

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 cancer doctors, nurses, other relevant specialists, and patients. The information in this booklet is an agreed view on this form of leukaemia, its diagnosis and management, and the key aspects of living with it. If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also make a note below of the main contacts that you may need quickly.

Specialist nurse Tel:

Family doctor Tel:

Haematologist Hospital Tel:

Radiation oncologist Hospital Tel:

Emergency Tel:

Treatments Review dates

If you like, you can also add:

Your name

Address



Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
Tel: 01 231 0500 Fax: 01 231 0555
Email: info@irishcancer.ie
Website: www.cancer.ie

The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer. This booklet has been produced by the Nursing Services Unit of 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.

EDITOR

Antoinette Walker

HEALTHCARE ADVISERS

Dr Paul Browne, Consultant Haematologist
Dr Helen Enright, Consultant Haematologist
Edel Brangan Gupta, Clinical Nurse Specialist
Lorraine Brennan, Clinical Nurse Specialist

SERIES EDITOR

Joan Kelly, Nursing Services Manager

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Contents

- 4 Introduction
- 5 What does that word mean?

Before diagnosis

- 7 What is leukaemia?
- 9 What is acute lymphoblastic leukaemia (ALL)?
- 9 What causes ALL?
- 10 What are the symptoms of ALL?
- 11 How does the doctor make the diagnosis?

Treatment and side-effects

- 15 How is ALL treated?
- 16 Chemotherapy
- 21 Steroid therapy
- 23 Side-effects of treatment
- 30 Radiotherapy
- 33 Will treatment affect my sex life or fertility?
- 36 Bone marrow/stem cell transplant
- 37 What is remission?
- 37 What if ALL comes back?
- 38 Research – what is a clinical trial?
- 39 Cancer and complementary therapies

Coping and emotions

- 41 How can I cope with my feelings?
- 46 How can my family and friends help?
- 47 How can I talk to my children?
- 49 What else can I do?

Support resources

- 51 Who else can help?
- 52 Health cover
- 59 Irish Cancer Society services
- 61 Useful organisations / useful reading
- 66 Frequently asked questions
- 67 Your own questions

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Introduction

This booklet has been written to help you learn more about acute lymphoblastic leukaemia (ALL). ALL can affect both adults and children. This booklet has been written for adults with ALL only. If you would like information on childhood ALL, please contact the National Cancer Helpline on freefone 1800 200 700.

By reading this booklet, we hope it answers some of the questions you may have about the diagnosis and treatment of ALL. The treatment can vary a little between doctors and hospitals. As a result, you may have questions and concerns about your own treatment which this booklet does not answer. It is best to discuss details of your own treatment with your doctor.

This booklet also deals with some of the feelings you and those close to you may have when a diagnosis of ALL is made. At the end of the booklet you will find a list of useful organisations, books, websites and special groups that can support you at this time.



Reading this booklet

Read the sections of this booklet that are of interest to you only. Some of the information may not be relevant to your situation. You may find that there is a lot of information to take in and that it can be hard to concentrate, especially if you are feeling anxious or worried. Remember that you do not need to know everything about ALL straight away. Read a section and 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 **1800 200 700**.

If the booklet has been of help, you might like to pass it on to your family and friends who might find it helpful too.

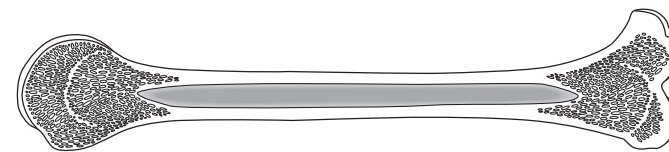
What does that word mean?

Allogeneic transplant	Bone marrow or stem cells that come from another person, e.g. your brother or sister.
Anaemia	Less red blood cells which may cause fatigue and shortness of breath.
Anti-emetic	A tablet, injection or suppository given to stop you feeling sick or vomiting.
Autologous transplant	Bone marrow or stem cells that come from yourself.
Biopsy	The removal of a small amount of cells or tissue for analysis.
Blast cell	Early or immature white blood cells. They become either neutrophils or lymphoblasts. In leukaemia there is an increased number of blast cells.
Bone marrow	The spongy tissue inside bones where blood cells are made.
Chemotherapy	A treatment to cure or control cancer with drugs.
Chromosome	All cells contain genetic material in the form of chromosomes. These may be altered in number and structure in leukaemia cells.
Granulocyte	A type of white blood cell involved in fighting infection. It can be subdivided into neutrophils, basophils and eosinophils.
Haematologist	A doctor who specialises in treating patients with blood or bone marrow diseases.
Haematology	The study of blood and bone marrow.
HLA	The human leukocyte antigens used in tissue typing.

Immunophenotyping	A way of identifying cells in your blood or bone marrow based on the type of proteins on the surface of the cell.
Lymph nodes	Small glands that are part of the immune system which are found in your neck, armpits and groin. They are sometimes called glands.
Lymphocytes	White blood cells that helps fight infection.
Neutropenia	When there is a less than normal number of neutrophils in the blood.
Neutrophils	White blood cells involved in fighting infection.
Platelets	Blood cells responsible for clotting.
Radiation oncologist	A doctor who specialises in treating patients with radiotherapy.
Radiotherapy	The treatment of cancer and other diseases using high-energy X-rays.
Red blood cells	Blood cells that carry oxygen to every cell in your body.
Relapse	When a disease returns after it has been in remission.
Remission	When there is no evidence of disease after treatment.
Resistance	When leukaemia cells do not respond to treatment.
Stem cells	Immature cells that develop into different blood cells – red blood cells, white blood cells and platelets.
White blood cells	Cells that help to fight infection. They include neutrophils, eosinophils, basophils, monocytes/macrophages and lymphocytes.

What is leukaemia?

Leukaemia is a cancer of white blood cells. This occurs in the bone marrow where all your blood cells are made. Sometimes young white blood cells grow rapidly but do not mature properly. Other times old white blood cells do not die off naturally. These young or old abnormal cells build up in the bone marrow and prevent normal blood cells from growing.



Bone marrow

Bone marrow

Bone marrow is the spongy tissue that fills your bones. All the various types of cells in your blood are made by the bone marrow. The most basic cells found in your bone marrow are called **stem cells**. These cells mature into white blood cells, red blood cells or platelets.

- **White blood cells** are involved in fighting infection.
- **Red blood cells** carry oxygen to all the tissues in your body.
- **Platelets** are involved in blood clotting.

Once made, these blood cells leave your bone marrow and enter your bloodstream. Normally, they are replaced by the bone marrow as needed and the process is controlled. However, in leukaemia this control is lost.

Types of leukaemia

Stem cells in the bone marrow produce two families of cells. These are called **myeloid** cells and **lymphoid** cells.

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Myeloid cells are made up of red blood cells, platelets and some white blood cells. The type of white cells can be monocytes or granulocytes, including neutrophils.

Lymphoid cells contain all the other types of white blood cells and are called lymphocytes.

Both cells fight infection in different ways. Myeloid cells are the body's quick defence against general infection. Lymphocytes, on the other hand, develop slowly. But they are more specific and build up your immunity to certain types of infection.

This leads to four main types of leukaemia:

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloblastic leukaemia (AML)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML).

The types of leukaemia describe the nature of the disease. It can be either **acute** or **chronic** and the type of cell involved can be either **myeloid** or **lymphoid**. Acute is when the cells are early in their life stage and the leukaemia develops quickly. Chronic is when cells are older and the disease progresses slowly. Each type of leukaemia has its own features and treatment.



To sum up

- Leukaemia is a cancer of the white blood cells.
- Leukaemia cells divide rapidly in the bone marrow preventing normal blood cells from growing.
- Leukaemia cells can either grow rapidly (acute) or fail to die naturally (chronic).
- There are four main types of leukaemia.

What is acute lymphoblastic leukaemia?

In ALL, immature white blood cells (lymphocytes) grow very quickly. These lymphocytes are known as **lymphoblasts** or **blast cells**. The bone marrow becomes crowded with these blast cells and blood cells cannot develop properly.

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 in ALL, the body cannot fight infection very well.

Because the bone marrow cannot work properly, it cannot make the right amounts of red blood cells and platelets. This means that fatigue and blood-clotting problems occur.

The word 'acute' describes how quickly the disease develops. Acute lymphoblastic leukaemia is also called acute lymphoid leukaemia.

»»» ALL is a cancer that affects the white blood cells called lymphocytes. They are important cells for fighting infection.

ALL 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 when aged over 75. It is slightly more common in men than in women.

What causes ALL?

ALL is a rare disease and in most cases the cause is unknown. Many scientists believe it is linked to mutations or changes in the genes that make blood cells. But this does not mean it is an inherited faulty gene. Your family are unlikely to be affected, if you develop ALL. Some types of infection may lead to ALL. But, like other cancers, ALL is **not** infectious and cannot be passed on to other people.

Sometimes ALL can develop if you have had treatment in the past with chemotherapy or drugs that affect your immune system. Or if you've been exposed to high doses of radiation/radiotherapy or certain pesticides/chemicals like benzene. With some genetic disorders, such as Down's syndrome or Fanconi's anaemia, ALL can occur too.

Research into the possible causes of ALL continues all the time.

>>> With ALL, it does not 'spread' and so you do not get a second tumour.

ALL is a disease of the blood and bone marrow. It is not like cancer, where you get a single solid tumour that can spread. With ALL, it does not 'spread' and so you do not get a second tumour.

What are the symptoms of ALL?

- Tiredness
- Feeling weak and unwell
- Shortness of breath
- Bleeding and bruising easily – nosebleeds, bleeding gums, heavy periods, etc.
- Fever
- Recurrent infections – flu's, sore throats, etc.
- Aching bones and joints
- Enlarged glands
- Painless lumps in the neck, underarm, stomach or groin
- Headaches and vomiting
- Weight loss or loss of appetite.

The early signs of ALL can be vague and you might think you are having just a bout of flu. All the above symptoms can be caused by conditions other than ALL. However, if your symptoms persist or you are concerned, you should go to your family doctor (GP) for a check-up.

How does the doctor make the diagnosis?

Once your GP has examined you and taken details of your symptoms, he or she may suspect a diagnosis of leukaemia. If a blood test confirms the diagnosis, you will then be seen by a haematologist. This is a doctor who specialises in abnormalities of the blood and bone marrow.

Further tests

Before any treatment can be given, the haematologist will need to take a detailed medical history from you. Further tests will then be done to find out what type of leukaemia you have. These tests may include:

- Physical examination
- Full blood count (FBC)
- Bone marrow biopsy
- Chromosomes studies (cytogenetics)
- Immunophenotyping
- Lumbar puncture.

Physical examination

You will be given a full physical examination. It is important for the haematologist to check your general signs of health and also for signs of disease, such as swollen glands or anything that seems unusual. A chest X-ray may be done to check for any swollen glands.

Full blood count (FBC)

A full blood count will be taken. If you have an abnormal FBC, your blood is examined under a microscope by a haematologist. If leukaemia cells are seen, the diagnosis can be confirmed.

>>> Leukaemia can only be confirmed by a blood test.

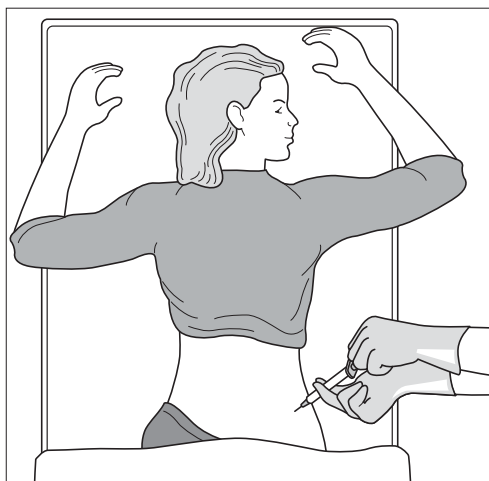
Bone marrow biopsy

A bone marrow biopsy involves a small sample of marrow being taken from the inside of one of your bones. Usually, it is taken from your hip or breastbone. Your doctor will give you a local anaesthetic to numb

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the area beforehand. The biopsy may be uncomfortable and may take up to 30 minutes. Some people have sedation while having it done. You can discuss this with your doctor or nurse beforehand.

Once the needle has been inserted into the cavity of the bone, a sample of bone marrow is drawn into a syringe. Bone marrow looks like a red liquid similar to blood. This red liquid is known as **bone marrow aspirate**. For more specific tests a piece of bony tissue may be removed. This is called a **trepphine biopsy**. When the test is finished, a small plaster will be placed on the area where the bone marrow was taken. You will then be asked to lie on your back for 10–15 minutes to prevent any possible bleeding. Some people find that mild painkillers can help with any discomfort that may occur afterwards.



Bone marrow biopsy

Chromosomes studies (cytogenetics)

This test will help your doctor find out the extent of your ALL and to know what to expect from the disease. **Chromosomes** are found in each cell in your body and are made up of genes. These genes control all the activities in each cell.

Tests may be done on blood and/or bone marrow samples. The number and shape of chromosomes in your blood cells, especially the lymphocytes, will be examined. These 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 the bone marrow. The chromosome cannot be inherited so it will not affect your children.

Immunophenotyping

This is a special test that gives more information about the cells in your blood or bone marrow. Under a microscope, 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 spinal column. 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 following a lumbar puncture to prevent any headaches, dizziness or blurred vision occurring.

Waiting for results

It may take a while for all your test results to come back. This can be an anxious time for you. It may help to talk things over with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to a specially trained nurse. Once all the results are available, your doctor will be able to decide exactly what type of treatment you should have.



To sum up

- In ALL, immature lymphocytes grow very quickly.
- The cause of ALL is unknown but may be linked to changes in the genes that make blood cells.
- Some of the symptoms of ALL include recurrent infections, tiredness, and bruising and bleeding easily.
- There are several tests that can diagnose ALL. These may include blood tests and a bone marrow biopsy.

Treatment and side-effects

How is ALL treated?

The aim of treatment with ALL is to destroy all the leukaemia cells so there is room in the 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 spread
- If your leukaemia has been treated before or has recurred (come back).

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.

Some people like to have a second medical opinion before deciding on treatment. If you wish, your doctor can refer you quickly to another haematologist.

Types of treatment

The first and main type of treatment for ALL is **chemotherapy**. Chemotherapy usually kills the leukaemia cells in most people with ALL. When there is no trace of the leukaemia cells in your blood and bone marrow it is known as **remission**. In a small percentage of people, the ALL does come back (**relapse**), usually within a few years of the treatment. If ALL does come back, treatment can be given with more chemotherapy or high-dose chemotherapy.

Steroid therapy may also be given with chemotherapy and for some time afterwards. If leukaemia cells spread to your head or spine,

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radiotherapy may be given. Depending on the progress of your disease and the risk of it recurring, you may be suitable for a **bone marrow** or **stem cell transplant**.

Giving consent for treatment

Before you start any type of treatment, your doctor will explain why you are receiving the treatment. You may be asked to sign a consent form saying that you give permission for the treatment to be given. In some cases you may give verbal permission. No medical treatment will be given without your consent. If you are unsure what the aims of the treatment are, talk to your doctor and nurse, before giving your consent.

Chemotherapy

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

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.

Before chemotherapy begins, a tablet called allopurinol is given to help your kidneys get rid of uric acid. Uric acid collects in the 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 reduce the risk of damage to your kidneys.

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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 become 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.

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

Treatment is usually given in three stages or phases.

1 Induction

Induction is the first phase of treatment. It involves two courses where you take a number of drugs to destroy as many leukaemia cells as possible. During this phase of treatment, chemotherapy may be given into the spinal cord as well. This is called intrathecal therapy. See page 20 for more details.

This stage can last between 3 weeks and 3 months. After the induction phase, remission usually happens. However, even though you may be in remission, it is important to continue with treatment as the risk of ALL returning is very high at this stage.

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 on your family to see if one of them is a suitable bone marrow/stem cell donor. This may affect what treatment is given next.

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New treatments: Glivec

In recent years a new type of drug has been given for some types of ALL. It is called Glivec (imatinib). It is often given to those who have the Philadelphia chromosome. You are likely to receive Glivec at the start of the induction stage and continue to receive it throughout your treatment.

Glivec is known as a signal transduction inhibitor. Within leukaemia cells there is an enzyme called tyrosine kinase that makes the cells grow and divide. Glivec works by blocking this enzyme, causing the leukaemia cells to die.

Glivec is taken in tablet form and has some mild side-effects. Sometimes it 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 Glivec. As a result, you can develop skin rashes, itching, redness or severe sunburn. It is best to use a high protection sunscreen when outdoors.

After intensification, you may need a bone marrow/stem cell transplant or go on to maintenance therapy. See page 36 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 specialist nurse regularly in the hospital. It is unlikely that you will be admitted to hospital unless you experience a relapse or develop an infection.

How long will all the phases of treatment last?

Depending on how well you respond to treatment and your age and

sex, the length of time for these three phases of treatment 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 keep you informed of your progress.

Many leukaemia centres take part in clinical trials. These trials try to discover new and improved ways of treating leukaemia. Your doctor may discuss this option with you. See page 38 for more details on research and clinical trials.

How is chemotherapy given?

Because of the various phases of treatment needed to treat ALL, there are many chemotherapy drugs used. There are different ways of giving these drugs.

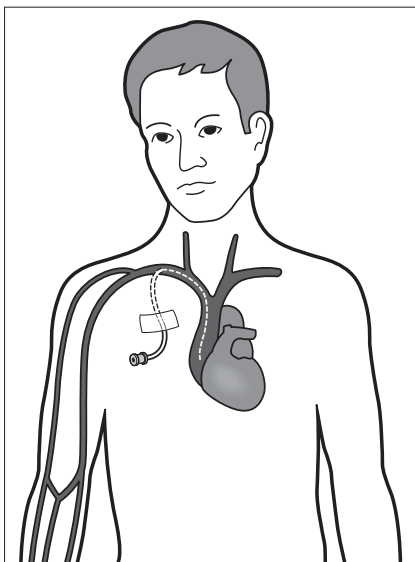
Intravenously

Most of the chemotherapy for ALL is given intravenously. This means it is given into a vein and goes directly into your bloodstream either as an injection or as a 'drip'. That way the drugs can travel to all parts of your body (except the brain).

The most common way to give chemotherapy intravenously is by a drip placed in a vein in your arm or by a central line. Because the drugs will be given to you over a long period of time, more than likely you will need a central line. A central line is a long, fine plastic tube put into a large vein in your chest near your collarbone. Blood samples can be taken from the line, transfusions or other drugs given, or stem cells returned to your blood. The most common types of central line are Hickman or Groshong.

In some cases the tube may be first placed in a vein in your arm or leg and then threaded so that the tip lies in one of the large veins in your chest. This is called a peripherally inserted central catheter (PICC).

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A central line

A central line can stay in place for months if it does not become infected or blocked. The nurses will show you how to care for your central line to help prevent any complications. 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 1800 200 700 if you would like a copy of either.

Intrathecally (into the spinal column)

Chemotherapy can also be given into the spinal column (intrathecally). This is where the drugs are given directly into the fluid surrounding your brain and spinal cord. This is done by means of a **lumbar puncture**. First you will be placed on your side. Then the doctor will give you an injection to numb your lower back area, before placing a small needle into your spinal column.

A small amount of fluid will be taken first and the chemotherapy drugs are then injected into the spinal column. This allows the drugs to travel to the brain, which cannot be reached by intravenous chemotherapy.

Orally (by mouth)

Many drugs given for ALL can also be taken in tablet form. These drugs may include steroids, antibiotics and chemotherapy. Sometimes it is better for you to eat or drink something before taking the tablets. You should check this with your doctor or nurse first.

Intramuscularly (into muscle)

Some chemotherapy 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 injection to you. However, if you are an outpatient, 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 will be able to visit you at home to give you the injection instead.



To sum up

- Chemotherapy is a treatment using anti-cancer 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 by injection into muscle or intrathecally into the spinal column.

Steroid therapy

Steroids are often used with chemotherapy in the treatment of ALL. These are hormones made in your body. However, 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 may also 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.

In high doses they can give rise to 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
- Mood changes – irritability, anxiety, sleep disturbances, tearfulness, or high spirits.

While receiving steroids, blood tests will be done regularly to check your blood sugar levels.



Tips & Hints – steroids

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

Supportive care

During the course of your treatment supportive care will be given. This means that you will be treated for any symptoms of ALL you have or the effects of chemotherapy. For example, if you are anaemic due to a lack of red blood cells, you may need a blood transfusion. Or if you have any bleeding problems, you may need a transfusion of platelets. If you develop any serious infections, you may need antibiotics quickly. Antibiotics and transfusions can be given through your central line.

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

Side-effects of treatment

The side-effects of chemotherapy vary from person to person. Often they depend on the drugs used and the individual reaction to them. These unwanted effects happen because chemotherapy not only affects leukaemia cells but normal cells too.

Because leukaemia is a disease of the bone marrow, chemotherapy is aimed at the bone marrow. In general, side-effects are likely to occur 10–14 days after receiving treatment. Your blood count will be checked regularly to keep a close eye on your condition. After each treatment, your blood count will return to normal. Sometimes this may take a little longer and so your next cycle of treatment may need to be delayed to allow your bone marrow to recover.

Most of the side-effects do not last long and some of the more common ones are listed here.

Bone marrow side-effects

Anaemia

Anaemia occurs when you have a low number of red blood cells. This can cause shortness of breath, tiredness and paleness. You may need a blood transfusion to treat the anaemia. This can boost your energy levels too.

Bruising

Bruising occurs when there is a reduced number of platelets. Platelets help to make your blood clot and stop any bleeding if you injure yourself. If you have any bleeding, let your nurse or doctor know immediately. You may need a platelet transfusion to help reduce any bleeding or bruising. Bleeding gums is also a common symptom of low platelets.

Infection

Because you have fewer white blood cells, you are more prone to infection. This is called neutropenia and means that your body's immune system cannot fight infections. If you do not have enough

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white blood cells, even minor infections such as a cold or sore throat could make you quite ill. If your temperature goes above 38°C (100.4°F) or if you suddenly feel unwell, contact your doctor or the hospital immediately. You may need to be admitted to hospital to receive antibiotics into your vein.

You will be more at risk of picking up infections while on treatment, so try to avoid close contact at this time. Infection can be a serious complication of chemotherapy. Talk to your doctor or nurse, who will give you more information.



Tips & Hints – anaemia, infection, bleeding

- Contact the hospital immediately if you have a temperature of 38°C (100.4°F) or higher, shortness of breath or bleeding that cannot be stopped.
- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid crowds and close contact, such as hugging or kissing, with people who have colds, flu's and other infections, especially chickenpox, shingles or measles. Let your doctor know if you have been in contact with these infections.
- 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 of fresh fruit.
- Take care to avoid injury. Avoid contact sports. Use an electric razor when shaving, a soft toothbrush when cleaning your teeth, and thick rubber gloves when gardening.
- Do not take aspirin as it can increase your risk of bleeding.

General side-effects

Feeling sick or not wanting to eat

You may feel sick (nausea) or vomit 1 to 2 days following treatment. However, you will be given anti-sickness drugs with the chemotherapy that will help you. Your doctor will also prescribe anti-sickness drugs for you to take regularly.

If you feel sick, drinking fizzy drinks or nibbling on dry biscuits and toast can help. You may not want to eat due to a sore mouth or because you are feeling anxious. Try to eat small amounts regularly. Talk to the hospital dietician who will give you advice on what to eat.

Sore mouth and taste changes

You may experience a dry and sore mouth during chemotherapy. This is called **mucositis**. Your treatment can cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean as this will reduce the risk of getting a mouth infection. Using a soft toothbrush like a child's toothbrush may help with cleaning your mouth. If you have dentures, remove them if your gums are sore. Do let your doctor and nurses know if it becomes too painful, as there are a number of mouthwashes and drugs available to help the discomfort.

Your sense of taste may also change while having treatment. But this usually returns once treatment has finished. Try different foods as some will taste better than others.

Tiredness and fatigue

Many people feel tired when on chemotherapy especially during the later months of treatment. Extreme tiredness is called fatigue and it is a common symptom of cancer as well as due to chemotherapy. It is often described as an overwhelming tiredness not relieved by rest. You may find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. 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 though it can be hard to identify the reasons for your tiredness,

there are some things you can do to help. For many people, treatment can help to relieve symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor what side-effects you can expect before your treatment begins.

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.

>>> Tips & Hints – fatigue

- Stop before you get overtired.
- Build rest periods into your day. If you are going somewhere special, have a rest before you go out. Save your energy for doing the things you most enjoy.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Keep your energy for eating. Eat little and often and use readymade 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.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep: gentle exercise, relaxation tapes, etc.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

There is a booklet on fatigue available called *Coping with Fatigue*. If you would like more information or a free copy, call the National Cancer Helpline 1800 200 700.

Hair loss (alopecia)

Chemotherapy can also cause temporary hair loss. Hair loss usually starts to happen 3 weeks after treatment begins. The amount of hair lost can vary from person to person and the type of drugs you receive. You may lose little or no hair. Or you may lose all your body hair, including eyelashes and eyebrows. But your hair will grow back once you have stopped treatment.

>>> Your hair will start to grow again once treatment stops.

You may feel upset, angry or embarrassed at the thought of losing your hair. Talk to your nurse about your feelings. He or she will help you to find ways to cope with hair loss. You can get a wig or hairpiece when this happens or you may prefer to wear a hat or scarf.

If you would like a wig, your medical social worker or nurse will be able to organise this for you. Try to do this before your hair starts to fall out so that you can get a good colour match to your own hair. If your hospital does not provide this service, ask them if they have the name of a wig fitter you could go to see.

In some cases it is possible to get financial assistance towards the cost of a wig. Ask your medical social worker or nurse for more information. A useful booklet is available called *Coping with Hair Loss*. If you would like more information or a free copy, call the National Cancer Helpline 1800 200 700.

Skin changes

Your skin may become dry and itchy due to chemotherapy. Your doctor will be able to prescribe something to help with this. Your skin may darken but this will improve when the treatment is finished. During treatment and for several months afterwards you will be more sensitive to the sun and your skin may burn more easily. You can still go out in the sun, but take more precautions than usual, such as wearing sunscreen with a high protection factor.

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Change in bowel habit

You may experience either some diarrhoea or constipation. These can be easily controlled with medication but you need to let your doctor know. If you do experience diarrhoea it is important that you drink plenty of fluids and let the nurses know because of the risk of infection.

Numbness or tingling in hands or feet

Some chemotherapy drugs used to treat ALL can cause tingling, numbness or burning sensations in your fingers and toes. You may also notice that you find it hard to tie up buttons or pick up small objects. This side-effect is almost always temporary and usually goes away after treatment stops. However, do tell your doctor or nurse if this happens, as some changes may need to be made to your treatment.

>>> Some chemotherapy drugs used to treat ALL can cause tingling, numbness or burning sensations in your fingers and toes.

Stomach upset

Sometimes steroids can cause an increase of acid in your stomach. This in turn can affect the lining of your stomach and cause ulcers. To prevent this, steroids should be taken with food. Your doctor may also prescribe some medication to prevent it happening. If you have any discomfort do let your doctor know.

Bladder/kidney changes

Some chemotherapy drugs such as cyclophosphamide can irritate your bladder and cause problems with your kidneys. It is important so that you drink plenty of fluids. Another drug you may receive called daunorubicin can turn urine red for 24 hours afterwards. If you notice any pain, discomfort or blood on passing urine, let your doctor know immediately.

Fertility and sex

Your ability to conceive or father a child may be affected by chemotherapy. As a result, men should consider sperm banking and women should discuss egg freezing or other options with their doctor. This should be done prior to starting treatment. It is important too that you do not become pregnant during treatment as the drugs may harm the foetus. It is best to use of a reliable method of contraception during treatment and for several months afterwards. See the section on fertility, page 33.

High blood sugars

Occasionally steroids and the chemotherapy drug asparaginase may cause a high level of sugar in your blood. While having this treatment your blood sugar will be checked regularly by blood and urine tests. 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.

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.

Headaches

When chemotherapy is given into the spinal column, you may get some headaches and dizziness or blurred vision. Tell your doctor if you experience any of these. It is important for you to lie flat for at least 4 hours following a lumbar puncture in case these symptoms occur.

Nail changes

You may notice that your nails become darker or white lines may appear on them. Once treatment has finished, these changes usually disappear over a few months.

Problems with central lines

It is important to take good care of your central line as it may become infected or blocked. You should flush and clean it as advised by your

nurse. If you notice any redness, pain or fluid around the tube, or swelling of one of your arms, let the hospital know straight away.

Other side-effects

You may experience a side-effect not listed here. More details on side-effects are available in a booklet called *Understanding Chemotherapy*. If you would like more information or a free copy, call the National Cancer Helpline 1800 200 700.

>>> Talk to your doctor and nurse if you experience any side-effects.

Radiotherapy

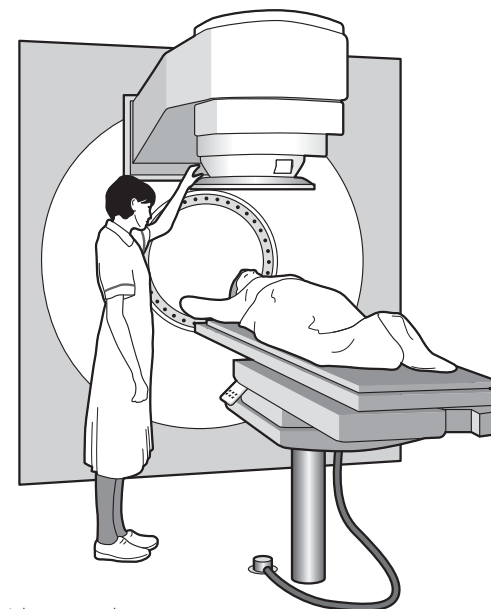
Radiotherapy is a treatment where high-energy X-rays are aimed at cancer cells. Sometimes radiotherapy may be used to prevent or to treat leukaemia that has travelled to the head or spine. The X-rays are usually given by a machine called a **linear accelerator**. This is known as external radiotherapy. The treatment session only lasts a few minutes and does not cause any pain. But you will be asked to lie very 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 transplantation where radiation is given to the whole body.

Planning your treatment

Before radiotherapy, your doctors and other specialists plan how to give it to you. 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.



A linear accelerator

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 will be able to see you all the time through a closed circuit camera. You can talk through an intercom if you wish.

There is a useful booklet on radiotherapy available called *Understanding Radiotherapy*. If you would like more information or a free copy, call the National Cancer Helpline 1800 200 700.

Side-effects of radiotherapy

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

Headaches

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

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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 to you by the 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.

Feeling sick

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 1800 200 700.

Other side-effects

These or any other side-effects you develop will be watched very carefully during 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.

Will treatment affect my sex life or 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 may also 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 put off 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.

Fertility

Some of the drugs used to treat ALL can cause either temporary or permanent infertility. This can depend on the type and dose of treatment given and your age at the time of treatment. Your doctor will explain this to you in more detail before starting your treatment. If you have a partner you may want them to join you so they too can discuss their concerns.

Treatment for ALL does not always cause infertility so it is important that you continue to use contraception during and after treatment. Pregnancy should be avoided as chemotherapy drugs can cause birth defects. People who have received a bone marrow or stem cell transplant are likely to be permanently infertile following treatment.

Men

Chemotherapy drugs can lower the number of sperm cells and reduce their ability to move about. These changes may be temporary or permanent. The prospect of infertility can be difficult to come to terms with. If you are young, you may not have yet considered having children.

Before starting treatment talk to your doctor about the possibility of sperm banking. This involves freezing and storing your sperm for future use. It is done at the HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin. In general, it does not take long and will not affect your treatment. For further information talk to your haematologist. You can also call the National Cancer Helpline 1800 200 700 for more details and advice.

It is important to use contraception with your partner during treatment and for a few months afterwards.

Women

Most women having treatment for ALL find that their periods become irregular or stop altogether. This is because chemotherapy affects the ovaries and reduces the amount of hormones they produce. Your periods may return to normal after treatment so it is important to continue taking contraceptive precautions during and after treatment as chemotherapy can cause birth defects.

If the risk of infertility is high, there are some options available. If you have a partner it may be possible to store a fertilised egg. This involves freezing and storing your eggs for future use. It is carried out at the HARI Unit at the Rotunda Hospital in Dublin. However, the procedure takes time and may not be an option, as ALL tends to need treatment immediately. In fact, your treatment for ALL will take priority. Do discuss these options with your haematologist. You can also call the National Cancer Helpline 1800 200 700 for more details and advice. See page 61 for details about contacting the HARI Unit for an information leaflet.

>>> Your treatment for ALL will take priority over egg freezing.

Menopause

Chemotherapy and/or radiotherapy may bring on an early menopause. This side-effect of treatment may be permanent or temporary. It is more common in women who are near the menopause age. Women who do experience the menopause may have hot flushes, dry skin, dryness of the vagina, which may make having sex uncomfortable, and be more prone to bladder and/or vaginal infections. Your doctor can prescribe some hormone treatment (HRT) to relieve or control these symptoms. Unfortunately, hormone treatment will not restore your fertility.

**Hints & Tips – coping with early menopause**

- Dress in layers, so you can cool off easily if you do have a hot flush.
- Avoid caffeine and alcohol.
- During intercourse use a vaginal lubricant containing water or mineral oil (e.g. KY Gel).
- If sex continues to be painful, discuss alternative treatments.

Coping with infertility

Infertility may cause feelings of anger or loss of identity. It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility it may also be helpful to talk to your nurse or doctor. If you cannot deal with any strong emotions you might have, your doctor may arrange for you to speak to a trained counsellor or a specialist. Do seek professional help if infertility is likely to trouble you.

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Bone marrow / stem cell transplant

Some patients may be suitable for a bone marrow or stem cell transplant. The aim of bone marrow and stem cell transplants is to provide a healthy bone marrow, which will produce healthy stem cells and then normal blood cells. Stem cells are immature cells that develop into different blood cells – red blood cells, white blood cells and platelets.

Bone marrow or stem cell transplants may benefit some people but are not suitable for all. Depending on your age, general health, donor availability, type of ALL and risk of recurrence, your haematologist may decide to opt for a transplant. He or she will first discuss it with you in greater detail.

There are two different types of bone marrow or stem cell transplant: allogeneic and autologous.

Allogeneic transplant

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

Autologous transplant

An autologous bone marrow or stem cell transplant is where bone marrow or stem cells are taken from you when you are in remission and free from disease. Your bone marrow is then destroyed with high dose chemotherapy and the healthy bone marrow given back to you.

If you would like more information or a free copy of the booklet *Understanding Bone Marrow and Stem Cell Transplants*, contact the National Cancer Helpline 1800 200 700. Two other booklets are

also available: *Understanding Allogeneic Bone Marrow or Stem Cell Transplants* and *Understanding Autologous Stem Cell or Bone Marrow Transplants*.

What is remission?

The aim of treatment for ALL is to bring about remission. This is where there is no evidence of leukaemia cells in your blood or bone marrow. You will have normal bone marrow and normal blood cells will grow. The number of patients with ALL who go into remission is increasing all the time.

Follow-up

Once you are in complete remission and have received all your treatment you can begin to return to a normal lifestyle. But you will need to attend the outpatient clinic for regular blood tests, chest X-rays and check-ups by your haematologist. At first these check-ups will be quite often but less so as time goes on and you are well and free from disease. Because your immune system will take some time to recover, you may need to go to hospital if you develop any infections.

You can start going back to work and resuming other activities such as sport and hobbies once your doctor gives you the all-clear. Food and alcohol intake within moderation can return to normal. You may even plan on going on holiday. Check with your doctor first about any special precautions or vaccinations that you may need. If you are between check-ups but you have any problems that concern you, let your doctor know as soon as possible.

What if ALL comes back?

Sadly, some patients will suffer a return or relapse of the disease. A relapse may occur even after a good response to treatment. It can occur while you are still receiving treatment or soon after coming off

treatment. A small number of patients will suffer a relapse months or years after treatment. ALL can be found in the blood, bone marrow, brain, spinal fluid or in men's testicles. Your haematologist will advise you on the best course of treatment if your leukaemia comes back.

If you relapse while on treatment, it is often because the disease has become resistant to the drugs being used. In this case different chemotherapy drugs can be given.

If a relapse occurs after treatment is finished, it is because all the leukaemia cells were not killed during treatment. In this case, further treatment may be with the same chemotherapy drugs used initially. Other treatments may include a bone marrow or stem cell transplant.

>>> Research – what is a clinical trial?

Research into new ways of treating leukaemia goes on all the time. If a treatment looks like it might be 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 treatment may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than existing ones.
- Find out if extra benefits result when the new treatment is given along with existing ones.
- Compare the new treatment with current best standard treatments.

Many patients with ALL take part in research studies. Your doctor may ask you to try a new treatment. There are many benefits in doing this. You will be helping to improve knowledge about leukaemia. You will also be carefully monitored during and after the study, so you will be quite safe.

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. You are also free to withdraw from a trial at any time if you change your mind.



As part of research into the causes of leukaemia, your doctors may ask your permission to store some samples of your blood cells or bone marrow. If you would like more information, a booklet called *Understanding Cancer Research Trials (Clinical Trials)* is available. Call the National Cancer Helpline 1800 200 700 for a free copy.

Cancer and complementary therapies

There is great interest today in complementary and alternative treatments for cancer. Lots of people find them helpful and beneficial during their illness. The way cancer is treated often depends on the culture and environment of the country in which you live. In Ireland cancer treatments are based on scientific research. This 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 standard treatments include surgery, radiotherapy, chemotherapy and biological treatments. They use tried and trusted methods where the experience with patients is over a long period of time. Many of these 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:

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

Many people find that complementary therapies are very 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. This can aid healing and promote a sense of well-being. Nowadays complementary therapies are often provided in hospitals, cancer treatment centres and support centres and can be given safely.

Alternative therapies

Alternative therapies are not conventional cancer treatments used by doctors. Generally they are treatments used **instead of** conventional treatments. Alternative therapies include:

- Diet therapy
- Megavitamin therapy
- Herbalism.

Because these therapies are not based on scientific evidence it is very hard to prove if they are generally effective or not. Most doctors do not believe that such treatments can cure or control cancer. They believe they should not be taken instead of conventional treatments.

Alternative treatments can interfere with standard treatment and may not be managed properly. At present in Ireland this area is not fully regulated, with no register of certified practitioners. For this reason, it is best to discuss your plans with your doctor.



Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have leukaemia. Reactions can differ from person to person. In fact, there is no right or wrong way to feel. But it is quite normal to be upset when told you have leukaemia. 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 you recover from your illness that your emotions hit hard.

>>> It is quite normal to be upset when told you have leukaemia.

Some of the more 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 leukaemia diagnosis can bring greater distress and cause anxiety and depression.

Shock and disbelief

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

Shock is often the first reaction to a leukaemia diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think leukaemia will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss it 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 don't really 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 nowadays many leukaemias can be cured or controlled with modern treatments. Another great fear is pain. But if your leukaemia causes physical pain it can be controlled with painkillers. You may also have fears that your experience of leukaemia will change who you are and that people will reject or avoid you. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your ALL recurs. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor and nurse, who will give you advice and help. 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 now 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 your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment.

When you experience a loss of control it can lead to feelings of helplessness and hopelessness. 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 help you feel more in control of your illness.

>>> Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

'I used to be so healthy.' 'I had so many plans.' 'I've left 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 that arise from treatment. Depending on your type of leukaemia, your fertility may be affected by treatment. 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 leukaemia.'

Sometimes after being told their diagnosis, people deny they have leukaemia. While this may seem absurd, it is a valid way of coping. As a result, people may not wish to mention or discuss their illness. Or else they may talk as if their 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 ALL 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 when told you have leukaemia. 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 your God

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for allowing 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.

Your family and friends may not always be aware that your anger is really about 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 leukaemia.'

'How come I'm not getting better?'

It is natural that you might be resentful and unhappy because you have leukaemia, 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 having to change your lifestyle in some way. 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 have watched my diet.' *'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 experts rarely know exactly what has caused leukaemia, 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 that your attitude will affect your health or leukaemia. Regret and guilt serves 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.'

There is no doubt 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 for you to want to be alone 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 your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. 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 leukaemia, there is a useful booklet available called *Who Can Ever Understand? – Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline 1800 200 700. If you are finding it hard to deal with any strong emotions, do talk to your doctor and nurse who will advise you.

How can my family and friends help?

Families and friends can support people through their leukaemia illness in different ways. Some family members and friends can offer a listening ear and give advice if needed. Some may gather up-to-date information on leukaemia to know what their loved one can expect and what they are going through. Others may prefer to help 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 friend or relative best.

How to talk to someone with leukaemia

When someone close to you has leukaemia it can be hard to know what to do. Their welfare may be a priority for you, but still you might 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. Although some people do die from leukaemia, many do not. Be honest with own your feelings too.

>>> Don't withdraw because you're afraid of what might happen to your relative or friend in the future.

Often those with leukaemia 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 not think you are doing much by just listening. In fact, it is one of the best ways to help.

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 and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

>>> Your friend or relative may sometimes get cross or irritable. These feelings are completely normal.

How can I talk to my children?

A leukaemia diagnosis can affect an entire family. It can bring changes that may be either large or small. Even so, it is best to keep family life going as much as possible. 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 changes in their lives.

Every family deals with leukaemia in a different 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 that you're letting the children 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. 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 left in the dark.

It is best that you yourself tell your children about your leukaemia

Cancer Helpline 1800 200 700

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 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 what to expect from the side-effects of treatments and to answer their questions simply and honestly. 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, anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief. 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 *What Do I Tell the Children? A Guide for a Parent with Cancer* gives practical advice for talking to children about cancer. If you would like a copy, call the National Cancer Helpline 1800 200 700.

What else can I do?

Everyone experiences leukaemia in a different way. And how each person copes with leukaemia varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about the illness itself but also about you as a person. Here is a list of things to do to make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with leukaemia.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while to adjust to your new routine. Change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your illness. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor and nurse as many questions as you can and get involved in decisions about your treatment. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your leukaemia and treatment as possible. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer

relaxation, meditation, massage, walking, listening to music, or something else. Do whatever suits you and makes you feel good. But if it's not working, be open to finding a new way to cope.

- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it. BMT Support is group that caters for bone marrow and stem cell transplant patients and their families, giving information and links to other resources, empathy and support. See page 62 for more details.
- **Seek professional help:** If you have any low moods or strong emotions talk to your close friends and family – or someone who is a good listener. If your emotions are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a leukaemia diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. Sometimes spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation can help you focus on what has value and meaning in your life. Even if you don't consider yourself a religious or spiritual person, it is still possible to get support from any belief system that has importance for you. Some complementary medicines that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you make sense of your illness and can bring great healing and relief. Other forms of creative expression, such as music and art may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 if you would like a free copy.

Support resources

Who else can help?

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

- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups
- Helpline nurses.

The **medical social worker** in your hospital can help in many ways. He or she provides support and counselling to patients and their families and can provide advice on benefits, entitlements and services available when you go home. They are also specially trained to help you talk to children about a leukaemia diagnosis.

Some of the major cancer treatment hospitals have **oncology liaison nurses** and/or **cancer nurse co-ordinators**. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These people along with other members of your medical team work together to meet your needs.

In some larger hospitals there are special units that provide **psycho-oncology services**. This means that psychological care and support is given to patients with leukaemia during diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists, nurses and medical and surgical doctors working closely together.

When you go home there are various **community health services** available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare

Cancer Helpline 1800 200 700

officers and home-help organisers. If you live in an area which is remote or far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as financial worries, etc. All these people in community health services can provide advice and support. You can get more information on the services available either from the social worker in the hospital before you go home or at your local health centre.

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 leukaemia. You may find it easier to share your thoughts and feelings with someone who has a similar experience than with anyone else. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet.

Often you might need practical advice about your financial matters, e.g. getting a mortgage or travel insurance. The Irish Cancer Society **Helpline nurses** will be happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support services in your area. Call **1800 200 700** for more details.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of what this involves is given in the following pages. At the end of this section there are also some useful telephone numbers and addresses 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 €60 a night charge up to a limit of €600 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 A&E unit of a public hospital, without being referred there by a GP, you may be charged €60. There is no charge if you are referred by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E unit 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, and outpatient services and medical appliances. Every person aged 70 or over has a right to a medical card and no means test is required. It covers the applicant only and not their dependants.

For most people, to qualify for a medical card depends on a means test. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office, i.e. the former health board. If your means are above but close to the guidelines, you should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a leukaemia diagnosis. In this case your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a new type of medical card. The ‘GP visit card’ was introduced in 2005. It 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 or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a limit of €85 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your pharmacy. If you opt for egg freezing, the cost of the drugs used in the procedure can be reclaimed through the DPS.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, BUPA, VIVAS Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

Benefits and Allowances

Disability Benefit

This is a benefit for insured people. Eligibility will depend on your PRSI contributions. You must be under 66 and unfit to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment.

Disability Allowance

You may qualify for Disability Allowance if you are not eligible for Disability Benefit and not able to work for at least a year. Disability Allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. You must have a means test and be

medically suitable for this allowance. To be medically suitable you should have an illness that has continued or may continue for at least 1 year. This means that you are unlikely to be able to work for at least a year due to your illness. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Invalidity Pension

This is a pension paid instead of a Disability Benefit or Allowance, if you are unable to work in the long term. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility for this pension will also depend on your PRSI contributions. You are allowed a free travel pass and certain extra benefits, such as bottled gas, telephone rental, fuel allowance and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. There are a number of benefits with this scheme such as a free travel pass for the carer, free television licence, and home energy allowance. A telephone allowance has been extended to carers giving full-time care. There is also a contribution towards respite care. This is a means-tested allowance. For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8940 or Dublin (01) 704 3000, Ext. 8940.

Cancer Helpline 1800 200 700

Carer's Benefit

If you are employed but wish to care for a sick relative, you may qualify for a Carer's Benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. You should apply for Carer's Benefit 8 weeks before you intend to leave employment so that your eligibility can be assessed prior to leaving your employment.

More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8787 / Dublin (01) 704 3000, Ext. 8787.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres.

Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, e.g. hardship, etc.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. 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:

Information Service	Tel: 01 874 8444
Dept of Social and Family Affairs	Leaflet line: 1890 202 325
Áras Mhic Dhiarmada	Email: info@welfare.ie
Store Street	Website: www.welfare.ie
Dublin 1	

If you have queries about health and social services, contact the HSE office in your area. In 2005 the functions of the health boards were transferred to the Health Service Executive (HSE). **HSE National Information Line:** 1850 241 850. **Email:** info@hse.ie **Website:** www.hse.ie

HSE Eastern Region
[formerly Eastern Regional Health Authority]
Customer Services Department
Dr Steeven's Hospital
Dublin 8
Tel: 01 635 2400
or Freefone 1800 520 520
Email: customerservices@erha.ie
Website: www.erha.ie

HSE North Eastern Area
[formerly North Eastern Health Board]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 9280 500
Fax: 046 9241 459
Website: www.nehb.ie

HSE Midland Area
[formerly Midland Health Board]
Head Office
Arden Road
Tullamore
Co Offaly
Tel: 057 932 1868
Fax: 057 935 1760
Website: www.mhb.ie

HSE North Western Area
[formerly North Western Health Board]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 9820 400 / 1850 636/313
Fax: 071 9820 431
Website: www.nwhb.ie

HSE Mid-Western Area
[formerly Mid-Western Health Board]
Head Office
31–33 Catherine Street
Limerick
Tel: 061 483 286
Fax: 061 483 350
Website: www.mwhb.ie

HSE South Eastern Area
[formerly South Eastern Health Board]
Head Office
Lacken
Dublin Road
Kilkenny
Tel: 056 7784 100
Fax: 056 7784 388
Website: www.sehb.ie

HSE Southern Area
[formerly Southern Health Board]
Head Office
Wilton Road
Cork
Tel: 021 4545 011
Website: www.shb.ie

HSE Western Area
[formerly Western Health Board]
Head Office
Merlin Park Regional Hospital
Galway
Tel: 091 751 131
Fax: 091 752 644
Website: www.whb.ie

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

Comhairle (formerly the National Social Services Board)

7th Floor, Hume House, Ballsbridge, Dublin 4

Tel: 01 605 9000

Citizen Information: 1890 777 121

Email: comhairle@comhairle.ie

Website: www.comhairle.ie

There are also some booklets available that may help you. These include:

Information Guide to Health Services (published by the Dept of Health and Children). Copies are available from your local HSE area office.

Tel: 01 671 4711 for local HSE numbers.

Guide to Social Welfare Services (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs.

Tel: 01 874 8444. Email: info@welfare.ie. Website:

www.welfare.ie

Entitlements for People with Disabilities (published by Comhairle).

Available from Comhairle. Tel: 01 605 9000. Email:

comhairle@comhairle.ie

Irish Cancer Society Services

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

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to seven nights to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer Information Service (CIS)

The Society also provides a Cancer Information Service with a wide range of services: the **National Cancer Helpline** 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 such as prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put patients in contact with the various support

groups that are available. The helpline 1800 200 700 operates weekdays from 9 am to 5 pm, and every Tuesday from 9 am to 9 pm. A **Prostate Cancer Information Service** 1800 380 380 also operates at the same time.

All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie. The walk-in caller service allows anyone with concerns about cancer to freely visit the Society to discuss them in private. **CancerForum** is a bulletin board on our website (www.irishcancer.ie) that gives the public the chance to post their comments.

The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Counselling

Coping with a cancer diagnosis can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the Cancer Helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

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.

Patient grants

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial assistance to patients in need. If you would like to request this kind of help contact your oncology or medical social worker at the hospital where you have been treated. He/she should then make the request in writing to the Irish Cancer Society.

If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.

Useful organisations

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Comhairle (formerly National Social Services Board)
7th Floor
Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000
Email: comhairle@comhairle.ie

Dept of Social and Family Affairs – Information Service
Áras Mhic Dhiarmada
Store Street
Dublin 1
Tel: 01 874 8444
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion Unit
Dept of Health and Children
Hawkins House
Hawkins Street
Dublin 2
Tel: 01 635 4000
Website: www.healthpromotion.ie

Irish Patients Association
Unit 1
21 Church Road
Ballybrack
Co Dublin
Tel: 01 272 2552
Out of Hours Emergency No.
087 6529448
Email: info@irishpatients.ie
Website: www.irishpatients.ie

Health insurers

BUPA Ireland

Mill Island
Fermoy
Co Cork
Local: 1890 70 08 90
Fax: 025 42122
Email: choices@bupa.ie
Website: www.bupa.ie

VIVAS Health

Paramount Court
Corrig Road
Sandyford
Dublin 18
Tel: 1850 717 717
Email: support@vivashealth.ie
Website: www.vivashealth.ie

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie

Support groups & support centres

ARC Cancer Support Centre

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

BMT Support

Bone Marrow Transplant Support Group
c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline 1800 200 700
Email: info@bmtsupport.ie
Website: www.bmtsupport.ie

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 482615
Website: www.mwhb.ie/cancercentre

Cancer Plus (support group for parents of children with cancer)

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline 1800 200 700
Email: support@irishcancer.ie

CanTeen Ireland

Young Peoples' Cancer Support Group
c/o Carmichael Centre
Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 434 6688
Email: Karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

The Cuisle Centre

Cancer Support Group
2 Park Villas, Harper's Lane
Mountmellick Road
Portlaoise
Co Laois
Tel: 0502 81492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support

12 Henry Street
Tullamore
Co Offaly
Tel: 0506 28268
Email: dochasoffaly@hotmail.com

Donegal Cancer Support Group

Clar
Co Donegal
Tel: 074 974 0837

The Gary Kelly Support Centre

Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Fax: 041 980 5101
Email: info@garykellycentre.org
Website: www.garykellycentre.org

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: kk@kathleenkelleher.com

HOPE

Enniscorthy Cancer Support & Information Centre
6 Church Street
Enniscorthy
Co Wexford
Tel: 054 38555

LARCC Retreat Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 71971
Callsave 1850 719719
Email: info@larcc.ie
Website: www.larcc.ie

Lios Aoibhinn Cancer Support Centre

St Vincent's University Hospital
Herbert House
St Anthony's
Herbert Avenue
Dublin 4
Tel: 01 277 3545

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 70399
Email: scsg@tinet.ie

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876629
Fax: 051 876718
Email: infosecf@eircom.net

The Tuam Cancer Care Centre

30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: info@tuamcancercare.ie
Website: www.tuamcancercare.ie

Turning Point – Positive Health Centre

23 Crofton Road
Dun Laoghaire
Co Dublin
Tel: 01 280 7888
Email: turningpoint@eircom.net
Website: www.turningpoint.ie

Useful contacts outside Ireland

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

Association of Cancer Online Resources
Website: www.acor.org

Cancerbackup (UK)
3 Bath Place
Rivington Street
London EC2A 3JR
Tel: +44 207 696 9003
Helpline: +44 207 7392280
Website: www.cancerbackup.org.uk

The Cancer Council South Australia
202 Greenhill Road, Eastwood, South Australia 5063
Fax: +61 8291 4122
Email: tcc@cancersa.org.au
Website: www.cancersa.org.au

CancerLink UK
Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Tel: +44 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Cancer Research UK
Website: www.cancerhelp.org.uk

Center for International Blood and Marrow Transplant Research (USA)
Website: www.cibmtr.org

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

Leukaemia Care Society
Website: www.leukaemia.org.uk

Leukaemia Research Fund (UK)
Website: www.lrf.org.uk

Macmillan CancerLine
Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Tel: +44 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Memorial Sloan-Kettering Cancer Center (US)
Website: www.mskcc.org

National Cancer Institute (US)
Website: www.nci.nih.gov

Royal Marsden Hospital Foundation NHS Trust
Website: www.royalmarsden.org

The Ulster Cancer Foundation
40/42 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

University of Pennsylvania Cancer Center
Website: www.oncolink.com

Wessex Cancer Trust (UK)
Website: www.wessexcancer.org

Useful reading

Adult Leukaemia: A Comprehensive Guide for Patients and Families
Barbara Lackritz
O'Reilly, 2004
ISBN 0-59650-001-7

Understanding Leukaemia and Related Cancers
Tariq Mughal & John Goldman
Blackwell Science UK, 1998
ISBN 0-63205-346-1

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Frequently asked questions

Here is a list of questions people often ask. 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 type of leukaemia do I have?
- What type of treatment do I need? Why is this one better for me?
- How successful is this treatment for my leukaemia?
- Are there other treatment options?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I have?
- Is there anything I can do to help myself during treatment?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

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We hope that this booklet has been of help to you. If you have any suggestions as to how it could be improved, we would be delighted to hear from you. Your comments would help us greatly in the preparation of future information booklets for people with leukaemia and their carers.

If, after reading this booklet or at any time in the future, you feel you would like more information or someone to talk to, please phone our Cancer Helpline Nurses on Freefone 1800 200 700.

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, education and research.

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.

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

Tel: 01 231 0500 Email: info@irishcancer.ie

The Irish Cancer Society
is the national charity for cancer care,
dedicated to eliminating cancer as a
major health problem and to improving
the lives of those living with cancer.

