

Understanding

Chronic Lymphocytic Leukaemia

Caring for people with cancer



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

National Cancer Helpline 1800 200 700
Open Monday to Thursday 9am–7pm; Friday 9am–5pm



Understanding chronic lymphocytic leukaemia (CLL)

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

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



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Haematologist	Tel:
Medical oncologist	Tel:
Emergency number	Tel:
Treatments	Review dates:



If you like, you can also add:

Your name _____
Address _____

This booklet has been produced by Nursing Services 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.

LEUKAEMIA ADVISERS

Dr Elisabeth Vandenberghe, Consultant Haematologist

Dr Gerard Crotty, Consultant Haematologist

Mary Kelly, Advanced Nurse Practitioner Haematology

Kathleen Beston, Clinical Nurse Specialist Haematology

CONTRIBUTOR

Anne-Marie McGrath, Cancer Information Service Nurse

EDITOR

Antoinette Walker

SERIES EDITOR

Joan Kelly, Nursing Services Manager

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Introduction

This booklet has been written to help you understand more about chronic lymphocytic leukaemia (CLL). It is a cancer that affects white blood cells and bone marrow. The booklet describes how it is diagnosed and treated and ways of coping with it.

We hope it answers some of your questions and encourages you to discuss them with your doctors and nurses too. We cannot advise you about which treatment to choose. You along with your doctors can only make this decision when all your test results are ready.

This booklet also discusses some of the feelings you and those close to you may have after a cancer diagnosis. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



Reading this booklet...

Remember you do not need to know everything about CLL straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm.



National Cancer Helpline 1800 200 700

What does that word mean?

Anaemia	A decrease in the number of your red blood cells. It can cause fatigue, breathlessness and pale skin.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Autoimmune haemolytic anaemia (AIHA)	A type of anaemia where antibodies attack your red blood cells and destroy them. It can cause fatigue, pain and irregular heartbeats.
Biological therapy	A treatment that uses your body's immune system to fight cancer.
Bone marrow	The soft spongy material found in your large bones. It makes three types of blood cells: red blood cells, white blood cells and platelets.
Bone marrow aspirate	A test that involves removing a small amount of bone marrow fluid and cells from your bone and looking at it under a microscope.
Bone marrow biopsy	A test that involves removing solid bone marrow from your bone and looking at it under a microscope.
Chemotherapy	Treatment using drugs to cure or control cancer.
Cytogenetics	Tests that look at the number and shape of the chromosomes in your blood cells.
Fatigue	Ongoing tiredness often not helped by rest.
Growth factors	Drugs that encourage the growth of white blood cells in your bone marrow, and which reduce the risk of infection.
Haematologist	A doctor who specialises in treating patients with abnormal blood or bone marrow.
Haematology	The study of blood and bone marrow.

Immunoglobulins	Proteins made by your white blood cells to help protect your body from infection and disease. Also called antibodies.
Immunophenotyping	Tests that check what kind of proteins or markers are on the surface of leukaemia cells.
Leukaemia	Cancer of the white blood cells.
Lymphocytes	A type of mature white blood cell that helps to fight infection.
Monoclonal antibodies	Antibodies made in the laboratory rather than by your own immune system. When you receive these antibodies, they use your immune system to destroy cancer cells.
Nausea	Feeling sick or wanting to be sick.
Neutropenia	A reduced number of white blood cells called neutrophils. It can put you at risk of sudden infections.
Platelets	Blood cells responsible for clotting.
Radiotherapy	A treatment of cancer using high-energy X-rays.
Red blood cell	Blood cells that carry oxygen to every cell in your body.
Stem cell transplant	A treatment where you receive high doses of chemotherapy to kill off all the blood cells and leukaemia cells in your bone marrow. You then receive stem cells donated from a suitable donor, which can make new healthy blood cells in your bone marrow.
Transformation	When one type of leukaemia changes into another type of leukaemia or lymphoma.
White blood cell	Blood cells responsible for fighting infection.

About CLL

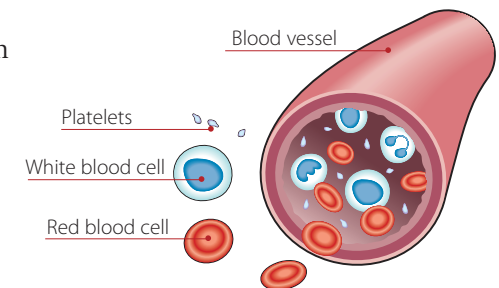
What is leukaemia?

Leukaemia is a cancer of your white blood cells and bone marrow. Sometimes it is simply called blood cancer. Other cells such as red blood cells or platelets can be affected as well. Blood cells are made in the bone marrow of your body. When leukaemia develops, immature blood cells continue to grow quickly but do not mature into white blood cells. These immature cells fill up your bone marrow and prevent normal blood cells from growing.

Bone marrow

All types of blood cells are normally made by your bone marrow. Bone marrow is the soft spongy tissue that fills the centre of your long bones. For example, your hips and breastbone. The smallest and most basic type of cells found in your bone marrow is stem cells. Stem cells develop and mature into red blood cells, white blood cells or platelets.

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



Once these cells are made, they leave your bone marrow and enter your bloodstream. White blood cells have a short life span and only live for a few days. Normally, all the blood cells are made and replaced by your bone marrow when needed. The entire process is well controlled but with leukaemia this control is lost.

Types of leukaemia

Leukaemia is a disease that can be hard to understand. This is because there are so many different types and subtypes. It can be

hard to follow where each type of blood cell comes from and what exactly it does. So it can help to know a little about blood cells.

In your bone marrow, stem cells make two types of white blood cells. These are myeloid cells and lymphoid cells. Myeloid cells mainly give rise to certain white blood cells, but also to red blood cells and platelets. Lymphoid cells develop into white blood cells called lymphocytes.

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

As a result, there are four main types of leukaemia:

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

Acute and chronic refer to how quickly leukaemia develops. Acute means the leukaemia develops very quickly over days and weeks. Chronic means it develops slowly usually over months or years. The types of leukaemia describe the nature of the disease, either acute or chronic, and the type of cell involved, either myeloid or lymphoid. Each type of leukaemia has its own features and treatment.

This booklet deals with CLL only. For free booklets on the other types of leukaemia, contact the National Cancer Helpline on 1800 200 700.

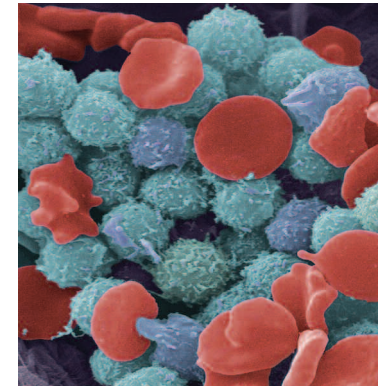


To sum up

- Leukaemia is a cancer of your white blood cells and bone marrow.
- Leukaemia cells can either grow rapidly (acute) or fail to die naturally (chronic).
- There are four main types of leukaemia: AML, ALL, CML, CLL.
- Stem cells make two types of white blood cells: myeloid and lymphoid.

What is chronic lymphocytic leukaemia (CLL)?

Chronic lymphocytic leukaemia (CLL) is a cancer of the white blood cells called lymphocytes. CLL used to be known as chronic lymphatic leukaemia in the past. Normally lymphocytes die off naturally at the end of their life span. However, with CLL these cells live on even when they can no longer fight infection. They may build up in your bone marrow until there is no space for normal blood cells to develop. This causes problems with fighting infection, carrying oxygen and blood clotting.



Blood cells showing lymphocytes in blue and green, and red blood cells

Lymphocytes are divided into T cells and B cells, depending on how they fight infection. Usually the B cells are affected in CLL.

>>> CLL is a cancer of the lymphocytes.

How common is CLL?

CLL is the most common leukaemia in the western world. That said, it is still fairly rare. About 109 people were diagnosed with it in Ireland in 2009. It is more common in older age groups and in men.

What causes CLL?

The exact cause of CLL is unknown. There may be a genetic link but more research is needed to prove it. However, there are certain things called risk factors that might increase your chance of getting the disease. These include:

- **Age:** CLL mainly occurs in people aged over 50. Most cases are aged 65–70 years when first diagnosed. It rarely affects people under 30 and does not affect children.

- **Gender:** It is more common in men than women.
- **Family history:** In some cases, close family members can develop CLL, for example, a brother or first cousin. This is called familial CLL.
- **Ethnic group:** CLL is most common in white populations of European origin. It is slightly less common in those of African origin and rare in Asian populations.

There is no strong evidence to link CLL to smoking, diet, radiation, viral infections or autoimmune conditions. Remember CLL is not infectious and cannot be passed on from person to person.

What are the symptoms of CLL?

CLL develops very slowly, so there may be no symptoms in the early stages. In fact, you may have the disease for many years before you develop any problems at all. Most cases of CLL are picked up on a routine blood test when you have no symptoms. Or else you may have vague symptoms such as fatigue, which is common to many other conditions.

The most common symptoms of CLL include:

- Tiredness, weakness or fatigue
- Anaemia (fewer red blood cells)
- Shortness of breath
- Repeated infections, especially shingles
- Bleeding and unexplained bruising
- Fever
- Severe sweating at night
- Aching bones and joints
- Loss of appetite and weight loss
- Swollen lymph glands in your neck, armpits and groin
- Enlarged liver or spleen
- Discomfort in your abdomen

Remember these symptoms can also be caused by conditions other than cancer. Do visit your doctor to get your symptoms checked out. For more information, contact the National Cancer Helpline on 1800 200 700.



To sum up

- CLL is a cancer of the lymphocytes. Abnormal lymphocytes build up in your bone marrow and prevent normal blood cells developing.
- The cause of CLL is unknown. There may be a genetic link, as close family members can develop it.
- CLL develops very slowly, so there may be no symptoms in the early stages.
- Some symptoms include tiredness, anaemia, repeated infections, bruising, fever, and night sweats.

How is CLL diagnosed?

If your GP suspects that you have any symptoms of CLL or if a routine blood test is abnormal, he or she will refer you to a haematologist. This is a doctor who specialises in treating blood and bone marrow disorders. The haematologist will arrange for you to have a series of tests at the hospital.

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

Leukaemia can only be confirmed by a blood test. Before treatment can be given, your doctor will ask you about your medical history. A full physical exam to check your general state of health will be done as well. Your doctor will also check for any signs of leukaemia, such as swollen glands or anything that seems unusual. You will then need further tests to find out the type of leukaemia you have. These tests will include:

- Full blood count
- Blood film
- Immunophenotyping
- Chromosome studies (cytogenetics)
- Bone marrow tests

Full blood count: A full blood count (FBC) will be taken first. This measures the number of white blood cells, including the types of lymphocytes that are increased in CLL. It also counts the number of red blood cells and platelets in your blood. The test can also give your doctor an idea of your general health.

Blood film: Your blood will also be examined under a microscope to identify the leukaemia cells. Sometimes the size and shape of these cells can be seen. A diagnosis of CLL can then be confirmed. If your doctor suspects that you have CLL, he or she will do a further test called immunophenotyping.

Immunophenotyping: In this test your blood or bone marrow cells is examined to see what kind of antigens (proteins) are on their cell surface. This can confirm a diagnosis of CLL.

Chromosomes studies (cytogenetics): Chromosomes contain information about the genes in all your cells. These tests can find out the number and shape of the chromosomes in your blood cells, using samples of blood, bone marrow or lymph glands. The chromosomes are then compared to normal cells. They check for known abnormal changes in the chromosomes that occur with CLL. For example, p17 deletion. The test method often used is FISH analysis. This stands for fluorescence in situ hybridisation. FISH gives your doctor a lot of chromosome information on how the disease might behave. This in turn can help them to plan the best treatment for you.

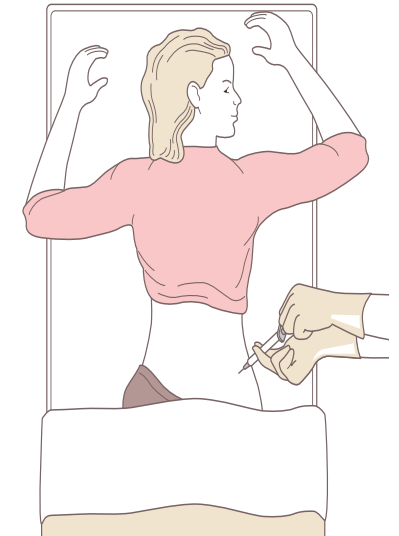
Bone marrow tests: These tests are not commonly done. Nowadays they are only done if your doctor does not get enough information from immunophenotyping. They might also be done if a different diagnosis is suspected. There are other reasons too. For example, they can be done before treatment and later to check your response to treatment. It might also be done if your disease has relapsed (becomes active) or if the test is needed as part of a clinical trial.

Bone marrow tests involve taking a tiny sample of your bone marrow and looking at it under a microscope. The sample is taken from inside your bone, usually your hipbone. If the sample of bone marrow cells is semi-liquid, it is called an aspirate. If a tiny narrow piece of solid

bone marrow is taken, it is called a trephine biopsy. Both can be done at the same time. Care has to be taken that you are not on warfarin or other blood-thinning drugs.

Your doctor will give you a local anaesthetic to numb the area beforehand. The biopsy itself may be uncomfortable and can last up to 10 minutes. The entire test can take about 30 minutes. Once the needle is put into your bone cavity, a sample of your bone marrow is drawn into a syringe. Bone marrow is red in colour and looks very like blood. A different kind of needle is used to do the trephine biopsy.

When it is over, a small plaster is put on the area where the bone marrow has been taken. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. You can take mild painkillers, like paracetamol, if you feel any discomfort later.



A bone marrow test

Other tests

There are many other tests that can give your doctor more information about the extent of your CLL. These include:

- Chest X-ray
- CT scan
- Lymph gland biopsy
- Ultrasound scan

Chest X-ray: This is done to check for any enlarged lymph glands. It can also find out if you have a chest infection or not and the state of your general health.

Lymph gland biopsy: This test is rarely needed. If your glands are enlarged, a biopsy (sample) of the tissue may be done. It involves a small operation usually under local anaesthetic. The gland is removed and then sent to the laboratory for tests.

CT scan: This special type of X-ray gives a detailed picture of the tissues inside your body from different angles. It can show if your spleen is enlarged or the presence or absence of lymph nodes. The scan itself is painless. Preparation for a CT scan can vary but your doctor and nurse will let you know. You might have to fast beforehand or be given a special drink or injection to help show up parts of your body on the scan.

Ultrasound scan: This is a scan that uses sound waves to look at organs and tissues in your body. It only takes a few minutes and does not hurt. Some gel is first put on the area, which is then scanned using a device called a probe. It looks for any abnormal changes, for example, to your lymph glands or spleen.

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call the National Cancer Helpline on 1800 200 700 to speak to one of our specially trained nurses.

What are the types of CLL?

There is a very wide range of CLL types. Usually the B-cell lymphocytes are affected, while the T cells are rarely affected. Some types of CLL can develop quickly. For example, a few patients can later develop other diseases related to CLL. When leukaemia changes from one type to another, it is called transformation. A sudden increase of symptoms, for example, fever, weight loss or swollen glands, may point to a transformation.

CLL can change to prolymphocytic leukaemia (PLL) or a rare type of lymphoma called Richter's syndrome. A condition called autoimmune haemolytic anaemia may develop as a complication of CLL or its treatment with the drug fludarabine. The risk of developing skin cancer is much higher as well. See page 44 for more details.

Do ask your doctor or nurse to explain your type of CLL, if you would like more information.

What are the stages of CLL?

Once all your test results are ready, your doctor will stage your CLL. Staging means getting an overall picture of the level of disease. It is important because it allows your doctor to decide the best treatment for you. The Binet system is one way to stage CLL. It has three stages: A, B and C. It measures your number of white blood cells, if your glands are enlarged, especially in your neck, armpits, groin, liver or spleen, and if you have anaemia or fewer platelets. Stage A is a low level of the disease, B is a medium level, while C is a high level.

Another way to stage CLL is the Rai system. It has five stages (0 to 4). It measures the number of white blood cells, if any lymph nodes are enlarged, if your liver or spleen is affected, and if you have anaemia or fewer platelets. The higher the number, the more advanced the disease.

If you would like more details about your stage of CLL, talk to your doctor or nurse.

>>> Staging allows your doctor to decide on the best treatment for you.



To sum up

- The following tests are used to diagnose CLL: full blood count, blood film, immunophenotyping and cytogenetics.
- Bone marrow tests are not routinely done.
- Other tests may show the extent of CLL: chest X-ray, lymph gland biopsy, CT scan, ultrasound scan.
- Staging measures the extent of CLL and allows your doctor to decide the best treatment for you.
- The Binet or Rai system can be used to stage CLL.



Treatment and side-effects

How is CLL treated?

CLL can vary from person to person. For some people the disease never moves beyond the early stages and you may never need any treatment at all. Or you might not have to start treatment immediately. Other people might have a form that grows more quickly and need treatment sooner. CLL can be treated successfully and you can often live with it for many years.

What does treatment do?

The aim of treatment is to stop the bone marrow making abnormal white blood cells. When this happens, it is called remission and symptoms like tiredness and swollen glands disappear. If CLL returns, it is called a relapse. CLL is rarely cured by current therapy apart from a few patients who have had allogeneic transplants. Even so, the treatments can control your disease and let you live a fairly normal life for some years.

>>> Remission is when no abnormal white cells are found in your blood or bone marrow.

Types of treatment

The treatment of CLL will depend on your age and general health as well as your own wishes and preferences. The stage and type of CLL may also be taken into account. There are a number of ways to manage it:

- Watch and wait (active surveillance)
- Biological therapies
- Chemotherapy
- Stem cell transplant
- Steroid therapy
- Treatment of symptoms

Watch and wait: This is also called active surveillance. It is not a treatment as such but a way of managing CLL. If your disease is not active, you will not receive any treatment but your doctor will watch

your condition closely instead. This is because there may be little or no benefit to treatment at this stage. See page 21 for more details.

Chemotherapy: This is the use of drugs to cure or control the cancer cells. It is the most common way to treat CLL. Chemotherapy may be given on its own or with other treatments like steroids or biological therapies. See page 23 for more details.

Steroid therapy: Steroids are hormones made naturally in your body. They can sometimes help to control CLL when used with other treatments. See page 33 for more details.

Biological therapies: These are drugs that use your body's own immune system to fight cancer. The type used are called monoclonal antibodies. They can be given along with chemotherapy. See page 34 for more details.

Stem cell transplant: A stem cell transplant (or bone marrow transplant) is done in a small number of cases. First, you receive high doses of chemotherapy to kill off all the blood cells in your bone marrow – both abnormal and normal cells. Next you receive stem cells from a suitable donor by means of a transfusion. These donated stem cells can then make new healthy blood cells in your bone marrow. See page 36 for more details.

Treatment of symptoms: Some of your symptoms of CLL may need to be treated straight away. For example, infection, bleeding or anaemia. Treating symptoms is also called supportive care. On rare occasions you might need surgery or radiotherapy. For example, if your spleen is enlarged and causing bleeding problems. See page 38 for more details.

If a treatment is used on its own, it is called monotherapy. If more than one treatment is used, it is known as combination therapy. Radiotherapy is not usually given for CLL, unless it is part of the preparation for a stem cell transplant. Or it may be given if your lymph nodes or spleen are enlarged.

Treatment centres

In Ireland, CLL is treated in specialist cancer centres throughout the country. The staff at these centres have great expertise and experience in managing patients with CLL. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Deciding on treatment

Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers.

Time to think: When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You might want more time to think things through. But remember there is always time for you to consider what sort of treatment you want.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully informed of the benefits and risks.

>>> No medical treatment will be given without your consent.

Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:

- The type of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any major side-effects of the treatment

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again.

Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Individual treatment

You may notice that other people with CLL are not getting the same treatment as you. Their leukaemia may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Do ask your doctor about your own treatment.



>>> Who will be involved in my care?

Some of the following health professionals may be involved in your care. Usually, a team of cancer care doctors will decide your treatment.

Haematologist	A doctor who specialises in treating blood and bone marrow diseases.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Clinical nurse specialist	A specially trained nurse who gives support and information to cancer patients.
Liaison oncology nurse	A specially trained nurse who works in a cancer care unit. She or he can give support and reassure you and your family from diagnosis and throughout treatment.
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
Medical social worker	A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of change. They can give advice on benefits, entitlements and services available to you when you go home.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.



To sum up

- CLL is managed by watch and wait, chemotherapy, steroid therapy, and biological therapies.
- Treatment may also be combined with a stem cell transplant.
- A team of specialists will decide which treatment is best for you.
- Symptoms like infection, anaemia, and bleeding will also be treated.

Watch and wait

You may be diagnosed with CLL but show few signs of active disease. This is because chronic leukaemias usually develop slowly. About one-third of patients with CLL have a form that grows so slowly that no treatment is needed.

As a result, your doctor may decide not to treat you, as there may be little or no benefit at this stage. Instead, you will visit your doctor for check-ups every few months and regular blood samples will be taken. This is called watch and wait or active surveillance. Various tests such as cytogenetics, immunophenotyping and prognostic markers can be done to check how slow growing your CLL is. It may take years for the disease to become active.

Follow-up

You will be advised to get the flu vaccine every year and pneumonia vaccine every 5 years. Do discuss this in more detail with your doctor. Always protect your skin from the effects of the sun, as your risk of skin cancer is higher. If you think you are developing symptoms of CLL, do get them checked out by your doctor. See page 43 for more details on follow-up.

Living with uncertainty

Even if your doctor decides not to treat your CLL, it can still be stressful for you. At first you may be relieved the disease is not active but later worry that it will get worse. This is a very normal reaction.

While it is easy to say ‘don’t worry’, it is not so easy in practice. In fact, it may be very hard not to think about anything else.

Remember that everyone deals with a diagnosis of CLL in his or her own way. But it certainly helps to keep busy with things you enjoy doing. You could distract yourself by reading books, watching films, listening to music, taking walks or doing exercise, yoga or meditation. It can also help to have a few goals. Make a list of things you always wanted to do. As you do them, you can start ticking them off. They can be as simple as taking up a new hobby or spending more time with the people you love. Or else it might be a little adventurous by visiting new places or trying new foods.

Fun and laughter can be a good way to boost your spirits too. Even a good cry can sometimes help. But do share your worries with your partner or a friend who is a good listener. As time goes on you will learn to adjust to the uncertainty, the regular blood tests and the check-ups. It is natural to be more anxious or irritable in the days before each check-up. You may even find it hard to sleep at night.

If you find it difficult to cope or adjust, it may be a good idea to join a support group. These groups have people in the same situation as you who can give you advice and support. Talking to a medical social worker or counsellor might help as well. Your doctor may also be able to calm your fears. See page 74 for more details on support groups.



To sum up

- Chronic leukaemias usually develop slowly.
- About one-third of patients with CLL have a form that grows so slowly that no treatment is needed.
- Your doctor may decide on a watch and wait approach. This involves regular check-up visits and blood tests.

Chemotherapy

The main treatment for CLL is chemotherapy. This is the use of drugs to cure or control the abnormal lymphocytes. These drugs travel through your bloodstream to almost every part of your body. Because they cannot tell the difference between leukaemia cells and normal cells they may cause unwanted side-effects. The main one is the risk of infection. Normal cells recover quickly so most of these side-effects do not last long. For this reason, chemotherapy is given in cycles. It allows time for the normal cells to recover.

You might also receive your chemotherapy as part of a clinical trial. Clinical trials are research studies that find out if the drugs can improve the treatment results. These studies are quite safe. See page 45 for more details about clinical trials.

»»» Chemotherapy is the main treatment for CLL.

How is chemotherapy given?

Chemotherapy drugs can be given as tablets or capsules or injected into a vein. Most drugs given for CLL can be taken as tablets. If given into a vein, it can be as an injection or through an infusion or drip. This is where a fine tube is put into a vein in your arm or on the back of your hand. The chemotherapy is then able to travel to all parts of your body, except your brain. Chemotherapy is usually given in the day ward of the hospital or as an inpatient for a few days. Most chemotherapy tablets can be taken at home.

What drugs are used?

The most commonly used drugs to treat CLL are cyclophosphamide, chlorambucil, steroids, fludarabine and bendamustine. Chlorambucil may be given on its own if you are an older patient. Rituximab, ofatumumab and alemtuzumab are newer drugs that are being used nowadays. These are a type of biological therapy known as monoclonal antibodies.

Before chemotherapy begins, you may be given a tablet called allopurinol to help your kidneys get rid of uric acid. Uric acid can build up in your body when a large number of leukaemia cells are killed by chemotherapy. This in turn can lead to gout and kidney stones. Allopurinol is usually given for the first cycle.

Combination therapy

Your doctor may decide to give you a number of different drugs at the same time. Chemotherapy, steroids and biological therapies can all be combined in various ways. Sometimes the combinations vary from hospital to hospital but they are all recognised treatments. Here are some examples:

- Fludarabine, cyclophosphamide and rituximab (FCR)
- Bendamustine and rituximab (BR)
- Alemtuzumab

See page 33 for more about steroids and page 34 for biological therapies.



If you would like more information on drugs used for CLL, see the Irish Cancer Society website: www.cancer.ie/cancer-information/treatments/chemotherapy/drugs

How much treatment do I need?

Each 4 weeks of treatment counts as 1 cycle. You may receive up to 6 cycles of chemotherapy. The entire course of chemotherapy usually lasts several months. After a few cycles your doctor should have a good idea if you are responding to the drugs or not.

Tests during chemotherapy

During this time you will have regular blood tests to check the effects of the drugs. A bone marrow biopsy may be done as well. A CT scan of your lymph glands during treatment can check how well you are responding. Sometimes a bone scan may also be done. Depending on the results of your tests, sometimes the drug or dosage may need to be changed.



How does my doctor know the treatment is working?

Your doctor will know if your treatment is working by doing some tests. Mostly blood and bone marrow tests will be done during and after your treatment. In general, your doctor measures your response to treatment by:

Minor response: This means there has been a small response to treatment. The CLL is still active.

Partial response: Here your enlarged glands have reduced by half and also the number of abnormal lymphocytes. This means that you have responded to treatment but not completely.

Minimal residue disease (MRD): This means there are very few CLL cells remaining. They can only be found using special blood or bone marrow tests.

Complete response: This means that no traces of CLL can be found. You have no symptoms of the disease such as enlarged glands or a raised number of abnormal lymphocytes. But remember complete response is not the same thing as cure.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the type of drugs used. Your doctors and nurses will let you know what kind of side-effects to expect and how likely they will last.

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

- Infection
- Anaemia
- Bleeding and bruising
- Nausea and vomiting
- Tiredness and fatigue
- Loss of appetite
- Mouth or taste problems
- Diarrhoea
- Constipation
- Hair loss
- Bladder or kidney changes
- Skin and nail changes
- Changes in hearing
- Changes to your nervous system: anxiety, headaches, dizziness
- Aching joints
- Infertility

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

Infection: You will be more prone to infection, especially chest infections. Infection is caused by having fewer white blood cells. This is also called neutropenia and means that your immune system cannot fully fight infections. By not having enough white blood cells, even minor infections such as a cold or sore throat could make you ill. If you have a temperature at home or feel shivery or unwell or have flu-like symptoms, you may need to go to hospital for antibiotics into a vein. Do talk to your doctor or nurse, who will give you more advice.

Growth factors may be given to reduce the risk of infection. These drugs encourage the growth of white blood cells. They are helpful if the number of white cells is low after chemotherapy. The most commonly used one is G-CSF (granulocyte-colony stimulating factor).

>>> Tips & Hints – infection

- Avoid crowds and close contact, such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles or measles.
- Let your doctor know if you are in contact with these or any other infections.
- Wash your hands often during the day, especially before you eat and after going to the toilet.
- Avoid unpasteurised milk, soft cheeses, undercooked meats and poultry, the skin of raw vegetables and of fresh fruit.
- If your temperature goes above 37.5°C (99.5°F), or if you suddenly feel shivery or unwell, contact your doctor or the hospital immediately.



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

A blood transfusion can be given if your red blood cells are low. This will help you to feel more energetic and less breathless. A drug called erythropoietin might also be given.

>>> You may feel tired and weak if you have anaemia.

Bleeding and bruising: Bruising is caused by a reduced number of platelets. This is called thrombocytopenia. Platelets help to make your blood clot and stop bleeding when you hurt yourself. You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes. Bleeding may develop under your skin, usually as blood spots on your legs, feet, trunk and arms. This is known as petechiae. Bleeding gums is also a common sign of low platelets. Do let your nurse or doctor know at once if you have this symptom. You may need a platelet transfusion to help reduce any bleeding or bruising.

Also, use a soft toothbrush when brushing your teeth and an electric razor when shaving. In women, periods can be heavier and longer than usual during the first few chemotherapy cycles. Take care to prevent injury and avoid contact sports. Do not take aspirin as it can increase your risk of bleeding.

>>> You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes.

Nausea and vomiting: Some chemotherapy drugs might make you feel sick (nausea) or vomit. Nowadays this side-effect is well

controlled. You will be given drugs along with your chemotherapy to help prevent it. These are called anti-emetics and can be taken regularly. Even so, you may experience some nausea and vomiting during the first few days after treatment. If you feel sick, fizzy drinks may help or nibbling on dry biscuits and toast.

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

A useful booklet on fatigue is available called *Coping with Fatigue*. If you would like more information or a free copy, call the National Cancer Helpline 1800 200 700. See page 39 for more about fatigue.

Loss of appetite: Some chemotherapy drugs can reduce your appetite for a while. Do get early advice from a dietitian, if this happens.

A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting your appetite. Call the National Cancer Helpline on 1800 200 700 for a free copy.

Mouth or taste problems: Some drugs can cause a dry, sore mouth that can lead to mouth ulcers. Your mouth will gradually clear up but your doctor can prescribe mouthwashes to help in the meantime. If your white cell count is low, the ulcers may become infected. Your doctor may prescribe medication, such as mycostatin, to help prevent or clear infections. Cleaning your teeth regularly and gently with a soft toothbrush will help to keep your mouth clean. If your mouth is very sore, there are gels, creams or pastes available to reduce the soreness. Do ask your nurse for advice.

Your sense of taste may also change during treatment. Food may taste more salty, bitter or metallic. Normal taste will come back once the treatment is over. It is worth trying various types of food and seeing which ones taste better. A booklet called *Diet and Cancer* has some helpful advice on how to manage taste changes. Call the National Cancer Helpline on 1800 200 700 for a free copy.



Tips & Hints – mouth care



- Gently brush your teeth with a small, soft toothbrush five or six times a day, especially after meals and before bedtime. It may help to soften the brush in warm water before brushing.
- Use a mild fluoride toothpaste only.
- If you have dentures, remove them every night and if your gums are sore.
- Use special mouthwashes to keep your mouth clean, fresh and to ease mild soreness or pain.
- Only use mouthwashes recommended by your dentist or nurse. Some mouthwashes contain alcohol and are too harsh.
- Keep your lips moist by using Vaseline® or a flavoured lip balm.
- Sip cool water during the day. Add ice cubes to keep it cool.
- Avoid eating hot, spicy or very cold food and drink.
- Avoid food that might be hard to eat like crusty bread, crispy bacon or crisps.
- Avoid alcohol (especially spirits) and tobacco as they can irritate the lining of your mouth and throat. They can also make side-effects more severe.

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

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

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

Hair loss: Chemotherapy can often cause temporary hair loss. This is also known as alopecia. It usually happens about 3 weeks after the start of treatment. You may lose all your body hair, including your eyelashes and eyebrows. But this can vary from person to person. You might experience some tingling or sensitivity of your scalp just before your hair starts to fall out. This may last a day or so. But your hair will grow back once you have stopped treatment. It usually takes about 6 weeks to grow.

>>> You may have tingling or sensitivity of your scalp before your hair starts to fall out.

It is natural to feel upset, sad, angry or embarrassed at the thought of losing your hair. Don't be afraid to talk to your nurse or medical social worker about your feelings. They will help you to find ways to cope with your hair loss. You can get a wig or hairpiece when this happens, or you may prefer to wear a hat or scarf. Talk to your medical social worker or nurse if you would like a wig or hairpiece. Arrange this before your hair starts to fall out, so that you can get a good colour match to your own hair.



In some cases, it is possible to get financial assistance towards the cost of a wig. Ask your medical social worker or nurse for more information. If you have a medical card, you are entitled to 1–2 free or subsidised wigs every year. Some private health insurers will cover a certain amount of the cost of a wig.

If you would like more details on hair loss, contact the National Cancer Helpline for a free copy of the factsheet, *Hair Loss and Cancer*.

Bladder or kidney changes: Some chemotherapy drugs can irritate your bladder and cause problems with your kidneys. For this reason, you must drink plenty of fluids, about 2 litres a day. If you notice any pain, discomfort or blood on passing urine, tell your doctor at once. You may be given fluids into a vein before you receive chemotherapy each time.

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

Chemotherapy might also make your skin more sensitive to sunlight, during and after treatment. Having CLL also increases your risk of skin cancer. It is best to stay out of the sun during the hottest part of the day. This is normally between 11am and 3pm. You can protect your skin from the sun by wearing a hat, covering your skin with loose clothing, and by using a high skin protection factor (SPF) sunscreen. Call the National Cancer Helpline on 1800 200 700 for more information.

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

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

Changes to your nervous system: Some drugs can cause feelings of anxiety and restlessness, dizziness, sleeplessness or headaches. Some people also find it hard to concentrate. If you have any of these side-effects, let your doctor or nurse know, as medication can often ease them. You may find it helpful to talk to a close relative or friend about your feelings too. If this is not possible, ask your doctor to refer you to a counsellor or psychologist.

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

Infertility and contraception: You may not be able to conceive or father a child due to chemotherapy. As a result, men should consider sperm banking and women should discuss their options with their doctor. This should be done before treatment starts. But do use contraception during treatment as the drugs may harm your baby if you become pregnant. See page 41 for more details on sex and infertility.

Other changes

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

If you would like more information about the side-effects of chemotherapy, contact the National Cancer Helpline for a free copy of the booklet, *Understanding Chemotherapy*.



To sum up

- Chemotherapy is a treatment using drugs to cure or control cancer.
- Chemotherapy can be given in tablet form, directly into a vein as an injection or through an infusion (drip).
- The side-effects vary from person to person and depend on the drugs used.
- Some common side-effects are infection, anaemia, bleeding, nausea and vomiting, fatigue and mouth problems.
- Most side-effects are well controlled with medication.

Steroid therapy

Doctors can prescribe steroids at any stage of your CLL treatment. Steroids are hormones made naturally in your body. They are not a cure for CLL but can help to control it when used with other treatments. Not only can steroids help to treat the disease but also the symptoms of CLL such as anaemia and fatigue. They also do not harm normal cells. Examples of steroids commonly used in CLL are prednisolone and dexamethasone.

They are usually given in tablet form, but might also be given directly into your vein too. The effects of taking steroids may become noticeable after a short time. They can boost your appetite and your energy levels and give a sense of well-being. Do continue taking these tablets as stopping them quickly may cause some health problems.

What are the side-effects of steroids?

High doses of steroids 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

If you develop any of these side-effects, do discuss them with your doctor and nurse. While receiving steroids, you will have regular blood tests 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 upsets.
- Talk to the hospital dietitian if you are putting on weight.
- Report any signs of infection to your doctor and nurse. For example, 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.



Biological therapies

Biological therapies use your body's immune system to fight leukaemia. They can also be used together with chemotherapy. The most common type of biological therapy used in CLL is monoclonal antibodies. Antibodies are proteins made naturally in your body that fight infection and cancer, whereas monoclonal antibodies are special proteins made in the laboratory. Once in your body, they stick to specific proteins on the surface of your white blood cells (lymphocytes) including the abnormal ones. Your immune system then attacks these cells and kills them. Normal lymphocytes can then replace the ones destroyed.

Unlike chemotherapy, biological therapies target cancer cells directly and do not harm normal cells.

What drugs are used?

Rituximab, alemtuzumab and ofatumumab are the most widely used monoclonal antibodies in CLL. Some brand names for these drugs are Rituxan® and MabThera®, Campath®, and Arzerra®.

How are the drugs given?

These drugs are normally given into a vein by drip infusion. For this reason, you will need to stay in the hospital day ward while receiving it. Normally it takes about 4–5 hours to give the first dose. The rate is

slowly increased depending on how well you tolerate the drug. In later cycles it is usually given over 2 hours.

With alemtuzumab, you usually receive it 3 days per week. The treatment may last up to 16 weeks. On the first week, the dose is gradually increased as you tolerate it.

During your treatment, your doctor will do weekly blood tests to check if the drug is working. A response to the drug is usually seen after 4 to 8 weeks. Your doctor will let you know how long you need to receive the drug.

What are the side-effects of biological therapies?

Your doctor and nurse will let you know if there are any side-effects. You will also be given written information to take home with you. But do let them know if you experience any problems. You might experience fever, headache, rashes, chills or feeling sick with the first dose. This is a kind of allergic response but it usually settles down after a short while. Paracetamol and antihistamines may be given for the fever, chills, pain or any allergy symptoms. If you have nausea and vomiting, you may become a little dehydrated. It is best to drink plenty of fluids when taking these drugs.

The following side-effects are known to occur, mainly with alemtuzumab:

- Higher risk of infection
- Low blood pressure
- Bleeding and bruising

You may be prone to infections for up to 2 months after treatment but this may last much longer for some people. Chest infections in particular can occur and need to be treated with antibiotics. The drug too may cause birth defects if you are pregnant or if your partner becomes pregnant. It is best to use a reliable form of birth control to avoid pregnancy during treatment and for at least 12 months afterwards. This is very important whether you are a man or a woman. If a pregnancy occurs while you are using this drug, tell your doctor immediately. See page 41 for more details on fertility issues.

Remember to tell your doctors and nurses straight away if you experience any of the above side-effects or others not listed above. There are many ways to relieve them and make you feel better. These drugs do not cause any hair loss.



To sum up

- Biological therapies use your body's immune system to fight leukaemia.
- Unlike chemotherapy, biological therapies target cancer cells directly and do not harm normal cells.
- The drugs are normally given into a vein by drip infusion, so you stay in the hospital day ward while receiving it.
- You might experience fever, headache, rashes, chills or feeling sick with the first dose.
- Some biological therapies can make you more prone to infection, low blood pressure, and bruising and bleeding.

Stem cell transplant

A small number of people with CLL may need a stem cell transplant to treat their disease. Stem cells are found in your bone marrow and can grow into many types of blood cells. The aim is to give you high doses of chemotherapy to destroy the blood cells in your bone marrow, both normal and abnormal cells, and replace them with stem cells. You then receive stem cells donated from a suitable relative or someone unrelated to you in a transfusion. This is called an allogeneic transplant or allograft. These stem cells can then grow into new healthy blood cells. In some cases bone marrow will be transplanted instead of stem cells.

Because it is an intensive treatment it is not suitable for everyone. You may benefit from a transplant if you are younger, under 60, fit and in good health. The results of cytogenetic tests are likely to be considered too.

Your doctor will discuss with you if your type of CLL is suitable for a transplant. After that, he or she can arrange tests on your kidneys, heart and lungs to check they are working well. For more information on transplants, contact the National Cancer Helpline on 1800 200 700.

What happens in a stem cell transplant?

Stem cell transplants take place in special treatment units only. You may spend up to 6 weeks in hospital from the time you come in for the transplant until you are ready to go home. Usually you are admitted to the hospital a week before the transplant. This allows time for more tests and to put in a special drip called a Hickman line so that you can receive the stem cells.

You will be given very high doses of chemotherapy to kill all the blood cells in your bone marrow – both abnormal and normal cells. In some cases you may also receive total body radiation to kill any remaining abnormal cells. For more information about radiotherapy, call the National Cancer Helpline on 1800 200 700 and ask for the free booklet, *Understanding Radiotherapy*.

The stem cells are collected from your donor. This is done using a machine called a stem cell separator or apheresis machine. The fresh stem cells are then given to you as a transfusion. After receiving the stem cells you will need to take anti-rejection (immunosuppressive) drugs daily. You then have to wait for the stem cells to settle in your bone marrow and start to grow and make new blood cells. It can take from 2 to 3 weeks for the new white blood cells to develop. Your doctor and nurse at the unit will give you more information about the transplant.

After the transplant

After the transplant your white cell count will be very low. This means your immune system will be very low and the risk of infection high. For this reason you will be nursed in a single room away from other patients and hospital staff during the transplant phase. You may also need antibiotics for this period. During your time in isolation your visitors might be restricted. The hospital staff will also explain any precautions you may have to take with food, etc. Because there is also a risk of developing anaemia and bleeding, you may need blood or platelet transfusions at this time too.

Going home

In general you can go home once your blood count is at a safe level.

This means that your bone marrow is now making normal blood cells. You may find that for the first 6 to 12 months that you are in and out of hospital for regular check-ups, antibiotics or blood transfusions.

If you would like more information, contact the National Cancer Helpline on 1800 200 700.



To sum up

- A few patients with CLL will need a stem cell transplant. It depends on your type of CLL and if you are younger and in good health.
- The treatment destroys all the blood cells in your bone marrow and provides you with stem cells to make healthy new blood cells.
- Allogeneic transplants mean that the stem cells are taken from another person. This could be a relative or someone unrelated to you.
- You are nursed in isolation after the transplant because the risk of infection is high.

How can my symptoms be relieved?

Treating symptoms is called supportive care. Some symptoms of CLL may need to be treated straight away. For example, infection, anaemia, bleeding or an enlarged spleen. You will also be checked closely for any signs or symptoms of the disease getting worse. Do let your doctor know if you develop any new symptoms.

Infection

If your white blood cells are low, you will be prone to infections. These can include viral ones like colds, shingles and chickenpox. Bacterial infections such as pneumonias can also occur. You may be prescribed antiviral or antibiotic medications to prevent infection. Antibodies called immunoglobulins may also be given to boost your immune system. At the hospital these are given by injection into a vein in your arm. You may need repeated doses of immunoglobulins while receiving chemotherapy too. Do discuss with your doctor if you need any vaccinations.

Anaemia and bleeding problems

If the number of your red blood cells is low, it can lead to fatigue and shortness of breath. If your platelets are low, you may have bleeding gums and find it hard to stop the bleeding from simple cuts and bruises. In both cases you may need to receive blood transfusions before and during your treatment.

Enlarged spleen

Some people with CLL get an enlarged spleen. This can cause pain as well as bleeding problems. Your doctors may prescribe painkillers to ease any pain or discomfort you have. Radiotherapy may also be used to ease the pain or reduce the swelling. A small dose is normally only needed. Usually, you attend the radiotherapy unit for 5 days (Monday to Friday) for 2 weeks for the treatment. The main side-effects of radiotherapy are skin changes like sunburn to the area being treated, tiredness, and a higher risk of infection. These are usually short term and do not last long. Call the National Cancer Helpline on 1800 200 700 for more information about radiotherapy or a copy of the free booklet, *Understanding Radiotherapy*.

In rare cases, your doctor may decide to remove your spleen. This operation is called a splenectomy and you will be referred to a surgeon. The surgery can relieve pressure but it is not a cure for CLL.

Fatigue

Fatigue is a common symptom of leukaemia and described as an overwhelming tiredness. Often it is not relieved by rest. You may also find it hard to concentrate or make decisions. The reason for the fatigue can sometimes be hard to identify. It can be due to anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are some things that may help.

For many patients, treatment may help by relieving symptoms such as anaemia, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try

talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, do some regularly. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.



Tips & Hints – fatigue



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

Will treatment affect my sex life and fertility?

Sex and sexuality

For some people sex is an important part of their relationships, while it is less so for others. Coming to terms with the fact that you have leukaemia can take quite a while. It may even affect your sex life. Your emotions will be turned upside down and it can be hard to relax when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment or from your symptoms. As a result, you may lose interest in sex. Do not worry about this, as it is quite normal.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine, your interest in sex should return too. If you have any queries about how treatment may affect your sex life, do talk to your doctor.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is safe for you to have sex again with your partner. But be careful about the risk of infection during sex. Do talk to your doctor and nurse for more advice on this matter.

Contraception

Some types of drugs used to treat CLL should not be taken during pregnancy, as they may harm your unborn child. For example, fludarabine and alemtuzumab. For this reason, you should use reliable contraceptives or stop having sex, if you prefer, so that you or your partner do not become pregnant. Both you and your partner should use contraceptive precautions during treatment and for at least

12 months afterwards. Do ask your doctor for more advice. He or she will let you know how long you should take contraceptive precautions. Remember treatment for CLL does not always cause infertility. If you do get pregnant, tell your doctor straight away.

Also, you may be told not to breastfeed during treatment and for 4 weeks afterwards, as the drugs may be passed on to your baby.

Fertility

Some drugs used to treat CLL can cause either short term or lasting infertility. It all depends on your type of treatment and your age at diagnosis. Your doctor will explain this in more detail to you before treatment begins. Bring your partner along when meeting your doctor so both of you can discuss your concerns.

Women and infertility

Chemotherapy can damage your ovaries and reduce the amount of hormones made. This means that you cannot get pregnant. This infertility may be temporary or permanent. It will all depend on the type and dose of drugs used in your CLL treatment and your age. If you receive a stem cell transplant, you are likely to be permanently infertile after treatment.

Before starting treatment, do talk to your doctor about the possibility of egg banking. This involves freezing and storing your eggs for future use. It is carried out at the HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin. For further information, talk to your doctor. You can also call the National Cancer Helpline on 1800 200 700 for more details and advice. See page 73 for details about contacting the HARI Unit for an information leaflet.

In general most women who receive treatment for CLL have been through the menopause. But there is a small number that has not. In this case, you may find that your periods become irregular or stop altogether. The nearer you are to the menopause, chemotherapy is more likely to stop your periods permanently. Talk to your doctor if you experience any symptoms such as hot flushes, a dry vagina and skin, and loss of interest in sex. He or she may prescribe hormone replacement therapy (HRT). If you are a younger woman, your periods

may return to normal after treatment, so it is important to continue taking contraceptive precautions during and after treatment.

Men and infertility

Chemotherapy drugs can lower your number of sperm cells and reduce their mobility, causing infertility. These changes may be temporary or permanent. Before treatment begins, do 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 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 doctor. You can also call the National Cancer Helpline on 1800 200 700 for more details and advice. See page 73 for details about contacting the HARI Unit for an information leaflet.

Coping with infertility

It is not easy to come to terms with infertility. You may feel devastated if told that you can no longer have a child in the future. It can bring deep feelings of loss and sadness. You may find it helpful to talk openly to your partner or a friend about these feelings. It is important to talk to your doctor or nurse too. He or she may arrange for you to speak to a trained counsellor or a specialist, if you cannot deal with any strong emotions that you might have. Do seek professional help if infertility is likely to trouble you.

What follow-up do I need?

Once you are in remission, you can begin to return to normal life. But you will still need to come back for regular check-ups. This is called follow-up. At the outpatient clinic, your doctor will examine you and blood tests will be done. Other tests can be arranged if needed. At first, these check-ups may be quite often but will become less frequent the longer you are well and free from illness. Sometimes you may need to go to hospital if you get an infection, as your immune system takes time to recover.

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

What should I do when in remission?

Taking care of your health: Watch out for any signs of infection or other problems. In particular, some people may experience pneumonia or other lung problems. You may find that you have excess mucus, coughing, pain, blocked sinuses or the sniffles. It is best to get the flu vaccine each winter too and the pneumonia vaccine every 5 years. Also, take good care of your mouth, teeth or dentures, as they can be a source of infection. If you develop any bowel problems such as ongoing abdominal pain, diarrhoea, bleeding or constipation, contact your doctor as soon as possible.

Cancer risk: Having CLL puts you at a higher risk of developing other cancers. For example, skin, prostate and lung cancers. It is best to avoid the sun at the hottest part of the day and look out for any skin changes. See the Sunsmart code at www.cancer.ie/reduce-your-risk/sunsmart. Do visit your GP every year so he or she can check for prostate cancer and do a PSA test and rectal exam. There is also help available if you smoke and would like to stop. Call the National Smokers' Quitline on 1800 201 203 for support.

Work and activities: If you stopped working during treatment, you can start to go back to your job. But you might want to take it slowly at first by working part-time or reduced hours. You can also resume other activities such as sport, hobbies and other pastimes.

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



Research – what is a clinical trial?



Research into new ways of treating CLL goes on all the time. At present, there is an ongoing All-Ireland clinical trial in CLL. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating leukaemia. Many patients take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

Your doctor will let you know if you and your type of CLL are suitable for a trial.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about leukaemia and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your blood cells or bone marrow.

For a copy of our factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit our website www.cancer.ie/cancer-information/treatments/clinical-trials

Cancer and complementary therapies

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

Conventional therapies

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

Complementary therapies

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

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- 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 it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy can often be

restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.

Most doctors do not believe that such treatments can cure or control cancer.



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



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

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

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700.

National Cancer Helpline 1800 200 700



Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.

Shock and disbelief

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

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot 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 cancer 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. You think the worst. But nowadays many cancers can be cured or controlled with modern treatments.

Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some leukaemias cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, 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 cancer will recur. 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, nurse or medical social worker, 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 cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about 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. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

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

>>> 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 let
my family down.'*

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

Depending on your type of cancer, your fertility or body image 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 cancer.'*

Sometimes after being told their diagnosis, people deny they have leukaemia. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you do not want to hear any information about your leukaemia until you are ready.

National Cancer Helpline 1800 200 700

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

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

Resentment

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

It is natural that you might be resentful and unhappy – even jealous – because you have 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 your healthy relatives or having to change your lifestyle in some way.

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

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

Blame and guilt

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

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

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

Withdrawal and isolation

'I just need to be on my own.'

It is true that a leukaemia diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal 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 cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700.

Learning to cope

After any treatment for leukaemia it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people are able to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give you more support.

How can my family and friends help?

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



How to talk to someone with 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 you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from leukaemia, many do not. Be honest with your own feelings too.

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

Be patient

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

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy.

How can I talk to my children?

As CLL is a disease of older age, your children are more likely to be adults. Even so, you may still try to protect them from your illness. You may feel that you do not want to upset your family life, or feel guilty that you cannot do activities with your children or grandchildren or that you are letting them down. These are all natural feelings to have at this time.

Even so, it is best to keep family life as normal as possible. Continue with activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Be honest

Every family deals with cancer in its own way. 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 family. It can put added pressures on them and lead to confusion. If you have very young children, they can be very sensitive to stress and tension. And if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news. Do prepare your family for the side-effects of treatment before they happen and answer their questions simply and honestly. For example, if you get hair loss due to treatment.

If you need some extra help in dealing with young children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a free copy, call the National Cancer Helpline on 1800 200 700.

What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer 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 leukaemia but also about you as a person. Here is a list of things to help 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: Do not 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.

Live well: Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

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 for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

Keep an open mind: Do not feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but do not feel guilty about it, as it will pass.

Seek information: Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. 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. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. 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. Call 1800 200 700 for a free copy of the *Journey Journal* to help you keep track of your cancer treatment.

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, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it is 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.

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 these moods and 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 cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies 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 to make sense of your cancer journey 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 on 1800 200 700 if you would like a free copy.

Caring for someone with CLL

Being a carer of someone with leukaemia can be both a challenging and a rewarding experience. In practice carers provide all sorts of emotional and physical support. It is true that caring for a loved one can bring great personal satisfaction. But there can be times when it is tiring, frustrating, distressing and isolating. You may become a carer overnight and feel that you are not experienced to handle the care of your relative or friend. And because leukaemia is an unpredictable illness, you may be worried or anxious about the future, have fears about the effects of treatment, of relapses, and about future tests. To keep your strength and spirits up, it is important to take good care of yourself. And remember to ask and accept help when you need it.



Tips & Hints – for carers



- **Information:** Find out as much information as possible about CLL, especially its symptoms, treatment and side-effects. Talk to the doctor, nurses, National Cancer Helpline, and so on. Get information too about financial supports and community services from the medical social worker or see the back of this booklet for details.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency.
- **Physical care:** Being a carer may involve helping your relative or friend with mobility, bathing and dressing, giving meals and medication. Ask the nurses for advice with any of these tasks.
- **Eating and drinking:** Gently encourage your relative or friend to eat but do not push them. Pre-prepare snacks for the times when they feel like eating.
- **Help:** Take up all offers of help, especially with finances, cooking, housework, shopping. Do not get weighed down by all your friend or relative's needs. Expect ups and downs with treatment. If you find it hard to cope, get help. There are many healthcare professionals to help you. Find out about self-help groups too, especially those for carers of people with leukaemia.

- **Caring for yourself:** Look after your own health too. Take regular meals and exercise. See your doctor sooner rather than later if you have any health concerns of your own. Talk to your doctor about any worries you have about caring for your relative or friend.
- **Time for yourself:** Make sure you share your worries with someone else. Stay in touch with your own friends. Get out when you can – even if you don't feel like it. Make time for a break each day: a walk to the shops, a trip to the library or cinema, or an evening out with friends. Give yourself little treats at home. Read a favourite magazine, sit down for a leisurely cup of tea or coffee, or have a relaxing soak in the bath.



Support resources

Who else can help?

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

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

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

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse coordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These nurses along with other members of your medical team work together to meet your needs.

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

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

Community health services: When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the medical social worker in the hospital before you go home or at your local health centre.

Cancer support groups and centres: 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. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet.

Irish Cancer Society: The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information or practical advice about your financial matters. For example, getting life insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

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

Health cover

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

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



At the end of this section there are 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 €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the 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 as well as outpatient services and medical appliances. You may have to pay a prescription charge of 50c per item up to a limit of €10 per family per month.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer 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 GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your

after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital 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 dependent children, pay a limit of €132 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance, for example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



For a free copy of *Social Welfare Support: A Guide for Cancer Patients*, contact the National Cancer Helpline on 1800 200 700.

Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, 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. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. 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 will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas,

electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your medical social worker and/or the Dept of Social Protection.

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) 334 0000 or Locall 1890 927 770.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might 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. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Leave

By law you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for

up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances

For patients who have medical cards most appliances are free of charge or subsidised.

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services 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, like hardship.

See page 72 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you.

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:

Dept of Social Protection – Information Service

Oisín House

212–213 Pearse Street

Dublin 2

Tel: 1850 662 244

Leaflet line: 1890 202 325

Email: info@welfare.ie

Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

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

HSE East Coast Area

[Co Wicklow, South East Dublin]

Southern Cross House

Southern Cross Business Park

Boghall Road

Bray

Co Wicklow

Tel: 01 201 4200

HSE Midland Area

[Counties Laois, Offaly, Longford,

Westmeath]

Head Office

Arden Road

Tullamore

Co Offaly

Tel: 057 932 1868

HSE Northern Area

[North Dublin]

Swords Business Campus

Balheary Road

Swords

Co Dublin

Tel: 01 813 1800

HSE Mid-Western Area

[Counties Clare, Limerick, Tipperary

North]

Head Office

31/33 Catherine Street

Limerick

Tel: 061 483 286

HSE South Western Area

[Co Kildare, West Wicklow, South Dublin]

Oak House

Millennium Park

Naas

Co Kildare

Tel: 045 880 400

HSE North Eastern Area

[Counties Cavan, Monaghan, Louth and

Meath]

Head Office

Navan Road

Kells

Co Meath

Tel: 046 928 0500

HSE North Western Area

[Counties Donegal, Sligo, Leitrim and

West Cavan]

Head Office

Manorhamilton

Co Leitrim

Tel: 071 982 0400 / 1850 636 313

HSE South Eastern Area

[Counties Carlow, Kilkenny, Wexford,

Waterford, South Tipperary]

Head Office

Lacken

Dublin Road

Kilkenny

Tel: 056 778 4100

HSE Southern Area

[Counties Cork and Kerry]

Head Office

Wilton Road

Cork

Tel: 021 454 5011

HSE Western Area

[Counties Galway, Mayo and

Roscommon]

Head Office

Merlin Park Regional Hospital

Galway

Tel: 091 751 131

Information is also available from your local Citizens Advice Centre.

Citizens Information Board (formerly Comhairle)

Tel: 01 605 9000; Locall 1800 777 121

Email: info@ciboard.ie; Website: www.citizensinformation.ie



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 72 for more details. You can also call the National Cancer Helpline 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 73 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 79 for more information.

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.

- Cancer Information Service (CIS)
- Daffodil Centres providing cancer information
- Cancer support groups
- Peer-to-peer support
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets
- Financial support
- Care to Drive transport project



Cancer Information Service (CIS)

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

- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- **Message Board** is a discussion space on our website (www.irishcancer.ie) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.

Daffodil Centres providing cancer information

Daffodil Centres are located in a number of Irish hospitals. These have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service.

They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

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

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 74 for more details.

Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. The Irish Cancer Society can put you in touch with someone who has been trained to give you emotional and practical support. All volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

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

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find

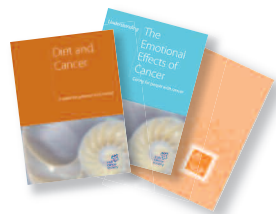
out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

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

Cancer information booklets

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 Society.



Financial support

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 help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.

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

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society.

Financial Aid: For this kind of help, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society.

See our website for more information: www.cancer.ie

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected and trained. You, the patient, are collected from your home, driven to your appointment and brought back home again.

For more information on any of the above services, call the National Cancer Helpline on 1800 200 700.



Useful organisations

Irish Cancer Society

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

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2933
Email: info@carersireland.com
Website: www.carersireland.com

Dept of Social Protection

Information Service
Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244
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

Irish Nutrition & Dietetic Institute

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

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Freefone 1890 283 438
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

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

Quinn Healthcare (formerly BUPA)
Mill Island
Fermoy
Co Cork
Locall: 1890 700 890
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

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

National support groups

ARC Cancer Support Centres
Dublin and Cork (see pages 75 and 76).

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

I've Got What?!
[Support for young adults affected by cancer]
c/o Cross Cause Charity Shop
Blackrock
Co Louth
Tel: 086 339 5690

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

Connaught support groups & centres

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

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

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

CD's Helping Hands
Lakeview Point
Corporate Park
Claregalway
Co Galway
Tel: 091 799 749
Email: info@cdshelpinghands.ie
Website: www.cdshelpinghands.ie

Gort Cancer Support Group
The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220

Inis Aobhinn – Cancer Care West
Costello Road
University Hospital Galway
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

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

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

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

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

Leinster support groups & centres

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

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

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

Balbriggan Cancer Support Group
74 Castleland
Parkview
Balbriggan
Co Dublin
Tel: 086 164 2234

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

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

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

Dundalk Cancer Support Group
Philipstown
Hackballs Cross
Dundalk
Co Louth
Tel: 086 107 4257

Éist – Carlow Cancer Support Group
5 Mount Clare Court
Carlow
Tel: 085 144 0510

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 086 195 9864
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

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

HOPE

Enniscorthy Cancer Support & Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie

Lakelands Area Retreat & Cancer Centre

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

Little Way Cancer Support Centre

4 Woods Way
College Road
Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website: www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 863 3725

Manorhamilton Cancer Support Group (Leitrim)

Tel: Maura Farry 071 985 6220

Rathdrum Cancer Support Centre

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

Stillorgan Cancer Support

c/o Marsham Court
Stillorgan
Co Dublin
Tel: 01 288 5725

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486

Wicklow Cancer Support Centre

1 Morton's Lane
Wicklow
Tel: 087 691 4657 / 0404 32696

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

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

CARE – Cancer Support Centre

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

Cork ARC Cancer Support House

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

Kerry Cancer Support Group

Acorn Centre
47 Liosdara
Oakpark
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@live.ie
Website: www.kerrycancersupport.com

Listowel Cancer Support Group

Bedford
Listowel
Co Kerry
Tel: 068 21741 / 087 237 0766

Recovery Haven

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

Sláinte an Chláir: Clare Cancer Support

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

South East Cancer Foundation

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

Suimhneas Cancer Support Centre

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

Suir Haven Cancer Support Centre

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

Youghal Cancer Support Group

161 North Main Street
Youghal
Co Cork
Tel: 024 92353

West Cork Cancer Support

Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

Ulster support groups & centres**Cootehill Community Centre Support Group**

Cootehill
Co Cavan
Tel: 087 622 0000

Éist – East Inishowen Cancer Support Group

c/o Serenity House
2 Montgomery Terrace
Moville
Co Donegal
Tel: 074 938 2874

Gary Kelly Support Centre

Monaghan
Tel: 086 195 9864 / 041 980 5100

Living Beyond Cancer

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

Solace – Donegal Cancer Support Centre

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

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

Useful contacts outside Republic of Ireland

Action Cancer

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

American Cancer Society

Website: www.cancer.org

Association of Online Cancer Resources

Website: www.acor.org

Cancer Network Buddies

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

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

Chronic Lymphocytic Leukaemia

Frequently Asked Questions
Website: http://clfaq.info/

Healthtalkonline

Website: www.healthtalkonline.org

Leukaemia & Lymphoma Research

Website:
www.leukaemialymphomaresearch.org.uk

Leukaemia Foundation of Australia

Website: www.leukaemia.com

Macmillan Cancer Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

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

National Cancer Institute (US)

Website: www.nci.nih.gov

Ulster Cancer Foundation

40/42 Eglantine Avenue
Belfast 9BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

Helpful books

Free booklets from the Irish Cancer Society:

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



Chronic Lymphocytic Leukaemia

Leukaemia & Lymphoma Research, 2011
[Download from
www.leukaemialymphomaresearch.org.uk]

Adult Leukaemia: A Comprehensive Guide for Patients and Families

Barbara Lackritz
O'Reilly, 2004
ISBN 0596500017

Understanding Leukaemia and Related Cancers

Tariq Mughal & John Goldman
Blackwell Science, 1998
ISBN 0632053461

101+ Square Meals

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

Explaining cancer to children

The Secret C: Straight Talking About Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Helpful DVD

A Guide to Chemotherapy
HSE/Mid-Western Cancer Centre/ICS,
2008
[Call 1800 200 700 for a copy.]



Questions to ask your doctor

Here is a list of questions that you might like to 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 tests will diagnose CLL?
- What stage is my CLL at?
- What symptoms should I watch for?
- What are my treatment options?
- What is the aim of my treatment?
- How is the treatment given and how long will it last?
- Do I have to stay in hospital for treatment?
- Do I need other types of treatment?
- What are the chances of my CLL going into remission?
- What side-effects can I expect? Will they last long?
- Do I need to use contraception during my treatment?
- Will treatment affect my chances of having children?
- How often do I need check-ups and blood tests after treatment?
- How will I know if my CLL has come back?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

>>> **Notes**



>>> **Notes**



Acknowledgements

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

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

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

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

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