just feel too tired or perhaps not strong enough for the level of physical activity you are used to during sex. If your treatment is making you feel sick, then you may want to postpone having sex until you feel better. Anxiety or stress about your illness may also play a part in losing your desire for sex.

There is no set time for you to be ready to have sex again. It varies from person to person and may take a while. Often it depends on how long it takes you to adjust to your illness and treatment. Most changes are usually short term.

You may find that talking to your partner will help. Your partner may have anxieties too and could be waiting for a sign that you are ready to discuss them. You can also talk to your nurse or doctor. Sometimes people find it easier to discuss their feelings with someone they don't know, such as a medical social worker or a counsellor.

Pregnancy

It can sometimes happen that you are pregnant when diagnosed with ALL. 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.

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. A lot can depend on the type and dose of treatment given and your age at the time. 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.

If you receive a stem transplant you are likely to be permanently infertile after treatment.

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 chemotherapy or biological therapy.

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, do talk to your doctor. It might be possible to freeze 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 need 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.

»»» Your chemotherapy will take priority over egg freezing.

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

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. Do not worry if you experience none of the emotions listed below. It does not mean that you are not coping well.

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 free copy or visit a Daffodil Centre or download a copy from 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 probably the biggest reaction to a diagnosis of leukaemia. 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 your 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.

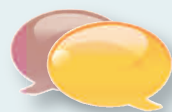
If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. For a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre or download it from www.cancer.ie

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

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 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

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 cancer 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/oncology nurse specialists: Some of the major cancer treatment hospitals have haematology/oncology units where there are specially trained nurses. These are called haematology/oncology 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

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 and websites 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) 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) 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 ALL. 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 ALL. 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

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 or 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 64 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 Email: information@citizensinformation.ie
Tel: 0761 07 4000 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 63 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 65 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 71 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 66–69 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.

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 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

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 or a Daffodil Centre.

National Cancer Helpline Freefone 1800 200 700

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
Website: www.cancer.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2920
Freefone: 1800 240 724
Email: info@carersireland.com

Citizens Information

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

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Irish Oncology and Haematology Social Workers Group

Website: socialworkandcancer.com

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: 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
Website: www.mabs.ie

Health insurers

AVIVA Health

(formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: 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
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres
Dublin and Cork (see pages 67 and 68).

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

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

Cois Nore: Cancer Support Services
Kilkenny
8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.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 Allenvieu Heights
Newbridge
Co Kildare
Tel: 083 360 9898
Email:
newbridgescancerhealinghelp@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
Solus 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 group & centres unaffiliated to Irish Cancer Society

Cancer Care West
Inis Aoi bhinn
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

Association of Cancer Online Resources
Website: www.acor.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

European Group for Blood and Marrow Transplantation
Website: www.ebmt.org

Healthtalkonline
Website: www.healthtalkonline.org

Leukaemia CARE: Blood and Lymphatic Cancers (UK)
Tel: 0044 1905 755 977
Email: care@leukaemiacare.org.uk
Website: www.leukaemiacare.org.uk

Leukaemia & Lymphoma Research (UK)
Tel: 0044 20 7504 2200
Email: info@beatingbloodcancers.org.uk
Website: leukaemialymphomaresearch.org.uk

Leukemia & Lymphoma Society (US)
Website: www.lls.org

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 Lymphoblastic Leukaemia
Leukaemia & Lymphoma Research, 2011
[Download from website:
leukaemialymphomaresearch.org.uk]

Adult Leukaemia: A Comprehensive Guide for Patients and Families
Barbara Lackritz
O'Reilly, 2004
ISBN 0596500017

Understanding Leukaemia and Related Cancers
Tariq Mughal & John Goldman
Blackwell Science UK, 1998
ISBN 0632053461

The ALL Guide: Information for Patients and Caregivers
Leukemia & Lymphoma Society, 2011
[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

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?

Alopecia	Loss of hair. No hair where you normally have hair.
Anaemia	When there are fewer red blood cells in your blood. This can cause tiredness and shortness of breath.
Allogeneic	The use of someone else's tissue for a transplant. For example, when cells are taken a donor's bone marrow or blood.
Autologous	The use of a person's own tissue for a transplant. For example, when cells are taken from your bone marrow or blood.
Biological therapy	Treatment that kills or prevents the growth of cancer cells using your immune system or by targeting specific cells.
Biopsy	Removing a small amount of tissue from your body and looking at it under a microscope to see if leukaemia cells are present.
Bone marrow	The soft spongy material found in the centre of large bones. It makes red blood cells, white blood cells and platelets.
Bone marrow aspirate or biopsy	When a sample of bone marrow cells or bone is taken and looked at under a microscope.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment that uses drugs to cure or control cancer.
Chromosomes	Tiny structures that contain the genetic information of the cells in your body.
Cytogenetics	Tests that look at the chromosomes of the leukaemia cells.
Gene	All the cells in your body have biological information that is inherited from your parents. This information is stored in genes.

Haematologist	A doctor who specialises in treating patients with abnormal blood or bone marrow.
Immunophenotyping	A test that checks what kinds of proteins or markers are found on the surface of the leukaemia cells.
Intravenous	Into a vein.
Leukaemia	Cancer of the white blood cells.
Lymphocytes	A type of white blood cell that helps fight infection.
Medical oncologist	A doctor who treats cancer with chemotherapy and other drugs.
Mutation	Faults in genes. Cancers are caused by mutations in genes that control how the cell grows and dies.
Neutropenia	Fewer white blood cells called neutrophils in your body. As a result, you develop infections easily.
Neutrophils	Important white blood cells that fight infection.
Petechiae	Bleeding under your skin, usually on your legs, feet, trunk and arms, due to a low platelet count.
Platelets	Blood cells responsible for clotting.
Red blood cells	Blood cells that carry oxygen to all parts of your body.
Refractory disease	When the leukaemia cells become resistant to certain drugs.
Relapse	When the leukaemia returns after treatment.
Remission	When there are no signs of leukaemia in your blood and bone marrow.
Stem cell	The smallest and earliest cells found in bone marrow. They are responsible for making all blood cells.
Thrombocytopenia	When there are fewer platelets in your blood. This can cause you to bleed and bruise easily.
White blood cells	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?
- 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?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?
- Should I eat special foods?

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:

Liz Higgins, Transplant Co-ordinator

Melanie Strickland, Clinical Nurse Manager

Nicky Martin, Medical Social Worker

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

W: 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

