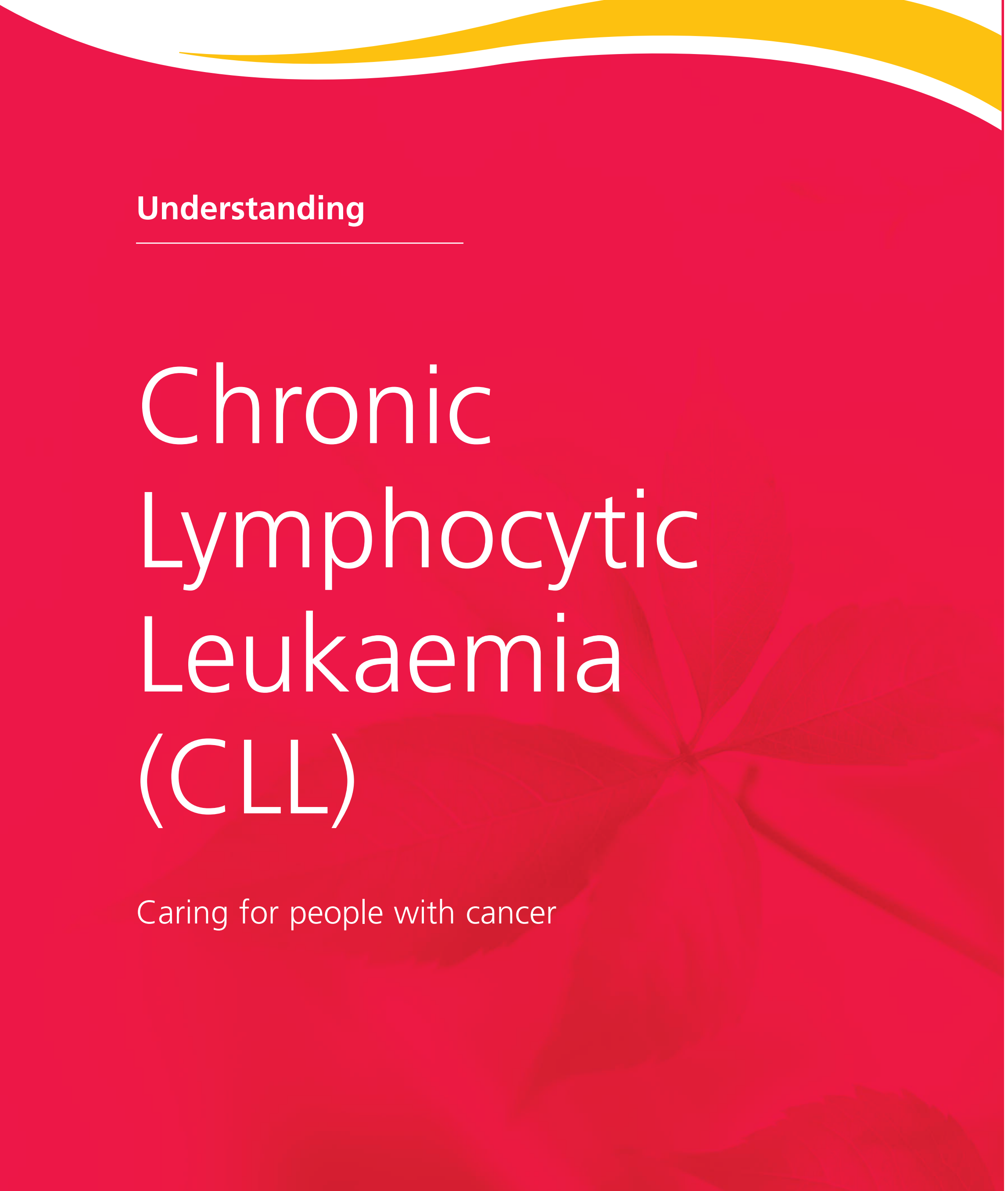
Irish
Cancer
Society



Understanding

# Chronic Lymphocytic Leukaemia (CLL)

Caring for people with cancer

## Understanding

# Chronic lymphocytic leukaemia (CLL)

This booklet has been written to help you understand more about chronic lymphocytic leukaemia (CLL). If you have small lymphocytic lymphoma (SLL), you may also find this booklet helpful, as the two diseases are very similar. It has been prepared and checked by haematologists (specialists in diseases of the blood and bone marrow), 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.

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

| | Name | Telephone |
|---|---|---|
| Specialist nurse | | |
| Family doctor (GP) | | |
| Haematologist | | |
| Medical oncologist | | |
| Medical social worker | | |
| Emergency | | |

This booklet has been produced by 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.

We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to previous editions of this booklet.

LEUKAEMIA ADVISERS
Dr Ronan Desmond, Consultant Haematologist
Karena Maher, Haematology Clinical Nurse Specialist

PATIENT REVIEWERS
Chronic Lymphocytic Leukaemia Ireland (CLLI)

CONTRIBUTORS
Emer Hannigan, Cancer Nurseline Nurse
Anne-Marie McGrath, Cancer Nurseline Nurse

EDITOR
Sarah Lane

The following sources were used in the publication of this booklet:

- *Guidelines on the diagnosis and management of chronic lymphocytic leukaemia.* British Society for Haematology. British Journal of Haematology 125, 2004.
- *A Strategy for Cancer Control in Ireland.* National Cancer Forum, 2006.
- *Cancer in Ireland: A Summary, 1994–2007.* National Cancer Registry Ireland, 2009.
- *Cancer Nursing: Principles and Practice.* CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.
- *The Chemotherapy Source Book.* M Perry. Lippincott Williams and Wilkins, 1997.

Published in Ireland by the Irish Cancer Society.

Next revision: 2019

ISBN 0953236901

# Contents

## About CLL

## Treatment and side-effects

## Coping and emotions

## Support resources

# Introduction

This booklet has been written to help you understand more about chronic lymphocytic leukaemia (CLL). CLL causes your bone marrow to make abnormal white blood cells.

The booklet is divided into four parts:

- **About CLL** gives an introduction to CLL, including causes and symptoms.
- **Treatment and side-effects** looks at the different treatments and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having cancer.
- **Support resources** gives information on where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout the booklet.

We hope this booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on your particular cancer and your individual circumstances.

## Reading this booklet

You don't need to know everything about CLL straight away. Read a section about a particular item as it happens to you. Then when you 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 our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 51 for more information about Daffodil Centres. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

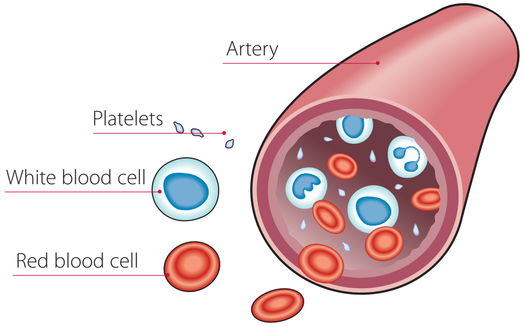
# About CLL

## About blood cells

Your body produces 3 main types of blood cells:

- **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.

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 breast bone. The smallest and most immature type of cells found in your bone marrow are called stem cells.



Blood cells

Once these cells are made, they leave your bone marrow and enter your bloodstream. 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.

## What is leukaemia?

Leukaemia is caused when your bone marrow makes too many white cells. Sometimes it is simply called blood cancer. Other cells such as red blood cells or platelets can be affected as well.

When leukaemia develops, immature blood cells (blast 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 there.

## Types of leukaemia

There are four main types of leukaemia:

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

The names of the different types of leukaemia describe which type of cell is affected and how fast-growing the leukaemia is.

**Lymphocytic leukaemia** affects lymphocyte white blood cells, which develop from lymphoid stem cells.

**Myeloid leukaemia** affects granulocyte white blood cells, which develop from myeloid stem cells.

## What do 'chronic' and 'acute' mean?

'Chronic' and 'acute' refer to how quickly leukaemia develops.

**Chronic:** The leukaemia develops slowly, usually over months or years.

**Acute:** The leukaemia develops very quickly, over days and weeks.

This booklet is about CLL. For free booklets on the other types of leukaemia, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download booklets from our website **www.cancer.ie**

### Types of lymphocyte cells

Lymphocytes are a type of white blood cell and are divided into T cells, B cells and NK (natural killer) cells.

- **NK cells** release chemicals that kill diseased cells
- **B cells** make antibodies that mark bacteria (bugs) for killing
- **T cells** warn your body that there are bacteria (bugs) in the body and help kill diseased cells

CLL usually affects the B cells.

### To sum up

- Leukaemia is a cancer of your white blood cells and bone marrow.
- Leukaemia cells can either develop rapidly (acute) or slowly (chronic)
- Leukaemia can affect granulocyte white blood cells (myeloid leukaemia) or lymphocyte white blood cells (lymphocytic leukaemia).
- White blood cells protect your body against infection.

# What is chronic lymphocytic leukaemia (CLL)?

CLL is a type of leukaemia (cancer of the blood). CLL is usually a slow-growing cancer of lymphocyte white blood cells. The cancer stops the white blood cells working properly to fight infection. CLL also means that the lymphocytes don't die off naturally at the end of their life span. The cells may build up in your lymph nodes and spleen, causing them to become swollen. They can also build up in your bone marrow, meaning there is not enough space for normal blood cells to develop. This causes problems with fighting infection, carrying oxygen and bleeding. Many people with slow growing CLL can live a normal life. Other people experience symptoms that affect their quality of life at different stages of their disease and treatment.

## Small lymphocytic lymphoma (SLL)

CLL and SLL both affect lymphocytes. The difference between CLL and SLL is where the cancer is mainly found.

**CLL:** Most of the cancer cells are in the blood and the bone marrow. The lymph nodes and spleen may be affected too.

**SLL:** Most of the cancer cells are in the lymph nodes.

Treatment and care for SLL and CLL are very similar. If you have SLL and need more specific information, you can call our Cancer Nurseline on 1800 200 700.

## Transformation

Occasionally CLL cells can change (transform) into different types of blood cancers (such as Richter's syndrome, a fast-growing cancer of the lymphatic system or prolymphocytic leukaemia – PLL). This is very rare and may occur with a sudden increase in symptoms. For example, fevers, extensive weight loss and swollen glands. If your CLL transforms into a faster-growing cancer, you are more likely to need immediate treatment. You doctor will advise you about your treatment options.

## Complications from CLL

- **Skin cancer**
  CLL may increase your risk of developing skin cancers. It is important to wear sunblock and protect your skin from the sun. Make sure you go to your doctor if you notice any change in your skin, so that he or she can examine you.
- **Blood conditions**
  **Autoimmune haemolytic anaemia:** CLL or treatment for CLL may upset your immune system, causing a big drop in red cell production in your body. This is called autoimmune haemolytic anaemia (AIHA).

  **Idiopathic thrombocytopenic purpura:** CLL may also trigger the body to destroy healthy platelet cells. This is called idiopathic thrombocytopenic purpura (ITP).

These blood conditions are very rare. Your doctor and nurse will discuss treatment options with you, if needed.

If you have any questions or concerns about CLL, ask your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700.

## How common is CLL?

CLL is a common type of leukaemia, but it is still a fairly rare cancer. About 230 people are diagnosed with it in Ireland every year. It is more common in older age groups and in men.

# What increases my risk of CLL?

The exact cause of CLL is unknown. But there are certain risk factors that can increase your chance of getting the disease. Having a risk factor doesn't mean you will definitely get cancer. Sometimes people without any known risk factor develop cancer.

Risk factors for CLL include:

**Age:** CLL occurs mainly in people over the age of 50. More than half of people are aged over 70 years when they are first diagnosed. It rarely affects people under 40 and does not affect children.

**Gender:** It is more common in men than women.

**Family history:** There is a genetic / family connection with developing CLL. If your parent, brother or sister has CLL, your risk of developing it is 6 to 9 times greater.

**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.

CLL is not infectious and cannot be passed on to other people. If you feel you may be at risk, first talk to your family doctor (GP) about your concerns. He or she may advise you to visit a specialist.

# What are the symptoms of CLL?

CLL usually develops very slowly, so there may be no symptoms in the early stages. In fact, many people are diagnosed by accident, when they have a blood test that shows abnormal levels of white blood cells.

The most common symptoms of CLL are:

- Getting infections more often, and recovering more slowly from infections
- Tiredness and looking pale
- Weight loss / loss of appetite
- Night sweats and fever
- Shortness of breath
- Headaches
- Swelling of your spleen and / or tenderness on the left side of your abdomen, caused by an enlarged spleen
- Swollen lymph nodes
- Aching bones and joints
- Unexplained bruising or bleeding

››› If you have any symptoms that are troubling you or new symptoms appear, tell your doctor.

# Being diagnosed with CLL

Hearing the words ‘leukaemia’ and ‘cancer’ can be a huge shock. After your diagnosis you may feel:

- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Scared about the future

If you need to talk to someone, or if you want more information or advice:

- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.
- Email our cancer nurses at cancernurseline@irishcancer.ie

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to understand CLL and give you support.
- Talk to other people going through the same thing. Join our online community at **http://www.cancer.ie/community**

## Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people’s reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand*, which can help you find ways to talk about your cancer and to ask for the help and support you need.

## To sum up

- CLL is a cancer of the lymphocyte white blood cells. The abnormal cells stop normal blood cells developing.
- The cause of CLL is unknown, but things that increase your risk are being older, being male and having a family history of CLL.
- CLL often develops very slowly, so there may be no symptoms in the early stages.
- Symptoms include repeated infections, tiredness, weight loss, night sweats, swollen lymph nodes and swelling or pain in your spleen.

# What tests will I have?

The following tests give doctors more information about your CLL. Some may also be used to monitor your response to treatment:

**Full blood count:** A full blood count (FBC) finds out the levels of the different types of blood cells in your blood. This test can also give your doctor information about your general health. This is an important test as CLL affects the blood cells. Ask your doctor if you don't understand what your blood test results mean.

## Normal blood cell counts

| Blood cell type | Normal levels |
|---|---|
| Haemoglobin | 13-18g/dl (men)<br>11.5-16.5 g/dl (women) |
| White blood cells (WBC) | 4.0-11.0 x $10^9$/l |
| Neutrophils | 2.0-7.5 x $10^9$/l |
| Lymphocytes | 1.5-4.5 x $10^9$/l |
| Basophils | up to 0.01 x $10^9$/l (0-1% of WBC) |
| Platelets | 150-400 x $10^9$/l |
| Eosinophils | 0.04-0.4 |
| Monocytes | 0.2-0.8 |

**Blood film:** Your doctor may look at a blood sample under a microscope in order to see the amount of leukaemia cells present. This is often called a blood film and is usually carried out in the haematology laboratory of the hospital.

**Bone marrow tests:** Bone marrow tests involve taking a tiny sample (biopsy) of your bone marrow and looking at it under a microscope to see how much CLL is there. The sample is taken from your hipbone. If the sample of bone marrow cells is semi-liquid, it is called an aspirate. If a 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 drugs that thin your blood. Your doctor will advise you about this and will tell you when it's safe to start taking blood thinning medication again after the biopsy.

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.

**Chromosome studies (cytogenetics):** Chromosome tests can find out about any abnormalities in your chromosomes connected to your CLL. For example, parts of chromosomes may be missing, or you may have an extra chromosome. Samples taken from your blood or your bone marrow will be checked for known abnormal changes in the chromosomes that happen with CLL. A test called FISH analysis (fluorescence in situ hybridisation) makes abnormal genes glow (fluoresce) so that the doctor can identify the particular type of genetic abnormality. In CLL cells, chromosomes 11, 12, 13 and 17 often have defects.

A FISH test can help your doctor to predict how your CLL might respond to a particular treatment, so he or she can recommend the best option for you.

## Chromosome changes in CLL

**Del (13q):** This is a positive cytogenetic (chromosome) change. People with only this change often have a type of CLL that develops very slowly and doesn't need any treatment for many years. Between 3 and 5 in every 10 people with CLL will have the del (13q) abnormality.

**Del (17p):** This change makes the leukaemia more difficult to control. Less than 1 in 10 people with CLL have the del (17p) change. If del (17p) is found, a FISH test (see page 13) may be done to see if a gene called TP53 is missing. This abnormality is associated with a poorer prognosis (outlook), but there are treatments for this type of CLL. Missing parts of chromosome 11 (del 11 q) is also associated with a poorer prognosis.

**Other changes:** Between 4 and 6 out of every 10 people with CLL will have other cytogenetic changes in their CLL cells (for example, Trisomy 12), or none at all. The leukaemia often needs treatment, but usually not immediately. It can usually be controlled for a number of years with treatment.

### IgVH gene mutations

Knowing if the IgVH gene is mutated can help to predict how your CLL will behave. B-cell CLL with mutated IgVH is typically less aggressive (progresses more slowly) than B-cell CLL with unmutated IgVH.

**Immunophenotyping:** This test checks what kind of proteins or markers are on the surface of the cells to help diagnose CLL. This test can be done on your blood or your bone marrow.

## Other tests

You may have other tests to give your doctor more information about how far your CLL has developed.

**Chest X-ray:** A chest X-ray uses high-energy rays to take pictures of the inside of your body. 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 taken. It involves a small operation, usually with a local anaesthetic. The gland is removed and then sent to the laboratory for tests.

**Ultrasound scan:** This is a scan that uses sound waves to look at organs and tissues in your body. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. Some gel is first put on the area, which is then scanned to give more information about the cancer. It looks for any abnormal changes, for example, to your lymph glands or spleen.

**CT scan:** This is a special type of X-ray that gives a detailed picture of the lymph glands inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

## Waiting for results

It may take some time for all the test results to come back. This can be an anxious time. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to one of our cancer nurses.

## Staging CLL

The tests that you have will help your doctor to ‘stage’ your CLL. Staging CLL means describing the extent of the disease. This helps your doctor to plan your treatment.

The Binet system is one way to stage CLL. It has three stages: A, B and C. It measures the number of white blood cells and if you have anaemia (low red blood cells) or a reduced number of platelets. The Binet staging system also counts the number of areas in your body where you have enlarged lymph nodes. Lymph nodes are mainly found in the neck, armpits, groin, liver and spleen.

**Stage A:** There are fewer than three areas of enlarged lymph nodes.

**Stage B:** There are three or more areas of enlarged lymph nodes.

**Stage C:** There are a reduced number of red blood cells, platelets or both.

Another way to stage CLL is the Rai system. It has five stages (0 to 4). This is not usually used in Ireland.

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

››› Not everyone with CLL has symptoms or needs treatment.

### To sum up

- You may need tests like blood and bone marrow tests, chromosome studies (cytogenetics) and scans to give your doctor more information about your CLL.
- The tests that you have will help your doctor to ‘stage’ your CLL. Staging means describing the extent of the disease. This helps your doctor to plan your treatment.
- The Binet system is one way to stage CLL. It measures the number of blood cells and the number of areas in your body where you have enlarged lymph nodes.

# Treatment and side-effects

CLL is a disease that usually develops very slowly. Some people never need treatment, because their CLL never moves beyond the early stages, or they may not need treatment for a long time.

If you have symptoms or if blood tests show that your disease is developing more quickly, you will need treatment. The aim of treatment is to put the CLL into remission. Remission means leukaemia cells can no longer be detected in your body and you feel well.

If the CLL starts to cause symptoms again after remission, this is called relapse. CLL can still be treated after a relapse to try to put it back into remission.

CLL can usually be treated successfully and you can often live with it for many years.

## How is CLL treated?

The type and amount of treatment you will need depends on which stage your CLL is in (see page 16), your general health and any symptoms you may have.

### Treating stage A

You may be advised not to have treatment if you don’t have any symptoms. You may never need treatment if your disease does not move beyond the early stage.

**Watch and wait:** If your disease is not active, there may be little or no benefit to treatment. Watch and wait is a way of managing CLL. If your disease is not active, your doctor will give you check-ups every few months and take regular blood samples to monitor your CLL. See page 22 for more details.

## Treating stage B or C

If your CLL is at a later stage you will be offered treatment. The main treatments for CLL are:

**Biological therapies:** These are drugs that use your body's own immune system to fight cancer. Biological therapies can be given along with chemotherapy. See page 23 for more details.

**Chemotherapy:** Chemotherapy uses drugs to kill the cancer cells. Chemotherapy drugs may be given on their own, in combination with each other or with other treatments like steroids or biological therapies. See page 25 for more details.

**Steroid therapy:** Steroids can sometimes help to control CLL when used with other treatments. See page 29 for more details.

**Stem cell transplant:** Rarely, a stem cell transplant (or bone marrow transplant) is used to treat CLL. Transplants replace diseased cells with new healthy cells from a donor. Transplants are not suitable for every patient. See page 30 for more details.

## Treating symptoms

Some symptoms of CLL may need to be treated straight away. For example, infection, bleeding or anaemia. Treating symptoms is also called supportive care. See page 33 for more details.

## Treatment centres

In Ireland, CLL is treated in specialist cancer centres. 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

**Multidisciplinary team:** A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, haematologists and specialist nurses. They will meet to discuss your test results and your suggested treatment plan.

**Treatment options:** Your doctor and nurse will explain your treatment options to you. Ask as many questions as you need to, so that you understand and can make an informed decision about the best treatment for you. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

**Time to think:** When faced with a serious illness, it can be hard to decide about treatment. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

**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 aware of the benefits and risks.

## 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. |
| **Oncology liaison nurse/ Haematology nurse specialist** | A nurse who specialises in blood cancers. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment |

| | |
|---|---|
| **GP (family doctor)** | Your GP can be a great support to you. You can talk to your GP about your medication, any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope. |
| **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 any social issues or practical needs. They can give counselling and emotional support. They can also 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 to make decisions. |
| **Psycho-oncology team** | These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses. |
| **Counsellor** | A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. |
| **Community health services** | These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services. |

## Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

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 still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

## 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. Ask your doctor if you have any questions about your treatment.

## To sum up

- CLL can be treated successfully and you can often live with it for many years.
- CLL is managed by watch and wait, biological therapies, chemotherapy and steroid therapy.
- A team of specialists will decide which treatment is best for you.
- You may need treatment for symptoms like infection, anaemia, or bleeding.
- It is important that you understand and are happy with your treatment plan.

# Watch and wait

Some people diagnosed with CLL show few signs of active disease. About one-third of patients with CLL have a form that grows so slowly that no treatment is needed. Instead of treatment your doctor may recommend watch and wait. This means you will go to your doctor every few months for blood tests and other tests to monitor your disease. For example, cytogenetic tests (see page 13). It may take years for the disease to become active, or you may never develop any symptoms.

## Worried about not having treatment?

If your doctor decides not to treat your CLL, it can be stressful. You may be relieved the disease is not active but you may start to worry that it will get worse. You may also feel very anxious before your check-ups. While it's easy to say ‘don’t worry’, it's not so easy in practice. The following may help you to cope while you are being managed with watch and wait:

**Understand watch and wait:** If you have any questions or worries about not having treatment, ask a doctor or nurse. You can also visit a Daffodil Centre or call our Cancer Nurseline to speak to a cancer nurse.

**Keep busy:** Try to focus on the present and make the most of the time while your disease isn't active.

**Share your worries:** Talk to friends and family or join a support group. Your doctor or a medical social worker or counsellor may also be able to calm your fears.

## To sum up

- Chronic leukaemia usually develops 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.

# Biological therapies

Biological therapies work with your body. They target and ‘switch off’ molecules within your body that help the CLL to grow.

Different types of biological therapies work in different ways. For example:

- **Targeted therapies** block the chemical signals that trigger cancer cells to divide and grow.
- **Monoclonal antibodies** trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.

**Targeted therapies:** Targeted therapies for CLL are drugs that are specifically designed to attack the CLL growth pathways outside and inside the cell. They may be used on their own or in combination with other treatments. Examples of these drugs are ibrutinib, idelalisib and venetoclax. Some of these medications may only be available as part of a clinical trial (see page 32).

Your doctor or nurse will explain these treatments and let you know if they are suitable and available for your type of CLL.

### How are targeted therapies given?

These medications are given as a tablet, which you take once or twice a day, depending on the drug. You will stay on these drugs as long as they are working to control your CLL and you are not having any problems with the medication.

It's very important to tell your doctor and your pharmacist about any other medications you are taking – both prescription and over-the-counter medications. This is because targeted therapies can interact with other drugs.

Common side effects include infections, diarrhoea, nausea, tummy pain, other aches and pains, rash, bleeding and tiredness.

**Monoclonal antibodies:** Antibodies are proteins made naturally in your body that fight infection and cancer, whereas monoclonal antibodies are similar 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 attacks these cells and kills them. Normal lymphocytes can then replace the abnormal ones that have been destroyed. Examples of monoclonal antibodies used for people with CLL include rituximab, alemtuzumab, ofatumumab and obinutuzumab.

### How are monoclonal antibodies given?

With CLL, the monoclonal antibodies are given into a vein by drip infusion. You will get your treatment in the hospital day ward. Your doctor will decide how many infusions you will need, but usually you will have treatment for about 6 months.

Often monoclonal antibodies are given in combination with chemotherapy or other drugs. This is called combination therapy. See page 26 for more information.

### Side-effects

Monoclonal antibodies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy.

Side-effects depend on the drugs being used and vary from person to person. It's more common for side-effects to happen after the first dose, a bit like an allergic reaction. Often the first infusion treatment is given very slowly, to try to reduce any negative reaction to the drug. It's very important that you tell your nurse or doctor immediately if you get any side-effects.

Common side-effects include fever, headache, rashes, chills, breathing problems, chest pain and low blood pressure. You may be advised to not take any blood pressure tablets on the morning of your treatment.

Your doctor and nurse will explain this treatment to you in more detail and tell you the specific timing schedule for your treatment.

New biological therapies are being developed all the time and existing therapies are being used in new ways. Ask your doctor if there are any biological therapies available to treat your cancer or if there are any clinical trials that are suitable for you.

### 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.
- Monoclonal antibodies are given into a vein by drip infusion, so you will be in the hospital day ward or stay in hospital for your treatment.
- Targeted therapies are given in tablet form. It's very important to take them as prescribed by your doctor.
- 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.

## Chemotherapy

Chemotherapy is a treatment that uses drugs to kill the abnormal lymphocyte cells. The drugs used in chemotherapy travel through your bloodstream to almost every part of your body.

### What drugs are used?

Often a combination of chemotherapy drugs is used to treat CLL. Examples of chemotherapy drugs used to treat CLL are cyclophosphamide, chlorambucil, fludarabine and bendamustine.

### How is chemotherapy given?

Chemotherapy for CLL is often given directly into a vein as an injection or through an intravenous infusion (drip). Chemotherapy into a vein is usually given in the day oncology ward of the hospital. How the chemotherapy is given depends on the drug being used and the dose needed. Chemotherapy may also be given in tablet form or as an injection under the skin of the tummy, thigh or upper arm (subcutaneous injection).

Chemotherapy is often given in cycles with a rest period between treatments to give your body time to recover from the side-effects of treatment. If your blood cell count is affected by chemotherapy, your next cycle of treatment will not start until your blood count has improved, even if this means a delay to your treatment schedule.

You might also get chemotherapy as part of a clinical trial. Clinical trials are research studies that find out if the drugs can improve the treatment results. See page 32 for more about clinical trials.

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 treatment cycle. If you are at high risk of these problems, your doctor may decide to admit you to hospital for a drip of fluids and in rare cases a special drip called rasburicase, which helps your kidneys get rid of this uric acid.

## 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.

See page 23 for more about biological therapies and page 29 for steroids.

## What are the side effects of chemotherapy?

The side-effects of chemotherapy depend on the drugs you are given and can vary from person to person. These unwanted side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

In most cases the side-effects go away when the treatment ends or soon after. With chemotherapy tablets the side-effects are usually mild.

Depending on the drug used, side-effects of chemotherapy can include:

- **Risk of infection:** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.
- **Anaemia (reduced number of red blood cells):** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Increased bruising and bleeding:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help to make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Feeling sick (nausea) or getting sick (vomiting):** Chemotherapy can cause nausea (feeling sick) and vomiting (throwing up). There are medicines to prevent nausea and vomiting.
- **Tiredness (fatigue):** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 35.
- **Sore or dry mouth:** Chemotherapy can cause problems including a dry mouth, ulcers and gum infections.  Your doctor can prescribe mouthwashes and medications to help with these problems.
- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).
- **Hair loss:** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the amount and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **Bladder or kidney changes:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be signs of kidney damage.

- **Skin and nail changes:** Your skin may be sensitive, itchy or discoloured. Your nails may change in shape or colour or become brittle or flaky.
- **Changes in hearing:** Some chemotherapy drugs can cause inability to hear high-pitched sounds or buzzing / ringing sounds.
- **Changes to your nervous system:** You may feel anxious, restless or dizzy. You may have headaches or find it hard to sleep or concentrate.
- **Loss of appetite**
- **Infertility:** For more on infertility see page 37.

### 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 meat and poultry, and the skin of raw vegetables and fresh fruit.
- If your temperature goes above 37.5°C (99.5°F), or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.

Most haematology units have a direct phone number to call for advice if your temperature is above 37.5°C (99.5°F).

If you have any other symptoms that are troubling you, let your doctor or nurse know. Most side-effects can be helped by medication.

For more information on side-effects and different types of chemotherapy you can read our booklet *Understanding Chemotherapy*. You can read it on our website **www.cancer.ie** or get a free copy by calling our Cancer Nurseline on 1800 200 700 or visiting a Daffodil Centre.

### To sum up

- Chemotherapy is a treatment using drugs to kill cancer cells.
- Chemotherapy can be given in tablet form, 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 can be well controlled with medication.

## Steroid therapy

Doctors may prescribe steroids at any stage of your CLL treatment. Steroids are made naturally in the body, but they can also be made artificially as a medical treatment. Steroids are not a cure for CLL, but they can help to control it when used with other treatments. Steroids can also help with the symptoms of CLL, such as anaemia and fatigue.

Steroids are usually given in tablet form, but they 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.

It is important to always take the correct dose of steroids. If you stop taking them suddenly it can make you ill, so always cut down gradually, following your doctor's advice.

### What are the side-effects of steroids?

High doses of steroids can give rise to several side-effects. Side effects vary from person to person. Some common side-effects are:

- Increased appetite and weight gain
- Increased blood pressure
- Osteoporosis (fragile bones)
- 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, discuss them with your doctor or nurse.

## 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.

# Stem cell transplants

Very rarely someone with CLL may be offered a stem cell transplant to treat their disease.

## How do transplants work?

A transplant works by destroying all the blood cells in your bone marrow and replacing them with healthy stem cells. Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells.

The stem cells are usually taken from a donor. This is called an allogeneic transplant.

> A transplant is not necessary for most people, as other treatments work very well to control their disease.

## How is an allogeneic transplant done?

The bone marrow is destroyed with high doses of chemotherapy, with or without radiotherapy. Then the healthy marrow or stem cells from the donor are given to you through a central line (drip). The cells then grow over a few weeks to replace the bone marrow that was destroyed.

Stem cell transplants take place in special treatment units only. You may spend up to 6 weeks in hospital. For 6 to 12 months after the transplant you may have to go to hospital very often for check-ups, antibiotics or blood transfusions.

Your doctor will discuss this treatment with you if they think it is suitable for you. For more information, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

## To sum up

- Transplants are rarely used to treat CLL. For most people, there are other suitable treatments.
- A few patients with CLL will need a stem cell transplant. It depends on your general health, your symptoms and the type of CLL you have.
- 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.

## Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing diseases.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it's safe to use in a clinical trial.

### More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, **www.cancer.ie**

You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

## How will I be monitored during my treatment?

During your treatment your doctor will do regular tests:

**Blood tests:** You will have regular blood tests to check the effects of the drugs and measure how well the CLL is responding to the treatment.

**CT scan:** If you had swollen glands from CLL at the beginning, a CT scan of your lymph glands may be done during treatment to check out how well you are responding.

**Bone marrow tests:** Occasionally your doctor may need to repeat the bone marrow test (see page 12).

### Response to treatment

**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 has reduced. 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. Complete response is not the same thing as cure, as symptoms may appear again after a time.

How well your disease responds to treatment depends on factors like the stage of your disease and your overall health.

## How can my symptoms be relieved?

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. Tell your doctor if you develop any new symptoms.

### Infection

If your white blood cell count is low, you will be more likely to get infections. These can include viral ones, like colds, shingles and chickenpox or bacterial infections like pneumonia. Your doctor may prescribe antiviral or antibiotic medications for you, to prevent infection. See page 28 for tips on avoiding infection. Ask your doctor about vaccines that may protect you. See page 39 for more details.

Your doctor may give you an injection of antibodies called immunoglobulins if you are getting a lot of infections and your blood tests show that you have a low level of antibodies.

Immunoglobulins boost your immune system. You may need the injection during the winter months, to help you to fight off the flu and other infections.

Very rarely, monoclonal antibodies can cause a reactivation of the hepatitis virus in your body if you have been exposed to it in the past. You doctor will do a blood test before you start treatment to see if you are at risk.

## Anaemia and bleeding problems

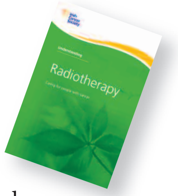
If your red blood cell count is low, it can lead to fatigue and shortness of breath. If your platelets are low, you may have bleeding gums and find it hard to stop the bleeding from simple cuts and bruises. In both cases you may need to receive blood transfusions before and during your treatment.

If you have a low red blood cell count because of autoimmune haemolytic anaemia (see page 8) or a low platelet count because of idiopathic thrombocytopenia purpura (see page 8), your doctor will prescribe specific treatments for you.

## Enlarged spleen

Some people with CLL get an enlarged spleen. This can cause pain and 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 needed. Usually, you attend the radiotherapy unit for 5 days (Monday to Friday) for 2 weeks for the treatment. Call our Cancer Nurseline on 1800 200 700 for more information about radiotherapy and its side-effects, or ask for 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 means feeling extremely tired. Fatigue is a very common symptom of CLL.

Fatigue when you have CLL can be caused by many things, including:

- CLL itself or the treatment you are having
- Not eating well
- Low levels of red blood cells
- Not sleeping well
- Dealing with difficult emotions and feeling anxious or depressed
- Symptoms like pain or fluid retention

Talk to your doctor or nurse if fatigue is affecting you, so that they can help you.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy. You can also download it from our website **www.cancer.ie**

## Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation or massage.

# Will treatment affect my sex life and fertility?

## Sex and sexuality

CLL can affect how you feel about sex and relationships. 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 and lose interest in sex as a result. There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

Talking about your feelings may ease any worries you have. 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 relationship counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It's quite safe for you to have sex again with your partner.

## Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

Many specialists recommend that you wait for up 2 years after treatment before trying to start a family or have more children. This time gives your body a chance to recover.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

## Fertility

Your fertility may be affected by some of the treatments. If you were planning to start a family or have more children, talk to your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before you start treatment. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

## Asking for advice

If you have questions about how treatment may affect your sex life or fertility, ask your doctor or nurse. They are well used to taking about these matters so there's no need to feel embarassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

# What follow up will I need?

Once you are in remission, you can begin to return to your normal life. But you will still need to go back to hospital for regular check-ups. This is called follow-up. It's important to attend your follow-up appointments, even if you feel well and have no symptoms. The tests you will have can spot any changes in your condition.

Tell your doctor or nurse about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor so that you don’t forget anything. If you are between check-ups and have a symptom or problem that is worrying you, tell your doctor. Make an appointment to see him or her as soon as possible.

You may also need to go to hospital if you get an infection, as your immune system will take time to recover.

# Living with CLL

Although many people with CLL can live a normal life, for others, living with CLL and its symptoms can be challenging. Here are some things you can do to feel more in control, avoid unnecessary complications and stay as well as possible.

## Leading a healthy lifestyle

Many people want to make positive changes to their lives after a diagnosis of CLL. If you are living with a chronic illness like CLL, a healthy lifestyle can help you to:

- Feel better
- Keep up your energy and strength
- Cope better with the side-effects of treatment

A healthy lifestyle is also important because having CLL puts you at a higher risk of developing some other cancers.

A healthy lifestyle includes:

- Exercising
- Taking vitamin supplements if blood tests show you have a deficiency.
- Staying at a healthy weight
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun and checking your skin for any changes
- Having all the recommended cancer screening tests, such bowel cancer screening

## Take care of your health

- Watch out for any signs of infection or other problems. Some people may experience pneumonia or other lung problems. You may find that you have excess mucus, coughing, pain, blocked sinuses or a mild cold. See page 28 for advice on avoiding infections.
- If you develop any bowel problems such as ongoing abdominal (tummy) pain, diarrhoea, bleeding or constipation, you should contact your doctor as soon as possible.
- Have regular dental and eye check-ups. Take good care of your mouth, teeth or dentures, as they can be a source of infection. Check with your haematologist before having dental treatment.

- Always tell doctors, dentists and other healthcare professionals that you have CLL. If your white cell count or platelets are low it can increase your risk of bleeding or infection, so some procedures or treatments may not be suitable.
- Contact your doctor straight away if you have signs of infection, symptoms of CLL (see page 10), or any other health problems.

## Vaccines

You will probably be advised to get the flu vaccine every year and the pneumonia vaccine every 5 years. Some vaccinations may not be suitable for you, because CLL can weaken your immune system. For example, live vaccines. Check with your doctor about which vaccinations are recommended for you and make sure you get them.

## Be involved in your healthcare

- Learn about CLL and treatment options so that you can make an informed decision and know what to expect. See pages 18-21 for more about making treatment decisions.
- Don't be afraid to ask questions. There are some questions you might like to ask on page 57.
- Keep all your appointments and take all your medications – ask your doctor or pharmacist if you have any questions about your medication.
- Let your doctor know straight away if you have any new symptoms or any symptoms that are bothering you.
- Don't feel like you have to wait until your next appointment if you have any health problems or worries.

## Mind your mental health

The uncertainty of living with CLL and coping with any symptoms can be stressful. The following may help:

- Try to avoid additional stress wherever possible. Spend time with your friends and family. Make time to relax and do the things that you enjoy.

- Use stress-management techniques if you do feel stressed. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 41 for more about complementary therapies.
- Counselling or a short course of medication may also help you, if you are finding it hard to cope. See page 43 for more information.
- Having the support of loved ones, healthcare professionals and other people going through the same thing can also make a big difference. See page 44 for more about getting support.

## Work and activities

Once you are on treatment and start to feel well, there is no reason why you cannot return to work or study and carry on with your usual activities like socialising, sports and hobbies. If you are planning a holiday, ask your doctor about any special precautions you need to take or vaccinations you should have before you go. It's best to have travel insurance too. We have information on travel insurance on our website, **www.cancer.ie**

You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more details.

# Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

**Complementary therapies:** Complementary therapies are treatments that can be given **in addition to** standard medical treatment. Examples of complementary therapies are yoga, meditation, aromatherapy and massage.

**Standard treatment:** Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

**Alternative therapies:** Alternative therapies are generally treatments that are used **instead of** standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

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

Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

### More information

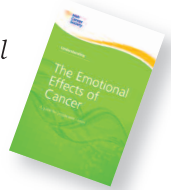
If you want to know more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

# Coping and emotions

## How can I cope with my feelings?

People react in different ways when they find out they have CLL. Shock, fear and uncertainty, sorrow, denial, anger and withdrawal are all common reactions. There is no right or wrong way to feel and there is also no set time to have one particular emotion or not.

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer.* Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.



The Emotional Effects of Cancer

### Anxiety and depression

Sometimes a CLL diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it’s important to get help. It's not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

### Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Free counselling is available at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. A list of Irish Cancer Society-funded counsellors is also available at **www.cancer.ie**

## Ways to get support

**Find out about cancer support services in your area:** There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 53 for more about cancer support services.

**Join a support or educational group:** Many people find it very helpful to get support from other people facing the same challenges, to learn from their experiences and to share information and advice.

**Get online support:** There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

**Talk things through:** It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or one of our cancer nurses.

**Seek spiritual support:** For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

**If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.**

# Coping with a CLL diagnosis

Everyone experiences cancer in a different way. And how each person copes with CLL varies too. There's no right or wrong way to cope, only your way.

During your illness there are many things you can learn, not only about CLL itself but also about you as a person.

Here are some 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 for you to deal with cancer.

**Use your support network:** People with CLL can often carry on with their usual activities, but there may be times when you need extra support. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

**Involve your family and close friends:** Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

**Gather information about CLL and treatment:** Understanding CLL and its treatment can help to relieve anxiety and stress for some people. Don’t be afraid to ask your medical team to answer any questions you have and explain anything you don’t understand.

**Get some exercise:** Exercising is a great way to boost your mood and sense of well-being and it can improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

**Try relaxation and stress management techniques:** Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

**Try complementary therapies:** Complementary therapies are treatments like yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 41 for more information on complementary therapies.

**Accept change in your life:** Accept that it may take time to adjust to having CLL and being on treatment.

**Know that there will be ups and downs:** Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

**Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

**Deal with your worries:** It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website **www.cancer.ie** for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

### Positive emotions

After being diagnosed with CLL you may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what's important in life for you.

# How can my family and friends help?

Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice. Some may gather up-to-date information on CLL 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.

### 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 and nurses and call our Cancer Nurseline if you need more information.
- **Healthcare:** Support your loved one by making sure they take any medication correctly and attend all appointments. Ask them about how they are feeling and encourage them to talk to their healthcare team if they have any symptoms or worries.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency situation and make sure you know the phone number to call.
- **Caring for yourself:** Many cancer support services offer help for friends and family of people with cancer. If you need any support or want to talk to someone, call our Cancer Nurseline on 1800 200 700 or contact your local cancer support centre (see page 53).

## How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of upsetting your friend or relative by saying the wrong thing. Often what people want most is a good listener.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline and ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**

# Talking to children and teenagers

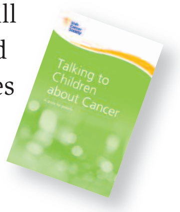
It can be hard to know the best way to talk to your children and explain CLL without frightening them too much. Although many people live a normal life with CLL, the words leukaemia and cancer can be very scary. You may worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

## Saying nothing

You may feel it's best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

## How to tell your children

It's best that you or your partner tell your children about your CLL. How you discuss your illness and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.


Talking to Children about Cancer

The booklet is available free of charge from Daffodil Centre or by calling the Cancer Nurseline. It's also available on our website, **www.cancer.ie**

## Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

# Support resources

## Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like medication, travel, heating, car parking and childcare costs. If you are not able to work or you are unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about money.

### Health cover

Health cover means the amount you pay for the medical care you receive. Things you might have to pay for include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances like wigs

**If you have a medical card**, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

**If you do not have a medical card** you will have to pay some of the cost of your care and medication.

**If you have health insurance** the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment.

### Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are enquiring about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

## If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, 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 help towards travel costs. See page 52 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

## More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: **www.cancer.ie**

# Irish Cancer Society Services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- Our **Cancer Nurseline Freephone 1800 200 700:** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**

  For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: **remote@slis.ie**

- Our **Daffodil Centres:** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer. You can find a list of Daffodil Centres on our website **www.cancer.ie**
- Our **Survivor Support:** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area:** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 53 for more information.

- **Patient travel and financial support services:** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

  To access either of these services please contact your hospital healthcare professional.
- Irish Cancer Society **Night Nursing:** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our **publications and website information:** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website **www.cancer.ie** or call our Cancer Nurseline for a free copy of our publications

If you would like more information on any of the above services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

## Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. These have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, psychologists, cancer nurses and counsellors
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Expressive therapies** such as creative writing and art
- **Mind and body sessions**, for example, yoga, tai chi, mindfulness meditation
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

To find your nearest cancer support centre call our Cancer Nurseline on Freephone 1800 200 700 or see our online directory at **http://www.cancer.ie/support/support-in-your-area/directory**

# Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie.**

You may find the following helpful:

## Treatment and side-effects

*Understanding Chemotherapy*

*Understanding Radiotherapy*

*Understanding Cancer and Complementary Therapies*

*Diet and Cancer*

*Coping with Fatigue*

## Coping and emotions

*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*

*A Time to Care: Caring for Someone Seriously Ill at Home*

*Managing the Financial Impact of Cancer. A Guide for Patients and their Families.*

# 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. |
| **Blood film** | A test that involves a blood sample. The sample is examined by your haematologist under a microscope to determine the amount of immature blood cells present. |
| **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. |
| **Chromosomes** | Strands of genetic material called DNA that carry the instructions that tell cells how to grow and reproduce. |
| **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 the 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. |
| **Relapse** | When disease returns following a stable/remission phase |
| **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. |

# 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's always better to ask than to worry.

What tests will I have?

What stage is my CLL at?

What symptoms should I watch for?

What are my treatment options? What are the benefits and drawbacks of them?

Which treatment do you recommend for me and why?

What is the aim of my treatment?

How is the treatment given and how long will it last?

How long will treatment take? Do I need to stay in hospital?

Do I need other types of treatment?

Will this treatment limit my treatment options in the future, if I relapse or my disease stops responding to treatment?

What are the chances of my CLL going into remission?

What side-effects can I expect? Will they last long?

Can I prevent or control the side-effects?

Are there any late or long-term side-effects?

How will I know the treatment is working?

How can I take the best care of myself before and after treatment?

What are the chances that treatment will be successful?

Will treatment affect my normal life and activities?

Do I need to take care of medical or dental issues before I start treatment?

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

## Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

### Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

### Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

### Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

## Did you like this booklet?

We would love to hear your comments and suggestions. Please email reviewers@irishcancer.ie.

## More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

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

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700
Email: cancernurseline@irishcancer.ie

Find us on Facebook
Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish
Cancer
Society