

Understanding

Chronic lymphocytic leukaemia (CLL)

Caring for people with cancer

Understanding

Chronic lymphocytic leukaemia (CLL)

This booklet has information on:

- Treatment for CLL
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

If you have small lymphocytic leukaemia you may also find this booklet helpful, as the two diseases are very similar.

Useful numbers

Specialist nurse

Family doctor (GP)

Haematologist

Medical oncologist

Medical social worker

Emergency

Hospital records number (MRN)



Contents

About CLL	7
Diagnosis and tests	17
Treating CLL	29
Types of treatment	45
Coping with side-effects	63
After treatment	75
Coping and emotions	83
Supporting someone with cancer	91
Support resources	97
What does that word mean?	111
Questions to ask your doctor	112

Fast facts



Can my cancer be treated?

If you need treatment, the aim is to put the disease into remission. Remission means leukaemia cells can no longer be detected in your body and you feel well. Some people with CLL never need treatment, because their CLL never moves beyond the early stages, or they may not need treatment for a long time.

Will I be OK?

CLL can usually be treated successfully and you can often live with it for many years. Many people with slow-growing CLL live a normal life. Other people experience symptoms that may affect their quality of life at different stages of their disease and treatment.

It's hard to predict exactly what will happen for any one individual. The best thing to do is to talk to your doctor.

What kind of treatment might I have? Page 29

Your doctor may decide to monitor your CLL if it is developing slowly. If you do need treatment, you may have targeted therapies, chemotherapy and / or steroid therapy. In some cases stem-cell transplants are used, but it is rare. You may also need treatment for symptoms like infection, anaemia or bleeding.

Are there side-effects from treatment?

Page 45

Most treatments cause some side-effects. Read about the different treatments – such as targeted therapies or chemotherapy – to learn more about their possible side-effects.

There are treatments to help with most side-effects, so tell your doctor. If you report them early, they can be managed.

We're here for you

Page 103

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre to speak to a nurse.
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 103 for more about our services.

Support Line Freephone 1800 200 700

Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About CLL

About blood cells	9
What is leukaemia?	10
What is chronic lymphocytic leukaemia (CLL)?	12
What caused my cancer?	12
What are the symptoms of CLL?	13
What is small lymphocytic lymphoma (SLL)?	14
Complications from CLL	15
How common is CLL?	15

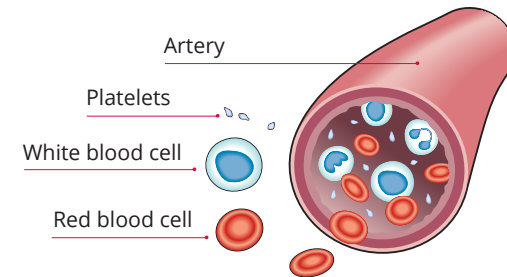


Email: supportline@irishcancer.ie

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.

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. Other cells such as red blood cells or platelets can be affected as well. Sometimes leukaemia is called blood cancer.

When leukaemia develops, immature blood cells (stem cells) continue to grow quickly but do not mature into white blood cells. These immature cells do not enter your blood stream. Instead, they 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.

To understand the different types of leukaemia it can help to know more about white blood cells:

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 disease develops slowly, usually over months or years.

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

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 our Support Line on 1800 200 700 or visit a Daffodil Centre.

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.

T cells warn your body that there are bacteria (bugs) in the body and help kill diseased cells

B cells make antibodies that mark bacteria (bugs) for killing

NK cells release chemicals that kill diseased cells

CLL usually affects the B cells.



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.

CLL 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.

What caused my cancer?



We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. With most cancers, including CLL, the risk increases as you get older. If you want to know more about why cancer happens or to learn about risk factors for CLL, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

Family history

Anyone can get CLL. You have a slightly higher chance of getting it if some of your close relatives (e.g. a parent or sibling) have had it, but the risk is small.

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 include:

- **Getting infections more often** and recovering more slowly from infections
- **Tiredness and looking pale**
- **Unexplained weight loss / loss of appetite**
- **Night sweats / fever**
- **Shortness of breath**
- **Headaches**
- **Swelling of your spleen and/or tenderness on the left side of your abdomen** (tummy area), 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.

Support Line Freephone 1800 200 700

What is small lymphocytic lymphoma (SLL)?

CLL and SLL both affect lymphocytes. They are different forms of the same disease. 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 Support Line 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 happen 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. Your 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 they 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 Support Line 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 215 people are diagnosed with it in Ireland every year. It is rarely diagnosed in people under the age of 50, and is more often found in people over 70. It is more common in men.



Diagnosis and tests

Being diagnosed with CLL	19
What tests will I have?	21
Staging CLL	26
Asking about your prognosis	28

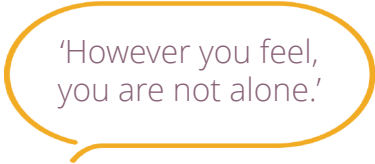
Being diagnosed with CLL

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
- **Angry** that this is happening to you

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

- **Ask to speak to the haematology clinical nurse specialist (CNS) and / or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Peer Support volunteer who has had a cancer diagnosis** and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people going through the same thing.** Join our online community at www.cancer.ie/community or get in touch with CLL Ireland.
- **Go to your local cancer support centre.** For more information, see page 110.



'However you feel,
you are not alone.'

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may not want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet *Understanding the Emotional Effects of Cancer*. It can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have?

- Tests you may have include blood tests, scans and bone marrow tests
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you

The following tests give doctors more information about your cancer. Some tests can also show how well you are responding 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 an idea of your general health. This is an important test, as CLL affects the blood cells. You will have frequent blood tests to monitor your disease if you have CLL. 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) 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

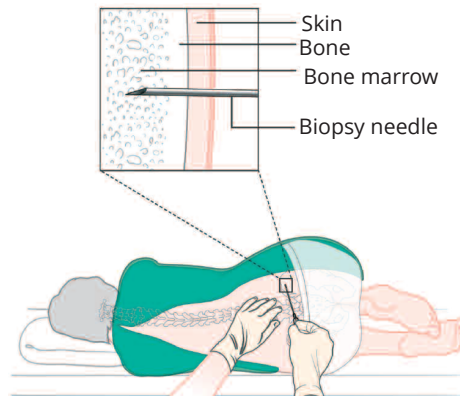
Blood film

Your doctor may look at a blood sample under a microscope to determine the amount of leukaemia cells present. This is often called a blood film. It 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 usually taken from your hip bone. If the sample of bone marrow cells is semiliquid, 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. Before this test, let your doctor know if you're on any medications to thin your blood, such as warfarin. Your doctor will decide if you need to stop taking the medication temporarily before the test.

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. Your medical team will advise you on suitable painkillers you can take if you feel any discomfort later.

Chromosome studies (cytogenetics)

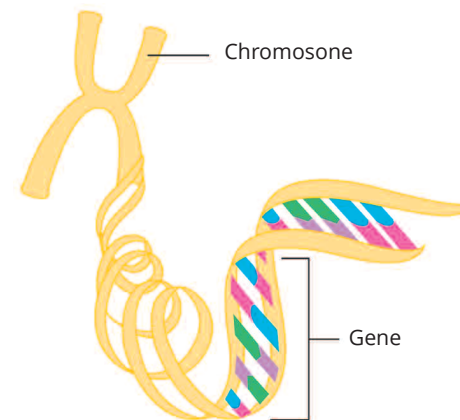
Chromosome tests can find out about any abnormalities in your chromosomes connected to your CLL. For example, parts of chromosomes may be missing, or you may have an extra chromosome. Samples taken from your blood or your bone marrow will be checked for known abnormal changes in the chromosomes that 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.

Immunophenotyping

This test checks what kind of proteins or markers are on the surface of the cells. This test can be done on your blood or your bone marrow.



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. Fewer than 1 in 10 people with CLL have the del (17p) change. If del (17p) is found, a FISH test (see page 23) may be done to see if a gene called TP53 is also missing. This abnormality is associated with a poorer prognosis (outlook), but there are treatments for this type of CLL. It doesn't respond as well to chemotherapy as some other types, but there are targeted therapies that work well. Missing parts of chromosome 11 (del 11q) 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.

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. It can check for any enlarged lymph glands. It can 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 or part of 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 (CAT scan)

This is a special type of X-ray, which can give a detailed 3D picture of your lymph glands and organs like your spleen. 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. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

Waiting for test results



It usually takes a few weeks 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 our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging CLL



Staging describes the extent of your disease.

- Knowing the stage helps your doctor to plan your treatment, as different stages need different treatments.
- Your prognosis is what your doctor expects to happen with your cancer.

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.

There are different ways to stage CLL. The 2 most common are called the Binet system and the Rai system. The Binet system 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. The stage is described as 0-4, shown in roman numerals: 0, I, II, III and IV.

Your consultant may use both the Binet and Rai systems, so you will see both a letter and a roman numeral. For example, stage A0 or CIV. Your consultant may also use a different system. You don't need to understand all the details. The important thing is to understand what it means for you and your treatment.

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.



Asking about your prognosis

Your prognosis is information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.


If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need time to think about what you have been told.** You may forget or not have understood some things. You may need to talk to your doctor or nurse again after you have thought about everything.

Treating CLL

How is CLL treated?	31
How will I be monitored during my treatment?	33
Response to treatment	33
Deciding on treatment	35
Giving consent for treatment	36
Who will be involved in my care?	38
How can I help myself?	41

How is CLL treated?

- 
- Targeted therapies, chemotherapy and sometimes stem cell transplants are used to treat CLL.
 - A team of healthcare professionals will look after you (multidisciplinary team).

The type and amount of treatment you will need depends on the stage of your CLL, your general health and any symptoms you may have.

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.

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 47 for more details.

Treating stage B or C

If your CLL is at a later stage you may be offered treatment.

The main treatments for CLL are:

Targeted therapies

These are drugs that use your body's own immune system to fight cancer. Targeted therapies can be given along with chemotherapy. See page 48 for more details.

Chemotherapy

Chemotherapy uses drugs to kill the cancer cells. You may have a single chemotherapy drug, a combination of drugs or have chemotherapy along with other treatments, such as steroids or targeted therapies. See page 52 for more details.

Steroid therapy

Steroids can sometimes help to control CLL when used with other treatments. See page 56 for more details.

Combination therapy

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

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 57 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 60 for more details.

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 how well you are responding.

Bone marrow tests: Occasionally your doctor may need to repeat the bone marrow test (see page 22).

Response to treatment

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.

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.

Minimal residue disease (MRD): MRD is the number of CLL cells in the blood or bone marrow after treatment. Sometimes the cells can't be detected, but this doesn't mean the CLL has been cured, as it may come back again.

Specialist haematology centres



CLL is treated in specialist haematology centres in Ireland. These are hospitals where the staff have great expertise in managing patients with blood cancers, including CLL. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.



Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a haematologist and specialist nurse. The team will meet to discuss your test results and your suggested treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in page at the back of this booklet for your questions and answers. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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 explained to you.

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP will refer you to another specialist for a second opinion if you feel this would be helpful. Getting a second opinion will not affect the care you will receive.

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 a particular 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.

Giving consent for treatment

Before you start any treatment, 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
- Possible side-effects from 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. Treatment decisions can also depend on any previous treatments you have had and your general health. Everyone's treatment needs will be different. Ask your doctor about your treatment if you have any questions.



Waiting for treatment to start

As CLL is often slow growing, you may not need treatment straight away. If you do need treatment, waiting while your treatment is being planned shouldn't affect how well the treatment will work.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to focus on your own health while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see page 41.

Who will be involved in my care?

Some of the following health professionals may be involved in your care.

Haematologist

A doctor who specialises in treating blood cancers and bone marrow diseases.

Medical oncologist

A doctor who specialises in treating cancer patients using chemotherapy and other drugs.



Advanced nurse practitioner (ANP)

ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Clinical nurse specialist

A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

Medical social worker

A person trained to help you and your family with your social issues and emotional and practical needs. They can give advice on social welfare benefits and financial matters and on practical supports and services, available to you from the time of your diagnosis, right through to returning to work.

Dietitian

An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.



GP (family doctor)

While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Pharmacists

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Psycho-oncology team

These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist

A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

Counsellor

A person trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Community health services

This includes family doctors, public health nurses (who can visit you at home), community welfare officers and home help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Palliative care team

This team is specially trained in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

Email: supportline@irishcancer.ie

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well

Eating well when you have cancer can help you feel better. It can:

- Help you to avoid unhealthy weight loss and maintain a healthy weight, which is important for cancer patients
- Help you to cope better with the side-effects of treatment
- Reduce the risk of infection
- Help your recovery



Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet *Diet and Cancer*. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website www.cancer.ie

Be active

Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.

Email: supportline@irishcancer.ie

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- **Non-smokers have fewer or less severe side-effects during cancer treatment.** For example, chest infections
- **Smoking can reduce how well chemotherapy or radiotherapy work**
- **Not smoking reduces the risk of other illnesses**



If you would like advice or support on quitting, visit QUIT.ie, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or 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. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, childminding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

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.

Try to cope day by day

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Types of treatment

Watch and wait (active surveillance)	47
Targeted therapies	48
Chemotherapy	52
Steroid therapy	56
Stem cell transplants	57
Clinical trials	59
Treating symptoms	60

Email: supportline@irishcancer.ie

Watch and wait (active surveillance)

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. 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:

- **Understand watch and wait:** Make sure you understand the tests, what the results mean for you and what kind of treatment you might have if the results show that you should start treatment.
- **Keep busy:** Try to focus on the present and make the most of the time while your disease isn't active.
- **Keep in touch with your medical team:** Contact your medical team if you have any worries or problems between appointments.
- **Coping with anxiety:** Share your worries with friends or family, or join a support group. Your doctor or a medical social worker can also support you. Complementary therapies like mindfulness or massage may help – contact your local cancer support centre to see what's available. You can also talk to our cancer nurses. They can support you and refer you for free counselling. See page 86 for more about counselling.

Support Line Freephone 1800 200 700

Targeted therapies

Targeted therapies are drugs that target certain parts of cancer cells to slow the cancer cells' growth or destroy them.

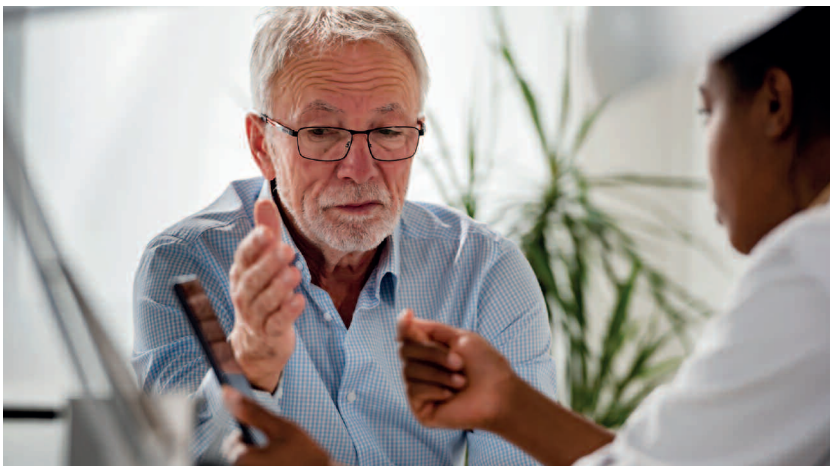
Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

The main targeted therapies used to treat CLL are cancer growth inhibitors (BTK inhibitors and BCL2 inhibitors) and monoclonal antibodies.

You may have more than one targeted therapy drug, or you may have targeted therapies together with other treatments such as chemotherapy. This is called combination therapy. See page 32 for more information.

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



Before treatment, 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 cancer drugs. This in turn can lead to tumour lysis syndrome (see page 67), gout and kidney stones. Allopurinol is usually given for the first treatment cycle.

If you are at high risk of these problems, you may need to have a drip of fluids and, in some cases, a special drip called rasburicase, which helps your kidneys get rid of uric acid.

Types of targeted therapies

BTK inhibitors

BTK inhibitors block a protein called Bruton's tyrosine kinase (BTK). BTK helps cancer cells to grow and survive. By blocking the BTK, BTK inhibitors can slow the growth of CLL cells or destroy them. Examples of BTK inhibitors include Ibrutinib, Zanubrutinib, and Acalabrutinib. They are given as tablets.

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.

Possible side-effects of BTK inhibitors include increased risk of infection, due to a low white blood cell count, nausea and diarrhoea, pain in muscles and bones, bruising and bleeding, rash, fever, irregular heartbeat and tiredness (fatigue). See page 63 for more about coping with side-effects.

BCL2 inhibitors

BCL2 inhibitors block a protein called BCL2. BCL2 interferes with the normal process where cells naturally die after a time. BCL2 helps CLL cells stay alive for longer, so they grow out of control. BCL2 inhibitors target the BCL2 protein so that the cancerous cells are not kept alive, instead they die off naturally. An example of a BCL2 inhibitor is Venetoclax. BCL2 inhibitors are given as tablets.

Possible side-effects of BCL2 inhibitors include increased risk of infection, due to a low white blood cell count, nausea and vomiting,

constipation and diarrhoea, anaemia (low red blood cell count), reduced appetite, headache and tiredness (fatigue). See page 63 for more about coping with side-effects.

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.

Monoclonal antibodies

Monoclonal antibodies are a type of targeted therapy used for CLL.

Antibodies are proteins made naturally in your body that fight infection and cancer. 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, ofatumumab, alemtuzumab 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 – usually as a day case. The nurse will monitor you for allergic or infusion reaction to the drug. Sometimes patients do need to stay in hospital overnight. Your consultant haematologist will decide if you need to stay in hospital. They will also 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, including other targeted therapies. This is called combination therapy. See page 32 for more information.

Side-effects of monoclonal antibodies

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. See page 63 for more about coping with side-effects.



Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go after treatment ends.

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.



How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment.

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 haematology / oncology day 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).

What kinds of 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. You may also have chemotherapy drugs in combination with targeted therapies and/or steroids. See page 32 for more.

Before chemotherapy

Before chemotherapy, 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 tumour lysis syndrome, 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 some cases, a special drip called rasburicase, which helps your kidneys get rid of this uric acid.

You might also get chemotherapy as part of a clinical trial. See page 59 for more about clinical trials.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your chemotherapy drug, you can visit the Health Products Regulatory Authority's website at www.hpra.ie for information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.



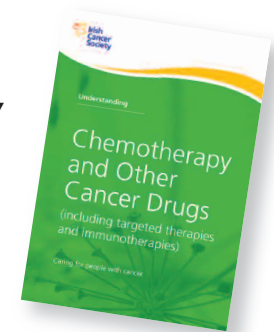
What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. With chemotherapy tablets the side-effects are usually mild. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. Ask your doctor or nurse if you're worried about side-effects or have any questions. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

- Risk of infection
- Bruising and bleeding
- Anaemia (low number of red blood cells)
- Feeling sick
- Diarrhoea or constipation
- Feeling tired
- Loss of appetite
- Sore mouth and throat
- Skin rash
- Build-up of fluid
- Numb or tingling hands or feet (peripheral neuropathy)
- Lung changes, cough, breathlessness
- Tumour lysis syndrome (TLS)
- Headaches
- Skin changes
- Hair loss
- Changes to your blood pressure
- Bladder irritation

See page 63 for more on coping with side-effects. You may also like to look at our booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, www.cancer.ie for tips on coping with different side-effects.



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 through a drip. 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 wellbeing.

It is important to always take the correct dose of steroids, so always follow 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, leading to symptoms such as feeling very thirsty or passing more urine than usual
- 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.

Support Line Freephone 1800 200 700

Hints and tips: Steroids



- Take steroids in the morning so you may sleep better at night.
- Take steroids with milk or food to prevent stomach upsets.
- Ask if there is a dietitian at the hospital, who can advise you 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.

Stem cell transplants

Most people with CLL won't need a transplant, as other treatments work very well to control their disease. Transplants are not suitable for every patient.

How do transplants work?

A transplant works by destroying all the blood cells in your bone marrow and replacing them with healthy stem cells via a transfusion into your bloodstream. 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.

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 your 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 needed and suitable for you. For more information, contact our nurses by calling our Support Line on 1800 200 700 or visiting a Daffodil Centre. You can also ask for a free copy of our booklet, *Understanding allogeneic stem cell transplants*.

For most people a transplant is not necessary, as other treatments work very well to control their disease.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer or reducing side-effects.

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

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For 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 Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at www.cancertrials.ie

Email: supportline@irishcancer.ie

Treating symptoms

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. Even if you have a high white cell count, you may still be more at risk of infections than someone who doesn't have CLL, because CLL affects your immune system. Infections 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 80 for tips on avoiding infection. Ask your doctor about vaccines that may protect you. See page 80 for more details.

Your doctor may give you antibodies called immunoglobulins if you are getting a lot of infections and your blood tests show that you have a low level of antibodies. The immunoglobulins are given by drip infusion into a vein or as an injection under the skin of the tummy or thigh (subcutaneous injection).

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. Your 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 15) or a low platelet count because of idiopathic thrombocytopenia purpura (see page 15), 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. If you need any further treatment, your doctor will discuss this with you.



Coping with side-effects

Side-effects of cancer drugs	65
How can I cope with fatigue?	69
Cancer and complementary therapies	71
Will treatment affect my sex life?	72
Will treatment affect my fertility?	74

Coping with the side-effects of cancer drugs

The side-effects of cancer drugs depend on the dose and the drug(s) used. Your doctor or nurse can tell you what to expect, but side-effects vary from person to person. Most side-effects can be helped by medication. Ask your doctor or nurse if you're worried about side-effects or have any questions.

Side-effects may include:

Fatigue

Fatigue is very common. It can make you feel tired and weak. For more information see page 69.

Nausea and vomiting

Cancer drugs can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurses if they are not working well for you.

Infection

Cancer drugs make you more likely to get infections. CLL, too, can affect the immune system so that it does not work as well to protect you from 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 or low temperature, having a cough, or pain passing urine. You should always contact the hospital if you have signs of infection. You may also be given antibiotics or other drugs to reduce the risk of infection. See page 80 for tips on avoiding infection.

Anaemia (causing tiredness and breathlessness)

Some cancer drugs 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. You may have a blood transfusion to treat your anaemia.

Bleeding and bruising

Some cancer drugs can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Blood clots

Certain drugs and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

Mouth and throat problems

Cancer drugs can cause mouth and throat problems including a sore mouth, dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.



Hair loss (alopecia)

Some drugs can cause hair loss. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after treatment.

Constipation and diarrhoea

Some cancer drugs can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help with these problems, if needed.



Tumour lysis syndrome

Tumour lysis syndrome (TLS) is when there is an imbalance of chemicals, such as calcium and potassium, in your blood. TLS is caused by build-up of uric acid in your body, which can happen when a lot of leukaemia cells are killed by cancer drugs. TLS can cause problems with your kidneys and heart. If necessary, your doctor will give you tablets or medicines / extra fluids through a drip to help your body get rid of the uric acid that can cause TLS.

Peripheral neuropathy

Some cancer drugs can affect your nerve endings. Tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney or liver function

Some drugs can irritate or damage kidney and liver cells. This is more common with chemotherapy drugs. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage; yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

Changes in hearing

Some chemotherapy drugs can cause buzzing / ringing sounds in your ears or an inability to hear high-pitched sounds.

Lung changes

Tell your doctor if you develop a cough, wheezing or breathlessness or if existing problems get worse.

Changes to your nervous system

You may feel anxious, restless or dizzy. You may have headaches or find it hard to sleep or concentrate. Tell your medical team if you have these side-effects.

Skin and nail changes

Your skin may become very dry, sore, itchy or you may have a rash. Tell your medical team about skin changes – they can advise you on products to use.

How can I cope with fatigue?



Fatigue means feeling extremely tired. Fatigue is a very common symptom of CLL. Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

- The CLL itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help.

Hints and tips: Fatigue

- **Balance rest and activity.** Ask your doctor about exercising. Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 86) may help too.
- **If you are not sleeping well, try to get a good bedtime routine and try relaxation techniques. Avoid stimulants like caffeine and alcohol in the evening** and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful**, as long as they don't stop you from sleeping at night.
- **Try complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

Our booklet *Coping with Fatigue* has more advice. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre for a free copy. It's also on our website www.cancer.ie

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses - call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie

Will treatment affect my sex life?

CLL can affect how you feel about sex and your relationships. Coming to terms with the fact that you have CLL can take quite a while. It can be hard to relax as well 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. Touching and holding each other can help you to stay physically close.

You may find that 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.

Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. 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.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor's advice about contraception and family planning.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Some treatments can also affect your fertility, either temporarily or permanently.

Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



After treatment

What follow-up will I need? 77

Living with CLL 79

What follow-up will I need?

Once you are in remission, you can start to return to your normal life, but you will still need to go back to hospital for regular check-ups. Some targeted therapies will continue – even when you are in remission.

At the start, you will probably have check-ups every month and then every 3 months.



It's important to go to your follow-up appointments, even if you feel well and have no symptoms, as the tests you will have can spot any changes in your condition. Your doctor can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

Tell your doctor or nurse how you have been since your last appointment. Tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. The symptoms may not be related to your CLL, but it's important to give your doctor as much information as possible about how you're feeling. It can help to write down what you want to say before you see the doctor, so you don't forget anything.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital. You may also need to go to hospital if you get an infection, as your immune system will take time to recover.

Relapse

If the CLL starts to cause symptoms again after remission, this is called relapse. Or if it did not respond to treatment, this is known as refractory CLL.

Relapsed or refractory CLL can be treated – often with targeted therapies and chemotherapy. Your haematologist will advise you on what your treatment options are.



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.

Be involved in your healthcare

- **Learn about CLL so you understand your treatment** and know what to expect.
- **Don't be afraid to ask questions.** There are some questions you might like to ask on page 112.
- **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.** Get a name and number from the hospital so you know who to contact if you have any worries or questions.

Take care of your health

People with CLL are more likely to get infections than people who don't have CLL. Watch out for any signs or symptoms of infection or other problems. Alert the hospital without delay should any respiratory (breathing) complaints arise – such as difficulty breathing or pneumonia-like symptoms. For others, you may find that you have excess mucus, coughing, pain, blocked sinuses or a mild cold.

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 and let your doctor or nurse know if you have any discomfort or pain in your mouth.

If you develop any bowel problems such as ongoing abdominal pain, diarrhoea, bleeding or constipation, you should also contact your doctor as soon as possible.

Tips for avoiding infection

- **If you have a high or low temperature, or if you suddenly feel shivery or unwell, have a cough or sore throat, or pain passing urine, contact your doctor or the hospital immediately.** Most haematology units have a direct phone number to call immediately for advice, so always call without delay if you have any symptoms.
- **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.**
- **Ask your doctor about which vaccinations are recommended for you – and make sure you get them.** See below for more.

Vaccinations

You will probably be advised to get the flu vaccine each winter and the pneumonia vaccine every 5 years. Some vaccinations may not be suitable for you, if your immune system is low. For example, live vaccines. Ask your doctor about any vaccinations you should have and make sure you get them.

Leading a healthy lifestyle



Many people want to live a healthy life after a diagnosis of CLL. Having a healthy lifestyle is important as it can help you to:

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

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

A healthy lifestyle includes:

- **Protecting yourself from the sun** and checking your skin for any changes. CLL may increase your risk of developing skin cancer
- **Avoiding alcohol**
- **Having all the recommended cancer screening tests,** such as bowel cancer screening
- **Exercising**
- **Taking vitamin supplements as advised by your doctor,** if blood tests show you have a deficiency
- **Staying at a healthy weight**
- **Not smoking**

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications on healthy living.

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 71 for more about complementary therapies.
- **Counselling or a short course of anti-anxiety medication may help,** if you are finding it hard to cope. Talk to your GP about how you are feeling. See page 86 for more about counselling.
- **Having the support of loved ones, healthcare professionals and other people going through the same thing can also make a big difference.** See page 87 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.

Holidays and insurance

You may decide to go on a holiday once your CLL is being controlled.

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 is best to have travel insurance too. We have information on travel insurance on our website, www.cancer.ie.

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

Coping and emotions

How can I cope with my feelings?	85
Ways to get emotional support	87
You and your family	89
Talking to children and teenagers	90

How can I cope with my feelings?



Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after your diagnosis.

A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

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

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, 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, help you to make decisions and learn ways to cope better.

The Irish Cancer Society funds free one-to-one counselling through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

Ways to get emotional support



Find out about cancer support services in your area:

Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 110 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people with cancer who are facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Get online support: Special websites called online communities let you 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 worries. 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 to 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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer support

Peer Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

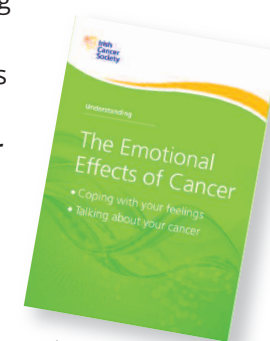
'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

'Counselling has helped me with every part of my life. I feel I have a future now.'

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding the Emotional Effects of Cancer*** can help you find ways to talk about your cancer and to ask for the help and support you need.



If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them.

Changing relationships



You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Support Line Freephone 1800 200 700

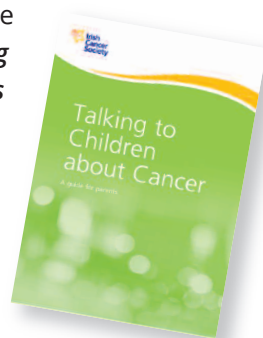
Talking to children and teenagers

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 cancer diagnosis. How you discuss your cancer 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.



The booklet is available free of charge from Daffodil Centres or by calling our Support Line. 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 Support Line on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Email: supportline@irishcancer.ie

Supporting someone with cancer

Supporting someone with cancer	93
How to talk to someone with cancer	94
Support for you	95

Supporting someone with cancer



Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through many local cancer support centres. Talk to your GP or see page 86.

Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

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 saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Caring for 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

Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, *Caring for Someone with Cancer* has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie





Support resources

Money matters	99
Irish Cancer Society services	103
Local cancer support services	110

Money matters

- If you have cancer you may not be able to work for a time. You may also have extra expenses.
 - You may have to pay for some of your cancer treatment.
 - You might be entitled to certain social welfare payments.
 - There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Practical and financial advice from the Irish Cancer Society



We provide individualised financial and practical advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**
- **Public supports**
- **Community supports**
- **Legal entitlements**

We can also act as advocates for patients and their families, for example when discussing your diagnosis with your employer or your financial provider.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre to access any of these supports.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

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 don't 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 tests or treatment to check you're covered.

Email: supportline@irishcancer.ie

Benefits and allowances

There are benefits 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: 0818 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 0818 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 asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.



If you have money problems

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 to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0818 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 give some help towards travel costs in certain cases. See page 107 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

Money and finances

Go to www.cancer.ie and see our **Managing money** page for information on:

- **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**

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Email: supportline@irishcancer.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:

- **Support Line**
- **Daffodil Centres**
- **Telephone interpreting service**
- **Peer Support**
- **Psychological support services**
- **Patient travel and financial grants**
- **Night nursing**
- **Publications and website information**
- **Support in your area**
- **Practical support and financial solution services (see page 99)**

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of the service, please go to <https://www.cancer.ie/Support-Line-Video-Form>

You can also email us any time on supportline@irishcancer.ie; or visit our Online Community at www.cancer.ie.



Daffodil Centres

Daffodil Centres in 13 hospitals nationwide are staffed by cancer nurses and trained volunteers. They provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.



This is a walk-in service. For opening hours and contact details for each of the Daffodil Centres, go to www.cancer.ie and search 'Daffodil Centres'. You can also email daffodilcentreinfo@irishcancer.ie

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Telephone Interpreting Service

Speak to our Support Line and Daffodil Centre nurses in your own language through our telephone interpreting service.

Call Freephone 1800 200 700 or visit a cancer nurse in a Daffodil Centre and we will connect you with an interpreter.

Peer Support Programme

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.



To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Email: supportline@irishcancer.ie

Psychological Support Services

The Society funds professional one-to-one counselling. The services we provide are:

- **Remote counselling nationwide**, by telephone or video call.
- **In-person counselling sessions** in cancer support centres around the country.

Counselling is available for the patient, family members and close friends.

For more information, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.



Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them.

For more information about what's available near you, contact your nearest Daffodil Centre, or call our Support Line on Freephone 1800 200 700.

Patient travel and financial grants

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- The Irish Cancer Society **Volunteer Driver Service** is available mainly to patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for radiotherapy patients attending University Hospital Cork and the Bons, Cork for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.



Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own homes. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.



The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Support Line Freephone 1800 200 700

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website www.cancer.ie to see our full range of information and download copies. You can also Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.



To find out more about the Irish Cancer Society's services and programmes:

- **Visit us** at www.cancer.ie
- **Call** our Support Line on Freephone 1800 200 700
- **Email** our Support Line at supportline@irishcancer.ie
- **Contact** your nearest Daffodil Centre
- **Follow us** on Facebook
- **Follow us** on Twitter
- **Follow us** on Instagram

Local cancer support services

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

- **Professional counselling.** The Irish Cancer Society funds free one-to-one counselling through many local support services
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **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.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to www.cancer.ie and search 'Find support'.



What does that word mean?

Anti-emetic A tablet, injection or suppository to stop you feeling sick or vomiting.

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.

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.

Leukaemia Cancer of the white blood cells.

Neutropenia A reduced number of white blood cells called neutrophils. It can put you at risk of infection.

Transformation When one type of leukaemia changes into another type of leukaemia or lymphoma.

Relapse When disease returns following a stable/remission phase.

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 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?

Are there any vaccinations I should have before or 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?

How often do I need check-ups and blood tests after treatment?

How will I know if my CLL has come back?

Notes / questions

About this booklet

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 up their time and expertise to contribute to previous editions of this booklet.

LEUKAEMIA ADVISERS

Dr Johnny McHugh, Consultant Haematologist
Liz O'Connell, Haematology Nurse Co-ordinator
Sinead Lawlor, Clinical Nurse Manager

CONTRIBUTOR

Anna Drynan Gale, Daffodil Centre 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.
- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2017 with estimates for 2017-2019:* Annual report of the National Cancer Registry of Ireland (2019)
- *Cancer Nursing: Principles and Practice*, CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 7th Ed (2011).

Published in Ireland by the Irish Cancer Society

© Irish Cancer Society 2006. Revised 2012, 2017, 2023

Next revision: 2025

The Irish Cancer Society is a registered charity, number CHY5863.

Product or brand names that appear in this booklet are for example only. The Irish Cancer Society does not endorse any specific product or brand. All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

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 Peer 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 Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4, D04 VX65

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

