

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
- Practical and financial matters

If you have small lymphocytic lymphoma (SLL), you may also find this booklet helpful, as the 2 diseases are treated in the same way.

Useful numbers

Haematologist

Specialist nurse

Family doctor (GP)

Medical social worker

Emergency

Medical records number (MRN)



Contents

About CLL	7
Preparing for your hospital appointments	19
Diagnosis and tests	27
Treating CLL	39
Types of treatment	57
Coping with side-effects	73
After treatment	87
Coping and emotions	97
Supporting someone with cancer	105
Support resources	111
What does that word mean?	127

Fast facts

Can my cancer be treated?

Page 39

Some people with CLL never need treatment because their disease never moves beyond the early stages. Others may not need treatment for a long time. If you need treatment, the aim is to put the disease into remission. Remission means your symptoms have gone, you feel well and your scans and blood tests are normal or near to normal.

Will I be OK?

Page 37

CLL can usually be treated successfully and you can often live with it for many years. Many people with 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 person. The best thing to do is to talk to your doctor.

What kind of treatment might I have?

Page 57

Your doctor may decide to monitor your CLL if it is developing slowly. If you do need treatment, you may have targeted therapies, including monoclonal antibody therapy. You may also need treatment for symptoms like infection, anaemia or an enlarged spleen.

Are there side-effects of treatment?

Page 73

Most treatments cause some side-effects. Anti-cancer drugs can cause a range of side-effects such as fatigue, anaemia and blood clots.

There are treatments to help with most side-effects, so tell your doctor if you are experiencing any. Do not suffer in silence!

We're here for you

Page 117

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 in to a Daffodil Centre.
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 117 for more about our services.



Email: supportline@irishcancer.ie

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

What is leukaemia?	9
What is chronic lymphocytic leukaemia (CLL)?	13
What are the symptoms of CLL?	14
What is small lymphocytic lymphoma (SLL)?	14
Possible complications from CLL	16
What caused my cancer?	17
How common is CLL?	17

What is leukaemia?

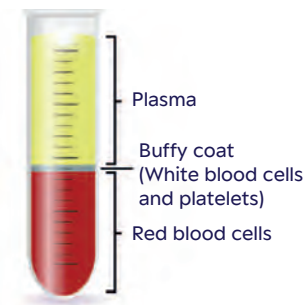
Leukaemia is a cancer that affects your blood. Your body has 3 main types of blood cells:

Red blood cells carry oxygen to all the tissues in your body.

White blood cells are involved in fighting infection. Lymphocytes are a type of white blood cell. They protect you from infection by making proteins called antibodies.

Platelets form clots, which stop you from bleeding.

What does blood look like?

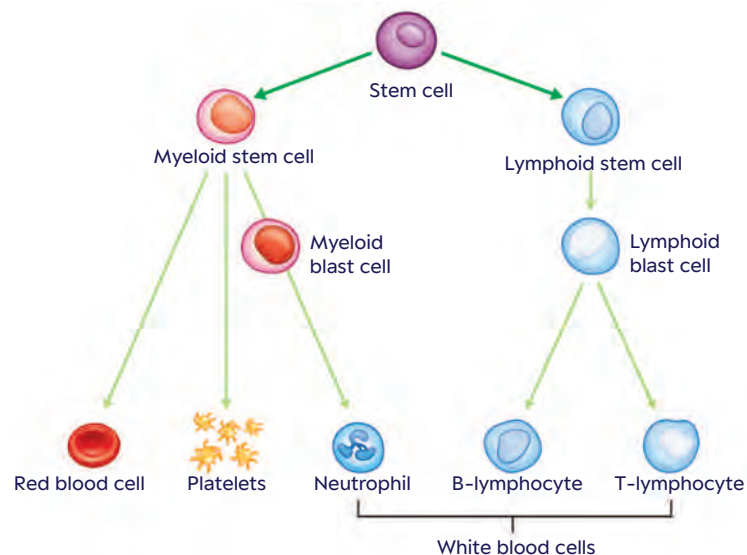


Blood has a liquid part (plasma) and circulating within that are tiny solid bits (cells). Every part of the body is made up of cells. In solid organs, like the liver or heart, cells are fixed in one place. But in the blood, cells flow around the body. This is what makes blood cancers different to cancers of solid organs.

If you were to look at blood in a test tube, blood cells would fall to the bottom of the tube because they are heavy. The plasma would settle on the top. The white blood cells and platelets are in an area known as the 'buffy coat'. If you have leukaemia, you will have a lot more white blood cells so the buffy coat layer will be thicker and the red blood cells layer will be smaller because fewer healthy cells are being produced.

To understand leukaemia, it helps to understand a bit about how blood cells are made.

New blood cells are made inside your bones, in your bone marrow. This is the soft spongy tissue that fills the centre of some bones. All blood cells come from cells known as stem cells. These are like seeds that you might plant in your garden. They grow and produce different types of healthy cells that help your blood to work properly. Stem cells split and develop into myeloid stem cells or lymphoid stem cells. They start out as immature cells (blast cells) and then they develop into different types of mature blood cells. Similar to a seed that grows into a plant with leaves and flowers – they look different but come from the same seed.



Lymphoid stem cells develop into lymphocytes (white blood cells that fight infection by making antibodies).

Myeloid stem cells go on to form red blood cells, platelets, neutrophils (a type of white blood cell that protects you from infection) and other types of white blood cells.

As blood cells develop, they move out of the bone marrow and into your bloodstream, where they do different jobs, such as fighting infection (white cells), carrying oxygen (red cells) and clotting your blood so you don't bleed (platelets). Your bone marrow is constantly producing enough cells to keep this process going. A healthy marrow makes over 600 billion red, white and platelet cells every day.



Patients with leukaemia have abnormal blood cells that grow out of control, filling up the bone marrow and preventing normal blood cells from being made. This changes the normal balance of healthy cells in your blood. You get sick because there aren't enough healthy blood cells to do their jobs in the body and the increasing number of leukaemia cells are a burden on your system.

Email: supportline@irishcancer.ie

Types of leukaemia

There are 4 main types of leukaemia:

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

The names of the different types of leukaemia describe which type of white blood cell is affected (lymphoid or myeloid) and how fast-growing the leukaemia is (acute or chronic).

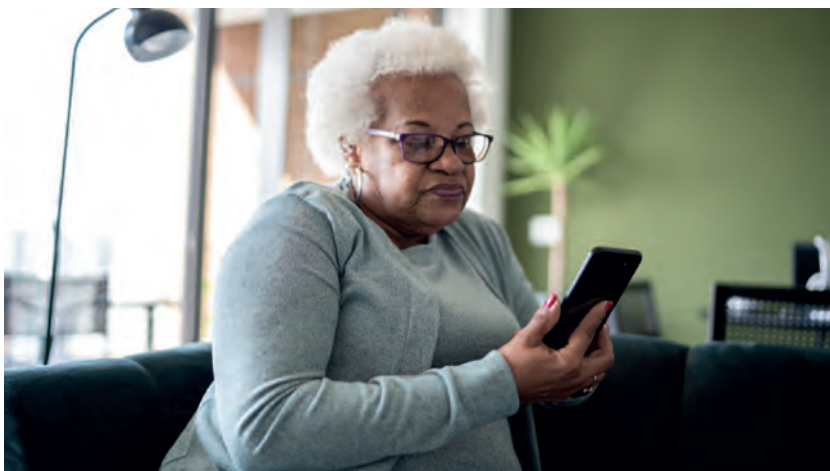
CLL is the most common type of leukaemia diagnosed in adults.

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. You can also download them from www.cancer.ie

What is chronic lymphocytic leukaemia (CLL)?

CLL is usually a slow-growing blood cancer that affects the lymphocyte white blood cells.

CLL stops your lymphocyte white blood cells from working properly to fight infection. These blood cells also don't die off naturally at the end of their life. 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 healthy blood cells to develop. This causes problems with fighting infection, carrying oxygen and bleeding.

Many people with CLL can live a normal life. Other people experience symptoms that affect their quality of life at different stages of their disease and treatment.

Types of lymphocyte cells

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

T cells help your immune system to fight infections and protect you from disease.

B cells make antibodies which are proteins that help the body to fight infection.

NK cells release chemicals that kill infected and diseased cells.

CLL affects the B cells.

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 chance, when they have a blood test for something else that shows abnormal levels of white blood cells. In Europe, more than 8 out of 10 people with CLL are diagnosed in this way.

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.

What is small lymphocytic lymphoma (SLL)?

CLL and SLL are different forms of the same disease – they both affect lymphocytes. The difference between CLL and SLL is where the cancer is mainly found.

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

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

Treatment and care for SLL and CLL are the same. If you have SLL and need more specific information, speak to your doctor or specialist nurse, or you can call our Support Line on 1800 200 700.



Transformation

Rarely, 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), an aggressive type of blood cancer.

This is rare. If it happens, you may notice a sudden increase in symptoms. For example, fevers, extensive weight loss and swollen glands.

If your CLL transforms into a faster-growing cancer, you will need immediate treatment. Your doctor will advise you about your treatment options.

Possible complications from CLL

Skin cancer

CLL increases your risk of developing skin cancer. It is important to wear sunblock (at least SPF30 sunscreen) 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. See our website www.cancer.ie for more information on how to reduce your risk of skin cancer.

Autoimmune blood conditions

Autoimmune haemolytic anaemia: CLL or treatment for CLL may upset your immune system, causing it to attack and destroy red blood cells. This results in low red blood cells (anaemia). You may notice jaundice (yellowing of the skin or white part of your eyes) or dark urine if this happens. This is called autoimmune haemolytic anaemia (AIHA).

Immune thrombocytopenia: CLL may trigger the body to destroy healthy platelet cells. This is called immune thrombocytopenia (ITP). You may notice easy bruising, petechiae (tiny red spots) and bleeding if this happens.

These blood conditions occur in up to 1 in 20 people with CLL. Other autoimmune blood conditions are much rarer, occurring in less than 1 in 100 people with CLL. 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.

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.

Most people with CLL do not have a family history of the disease. Around 1 in 30 people with CLL will have a relative with CLL or a similar B-cell leukaemia or lymphoma.

If you want to know more about why cancer happens or you want to learn about risk factors for CLL, see our website www.cancer.ie or talk to one of our Cancer Nurses – call our Support Line or visit a Daffodil Centre.



How common is CLL?

CLL is a common type of leukaemia, but it is still a rare type of cancer overall. About 220 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 than women.



Preparing for your hospital appointments

Before your appointment	21
What to take to your appointment	22
Before leaving the appointment	23
After the appointment	23
Questions to ask your doctor	24

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps your doctors and nurses get the information they need to plan your care.



Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and are not fasting, as it makes it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is OK to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals may be happy for you to record the meeting, but make sure you ask for their permission first)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time
- Your phone and your phone number
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave



After the appointment

- Arrange any tests before your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

It is important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Try not to 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 take?

-
- Do I need to stay in hospital when having my treatment?

-
- Do I need other types of treatment?

-
- What are my options if 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?
-



Diagnosis and tests

Being diagnosed with CLL	29
What tests will I have?	31
Staging CLL	36
Asking about your prognosis	37

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

However you feel, you are not alone.

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 similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our Cancer Nurses can put you in touch with a volunteer.
- **Talk to other people going through the same thing.** Join support groups online or get in touch with CLL Ireland (www.clli.ie).
- **Go to your local cancer support centre.** For more information, see page 126.

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 of 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 one of our Cancer Nurses, 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 chromosome 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.

Blood film

Your doctor may look at a blood sample under a microscope to determine the amount of leukaemia cells present. This is called a blood film. It is usually carried out in the haematology laboratory of the hospital.

Immunophenotyping using flow cytometry

This test checks what kind of proteins or markers are on the surface of your cells. CLL cells show a characteristic pattern of cell surface markers. This test can be done on your blood or bone marrow. This is often how CLL is diagnosed.

Bone marrow tests

Bone marrow tests are not needed for everyone with CLL. Talk to your doctor about whether you need one. If your doctor recommends a bone marrow test, they will explain the procedure to you.



Chromosome and DNA-based tests

Your doctor may arrange some tests to detect chromosome and DNA-based changes in your CLL cells. Chromosomes are structures that contain DNA. These carry genetic information. Genetic information tells your body how to grow and develop. For people with early-stage CLL, these tests are not always needed. For people needing treatment for their CLL, these tests can help determine the best treatment options for you.

Chromosome studies (cytogenetics)

Chromosome tests can find out about abnormalities in your chromosomes that are 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 occasionally your bone marrow will be checked for known abnormal changes in chromosomes that happen with CLL.

An example of a chromosome test is called FISH analysis. Genes are specific parts of DNA. 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. About 3 in every 4 CLL patients have chromosome changes in their CLL cells.

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

Chromosome and DNA changes in CLL

Your chromosome and DNA-based tests might check for some of the following abnormalities:

Del (13q): 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 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.

Del (11q): Missing parts of chromosome 11 (del 11q) are also associated with a poorer prognosis. This missing gene is called ATM. CLL with del (11q) tends to grow more quickly than CLL without del (11q). Modern targeted treatments generally work well for CLL with del (11q).

(...continued on next page)

(...continued) Chromosome and DNA changes in CLL

Tri (12): Trisomy 12 (tri 12) means you have an extra copy of the whole of chromosome 12. CLL with trisomy 12 often causes large lymph nodes. Modern targeted treatments often work well for CLL with trisomy 12.

IgVH gene mutation: 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.

TP53 gene mutation: TP53 is one of the most important genes that can be damaged in CLL cells. Between 5% and 10% of people with CLL have mutated TP53 or absent TP53. Mutated TP53 is detected by DNA sequencing. If you have CLL with TP53 abnormalities, there is a small chance that the disease may relapse (come back) sooner compared to people without an abnormal gene. However, many of the drugs available today are very effective in treating CLL with abnormal TP53 genes.

Other DNA-based testing: As our understanding of CLL grows, you may be offered testing for other DNA-based changes in your CLL cells.

Other tests

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

Chest X-ray

This 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 node 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 put on your skin over the area being checked. A small device, like a microphone, is moved over the area to take the scan. 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 that passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes.

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 one of our Cancer Nurses.

Staging CLL

- Staging CLL means finding out how much the cancer has developed.
- Knowing the stage helps your doctor to plan your treatment.
- 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 finding out how much the cancer has developed in your body. This helps your doctor to plan your treatment.

The Binet system is one way to stage CLL. It has 3 stages: A, B and C. It measures the number of white blood cells and checks 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 3 areas of enlarged lymph nodes.

Stage B: There are 3 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 5 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 A 0 or C IV.

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

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 doctors expect.

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 your 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 some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis, you can get support from family, friends or your hospital team.

You can also call our Support Line on 1800 200 700, email supportline@irishcancer.ie or visit a Daffodil Centre. Our Cancer Nurses can give you support, information and advice. They can also tell you about free counselling and other services that may help you.

Support Line Freephone 1800 200 700

Treating CLL

How is CLL treated?	41
How will I be monitored during my treatment?	44
Response to treatment	45
Deciding on treatment	46
Giving consent for treatment	48
Who will be involved in my care?	49
How can I help myself?	52

How is CLL treated?

- Some people never need treatment or do not need treatment for a long time.
- If treatment is needed, targeted therapies, including monoclonal antibody therapy, are used.

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 your symptoms are gone, you feel well and your scans and blood tests are normal or near to normal. The type and amount of treatment you will need depends on the stage of your CLL, your general health and any symptoms you have.



If the CLL starts to cause symptoms again after remission, this is called relapse. CLL can still be treated after 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.

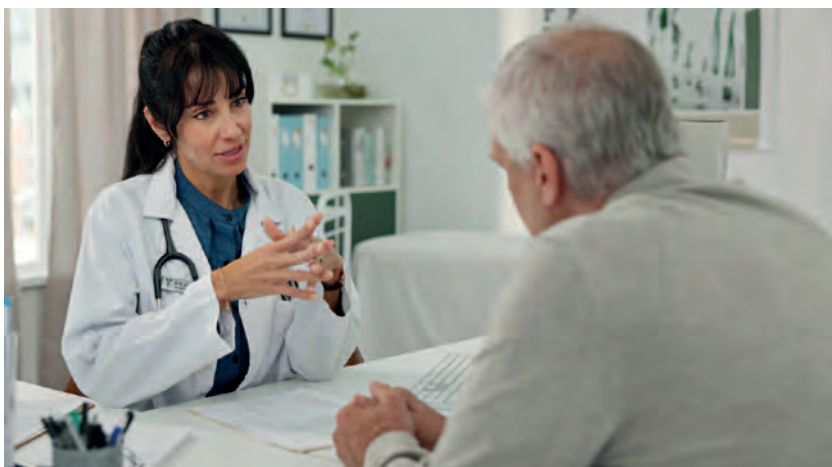
Management of early-stage CLL without symptoms

If your disease is not active, there is little or no benefit to treatment. Watch and wait (active surveillance) 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. The check-ups may be with your hospital specialist, your GP or a combination of both. See page 59 for more on watch and wait.

Most patients with (Binet) stage A CLL and some patients with (Binet) stage B CLL are managed with watch and wait (active surveillance). See page 36 for more on staging.

Your doctor will tell you the symptoms to look out for that may mean your CLL needs treatment. However, you may never need treatment if your disease does not move beyond the early stage.



Treating (Binet) stage B or C

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

The main treatments are:

Targeted therapies including monoclonal antibody therapy

Targeted therapy drugs target certain parts of the cancer cells that make them different from other cells. See page 61 for more details.

Steroid therapy

Steroids can sometimes help to control CLL when they are used with other treatments. Steroids can also help with some of the symptoms of CLL such as fatigue. See page 65 for more details.

Combination therapy

Your doctor may decide to give you a number of different drugs at the same time. This is known as combination therapy.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. CLL is rarely treated with chemotherapy.

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 68 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 69 for more details.

Email: supportline@irishcancer.ie

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 treatment.

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



Bone marrow tests: Rarely, your doctor may recommend a bone marrow test. If recommended, your doctor will explain this to you.

Support Line Freephone 1800 200 700

Response to treatment

Your doctor will monitor how your CLL responds to treatment:

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

Complete response: 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.

Measurable residual disease (MRD): Measurable residual disease (MRD) means looking for very small amounts of CLL remaining in the body after treatment, using sensitive tests on blood or bone marrow samples. MRD positive means that low levels of CLL can be detected. MRD negative means that no traces of CLL can be found. People with CLL who are MRD negative after treatment usually have a longer period of remission after treatment, but this doesn't mean the CLL has been cured. It may still come back.

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 nurses. 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 pages at the back of this booklet for your questions and answers. If you 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 first explained to you.



Second opinion

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

Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse 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 will 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. CLL tends to behave differently from one patient to the next, so your doctor will tailor your treatment to your specific needs. Treatment decisions can also depend on any previous treatments you have had and your general health. Everyone's 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. 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 one of our Cancer Nurses.

You might like to focus on feeling as well as possible while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see page 52.

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 and bone marrow diseases, including blood cancers.

Haematology liaison nurse/clinical nurse specialist (CNS): A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment. In some hospitals, ANPs run acute oncology clinics for people who need help with side-effects or have other problems during their treatment. Ask your doctor or nurse if there is an acute oncology clinic in your hospital.



Medical social worker: A person trained to help you and your family with your emotional and practical needs. They can also give advice on social welfare benefits, financial and family matters, and practical supports and services available to you.

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

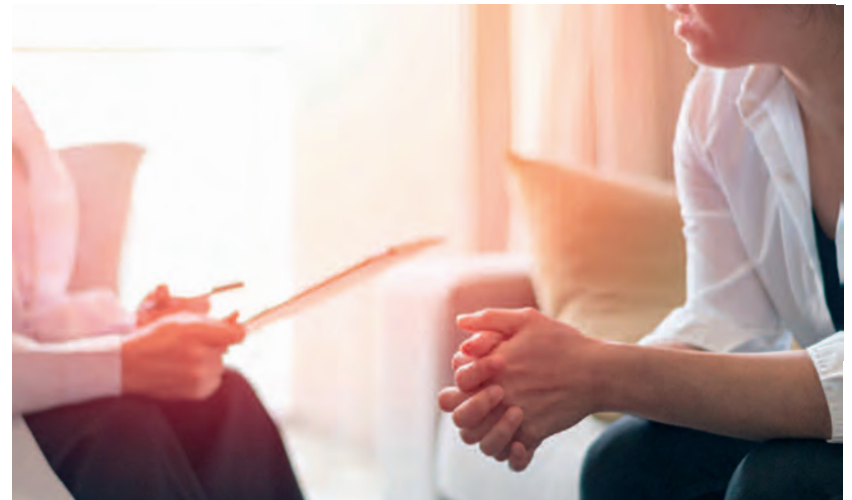
GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

Pharmacist: A healthcare professional who dispenses cancer drugs, including targeted therapy drugs. Pharmacists may be based in hospitals or in local pharmacies. 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), 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.

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 as well as possible.

Eat well

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

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better so you can finish your course of treatment
- Cope better with the side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster



Ask to talk to the dietitian at the hospital for advice on the best diet for you. We provide group online information sessions with an Oncology Dietitian, to support you to eat well during cancer treatment and beyond. You can also read our booklet ***Understanding diet and cancer***. For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels 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 and may have information on exercise programmes and classes. Call our Support Line or visit a Daffodil Centre for information on how you can make exercise part of your everyday life. Ask about our free exercise classes, to build strength and fitness in a supportive environment.

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 some cancer treatments work
- Not smoking reduces your risk of further illness



If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit www.QUIT.ie or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

Vaccinations

People with CLL have a higher risk of getting infections, so you will probably be advised to get certain vaccines, such as the flu vaccine and the pneumococcal vaccine. Some vaccines may not be suitable for you. See page 93 for more on vaccinations.

Sun protection

Take care of your skin in the sun. Always use a sun cream with a sun protection factor (SPF) of at least 30. Check your skin regularly for any changes. For more on how to protect your skin from the sun, visit our website www.cancer.ie

Support Line Freephone 1800 200 700

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. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE. You can also speak to one of our Cancer Nurses by calling our Support Line on 1800 200 700.



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

Activities 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

Some people find it helpful to concentrate on the present and on getting through each day of tests or treatment. This may help you to cope with your illness, especially if you are worrying a lot about the future.



Types of treatment

Watch and wait (active surveillance)	59
Targeted therapies	61
Clinical trials	67
Stem cell transplants	68
Treating symptoms	69

Watch and wait (active surveillance)

Most people diagnosed with CLL show few signs of active disease. About 1 in 3 of patients with CLL have a form that grows so slowly that no treatment is needed during their lifetime. Instead of treatment your doctor may recommend watch and wait (active surveillance). 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. Most people with CLL will be managed this way for a period of time.



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.
- **Get help 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 aromatherapy 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 100 for more about counselling. You can also get support from the patient-led voluntary group, CLL Ireland (www.clli.ie).



Targeted therapies

Targeted therapies are drugs that target certain parts of cancer cells to slow their growth or to 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 making new blood vessels that 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. See pages 62-63 for more about these drugs.

You may be given 2 or more drugs at the same time. This is called combination therapy. Your doctor or nurse will explain these treatments and let you know if they are suitable 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 78), 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.

Email: supportline@irishcancer.ie

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).

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 75 for more about coping with the side-effects of anti-cancer drugs.

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 need to stay in hospital overnight. Your 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 other drugs, including other targeted therapies. This is called combination therapy.

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. 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 73 for more about coping with side-effects.

Tell your doctor or specialist nurse if you experience any side-effects.

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 written information to take home with you.

If you know the name of your anti-cancer 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 one of our Cancer Nurses by calling our Support Line on 1800 200 700 or by visiting a Daffodil Centre.



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 cause 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.

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.

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 treatment. 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 2 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

Stem cell transplants

Most people with CLL won't need a stem cell 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?

Your 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 suitable for you. For more information, contact our Cancer 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.

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 blood 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. You will be recommended to get certain vaccines, such as the annual flu vaccine. Ask your doctor about vaccines that may protect you and make sure you get them. See page 93 for more about vaccinations and for tips on avoiding infection.

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. Immunoglobulins boost your immune system.

Immunoglobulins are given by drip infusion into a vein or as a slow injection under the skin of the tummy or thigh (subcutaneous injection). You may need the injection during the winter months, to help you to fight off 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 of this.



Anaemia and bleeding problems

If your red blood cell count is low (anaemia), 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 (AIHA) or a low platelet count because of immune thrombocytopenia (ITP), your doctor will prescribe specific treatments for you. See page 16 for more on these conditions.

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.



Email: supportline@irishcancer.ie



Coping with side-effects

Coping with side-effects of anti-cancer drugs	75
How can I cope with fatigue?	80
Cancer and complementary therapies	82
Will treatment affect my sex life?	83
Will treatment affect my fertility?	85

Coping with the side-effects of anti-cancer drugs

The side-effects of cancer drugs depend on the dose and the drugs 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 80.

Nausea and vomiting

Cancer drugs can cause nausea (feeling sick) and vomiting (getting 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 also affects 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 93 for tips on avoiding infection.



Anaemia

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. You will have regular blood tests during treatment to measure your red blood cell count. You may need a blood transfusion to treat your anaemia.

Bleeding and bruising

Some cancer drugs can stop your bone marrow from making enough platelets. Platelets help your blood to 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 cancer drugs can cause hair loss. How much hair falls out depends on the drugs 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 (poo) 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 a 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. 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.

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. Nails may become marked and chip/break easily. Tell your medical team about these changes – they can advise you on products to use.

How can I cope with fatigue?

Fatigue means feeling extremely tired despite rest. Fatigue is a very common symptom of CLL. 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

- **Ask your doctor about exercising:** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you or you could ask our Cancer Nurses about our free exercise classes. Call our Support Line or visit a Daffodil Centre for more information.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are most important 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 *Understanding 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 may help too (see page 100).
- **If you are not sleeping well, try to maintain 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 to have naps in the earlier part of the day.
- **Try complementary therapies** like meditation, acupuncture or aromatherapy 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 in to 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, reflexology, acupuncture 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, or supplements. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

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.

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.

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 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 and maintain intimacy.

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.

Our booklet, ***Understanding sex, sexuality and cancer***, also has lots of information. You can call our Support Line or visit a Daffodil Centre for a free copy. Or you can download it from **www.cancer.ie**

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 anti-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 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 one of our Cancer Nurses in confidence. Or email the nurses at supportline@irishcancer.ie

Support Line Freephone 1800 200 700

Will treatment affect my fertility?

Your fertility may be affected by some treatments so that you may not be able to have a child in the future.

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 one of our Cancer Nurses.





After treatment

What follow-up will I need?

89

Living with CLL

91

What follow-up will I need?

You will need long-term follow-up. CLL often progresses slowly and people can live for a long time with it, so it is important that they continue to be monitored.

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

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 later. 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 a relapse. If it did not respond to treatment, this is known as refractory CLL.

Relapsed or refractory CLL can be treated – often with targeted therapies, including monoclonal antibody therapy. 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 24.
- **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

- Take precautions to avoid infections. See the next page for tips on avoiding infections.
- Contact your doctor or hospital straight away if you have any signs of infection, symptoms of CLL or any other health problems.
- Having CLL can increase your risk of developing other types of cancer, so always take part in screening programmes when invited to, such as BowelScreen and BreastCheck.
- Take care of your skin in the sun. Use sun cream with a minimum sun protection factor (SPF) of 30. For more information on how to protect your skin in the sun, see our website www.cancer.ie
- Have regular dental 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. Let your doctor or nurse know if you have any discomfort or pain in your mouth.
- Have regular eye check-ups.
- If you develop bowel problems, such as ongoing abdominal pain, diarrhoea, bleeding or constipation, you should contact your doctor as soon as possible.

Support Line Freephone 1800 200 700

Tips for avoiding infection

- **If you have breathing problems, 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. Always call without delay if you have any symptoms.
- **Avoid 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 have come into contact with people who have these or any other infections.**
- **Wash your hands often during the day,** especially before you eat and after going to the toilet.
- **Some people with CLL may need to avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.** Your doctor or dietitian can advise you about this.
- **Ask your doctor about which vaccinations are recommended for you – and make sure you get them (see below).**

Vaccinations

You should get the flu vaccine every year. Anyone living with you should ideally also get the flu vaccine every year.

You should also get the pneumococcal vaccine every 5 years. Pneumococcal disease can lead to serious illnesses, including pneumonia and sepsis. People with CLL have an increased risk of mortality (death) from invasive pneumococcal infection.

Some vaccinations will not be suitable if you have CLL, so check with your doctor which you should have and make sure to get these.

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 feel stressed.** Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 82 for more about complementary therapies.
- **Counselling or a short course of anti-anxiety medication may help if you are finding it hard to cope.** See page 100 for more.
- **Having the support of loved ones, healthcare professionals and other people going through the same thing can also make a big difference.** See page 101 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.

Support Line Freephone 1800 200 700



Coping and emotions

How can I cope with my feelings?	99
Ways to get emotional support	101
You and your family	103

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 treatment.



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. You can also download it from www.cancer.ie

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 professional one-to-one counselling, remotely or in person, at 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. You can also email our Cancer Nurses at supportline@irishcancer.ie

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

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 126 for more about local 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 your hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services if they are available at your hospital.

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 visit a Daffodil Centre.

Peer Support

Peer Support is the Irish Cancer Society's free and confidential telephone service that connects 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. For more information, call 1800 200 700 or visit a Daffodil Centre.

Positive feelings

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.

“ I am very happy and content...
even though I have to live with this. ”

Support Line Freephone 1800 200 700

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 to 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. Our nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet, ***Talking to children about cancer***, which has practical advice about how to talk to children of different ages.

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

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.

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 one of our Cancer Nurses in confidence.



Supporting someone with cancer

Supporting someone with cancer	107
How to talk to someone with cancer	109
Support for you	109

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 in to a Daffodil Centre if you want to chat to one of our Cancer Nurses 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 at many local cancer support centres. Talk to your GP or see page 100.

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 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 loved one. 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	113
Irish Cancer Society services	117
Local cancer support services	126

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 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 your illness if you are worried about money.



Our Welfare and Supports Service



Cancer can create additional challenges. Our Welfare and Supports team can help. We can advise on benefits, social welfare entitlements, public services, medical card applications, community support, legal entitlements, housing and mortgages, childcare or talking to your workplace about your diagnosis. For more information or to be referred to our Welfare and Supports Service, visit www.cancer.ie/welfare-and-supports, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs and incontinence products

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 private health insurance, the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.



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 and 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 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 them.

If you have money problems

If you are in debt or worried about getting into 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 on 0818 072 000 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 123 for more details of our Transport Service and the Travel2Care fund.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre where our Cancer Nurses will suggest ways to help you manage.

Money and finances

Go to www.cancer.ie and see our **Welfare and support** 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 website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Service may also be able to help (see page 114).

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Telephone Interpreting Service**
- **Patient Education**
- **Peer Support**
- **Eating well information sessions**
- **Exercise information and support**
- **Counselling**
- **Transport Service**
- **Welfare and Supports Service** (see page 114)
- **Publications and online information**
- **Night Nursing**

Support Line Freephone 1800 200 700

Our Cancer Nurses offer confidential advice, support and information for anyone affected by cancer. Our Support Line is open Mon to Fri 9am – 5pm. Email us on supportline@irishcancer.ie

The Support Line also offers video calls. From the comfort of your own home, you can meet a Cancer Nurse virtually. To use this service, offered on the Microsoft Teams platform, visit

www.cancer.ie/Support-Line-Video-Calls. One of our nursing team will email you with the time for your video call and instructions on how to access Microsoft Teams on your phone, tablet or computer.



Daffodil Centres

Our Daffodil Centres, located in 13 hospitals nationwide, are staffed by Cancer Nurses and trained volunteers who provide face-to-face advice, support and information for anyone affected by cancer. This service is free and confidential. This is a walk-in service; you do not need an appointment.

To see your nearest Daffodil Centre, contact details and opening hours, visit www.cancer.ie/daffodil-centres



What information is available?

Our Cancer Nurses provide free and easy-to-understand information on:

- Screening, cancer prevention and early detection
- Cancer types
- Tests and investigations used to diagnose cancer
- Cancer treatments and side-effects
- Local cancer support services
- Life after cancer treatment
- Financial and practical supports
- End-of-life services

Our Cancer Nurses can also give you more information or refer you to any of our supports and services.

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Cancer Nurses in your own language through our Telephone Interpreting Service. To use the service:

- Tell us in English the language you would like.
- You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.
- We will connect you to an interpreter.
- The interpreter will help you to speak to us in your own language.



For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Patient Education

We offer free group sessions (online and in person) and video resources that provide information to guide you through and beyond cancer treatment.

Chemotherapy Education is for cancer patients who are due to have chemotherapy. The aim of the session is to guide the patient through the treatment from beginning to end: what chemotherapy is, how it is given, managing side-effects and available supports.



Our after-treatment education workshop is called **Life and Cancer – Enhancing Survivorship (LACES)**. It was developed in partnership with the National Cancer Control Programme. LACES aims to improve the quality of patients' lives after active treatment has ended.

Patient education sessions are led by our Cancer Nurses. Sessions take place online or in person in our 13 Daffodil Centres nationwide.

We also have pre-treatment video resources that you can watch in your own time. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre, visit www.cancer.ie/our-services or email patienteducation@irishcancer.ie

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. If you have a cancer diagnosis, you can be connected with a Peer Support volunteer who has had a similar cancer experience. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

More information on Peer Support is available at www.cancer.ie/our-services. To be connected to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.



Eating well information sessions

We provide group online information sessions with an Oncology Dietitian on the important role nutrition has for people with cancer. Using evidence-based specialist advice, we can support you to eat well during cancer treatments and beyond.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Exercise information and support

Exercise before, during and after treatment can improve quality of life. We provide information and support on how you can make exercise part of your everyday life. We also offer free exercise classes to help people with cancer to improve fatigue, quality of life, reduce anxiety and build strength and fitness in a fun and supportive environment.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services



Counselling

We fund professional one-to-one counselling for anyone affected by cancer – the person diagnosed with cancer, family members and close friends. Counselling sessions are available remotely (over the telephone/online) or in person in certain cancer support centres around the country.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Transport Service

We provide transport and limited financial grants for patients in need who are in cancer treatment.

Transport is available to patients having 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 patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.



Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they travel over 30 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme (NCCP).

To access this support, please contact your hospital healthcare professional. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit www.cancer.ie/our-services

Publications and online information

We provide information on a range of topics, including cancer types, treatments, 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 call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

Night Nursing

We provide end-of-life care for cancer patients in their own homes. We offer up to 10 nights of care free of charge for each patient. Our service supports 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 night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

To access this service please contact the healthcare professional looking after your loved one. For more information visit **www.cancer.ie/our-services**

“ We were really lost when we brought Mammy home from the hospital and the night nurse’s support was invaluable. She provided such practical and emotional support. ”

“ Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us. ”

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

Visit us at www.cancer.ie

Speak with one of our Cancer Nurses:

- **Call our Support Line on Freephone 1800 200 700**
- **Visit one of our 13 Daffodil Centres in hospitals nationwide**

Email the nurses at supportline@irishcancer.ie

Follow us on:

- **Facebook [@IrishCancerSociety](https://www.facebook.com/IrishCancerSociety)**
- **X [@IrishCancerSoc](https://twitter.com/IrishCancerSoc)**
- **Instagram [@irishcancersociety](https://www.instagram.com/irishcancersociety)**
- **LinkedIn [@irish-cancer-society](https://www.linkedin.com/company/irish-cancer-society)**



Local cancer support centres

Local cancer support centres 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 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.

Visit www.hse.ie to find a cancer support centre in your area or visit www.cancer.ie and search 'local cancer support centres'.

Our Cancer Nurses can also help you to find support and services. Call our Support Line or visit a Daffodil Centre to talk to one of our Cancer Nurses.

Support Line Freephone 1800 200 700

What does that word mean?

Active surveillance: Also called 'watch and wait', this is when doctors do not give you treatment for your CLL, but instead regularly monitor you.

Cytogenetics: Chromosomes contain genetic information. Cytogenetic tests look at the number and shape of the chromosomes in your blood cells.

Haematologist: A doctor who specialises in treating patients with blood or bone marrow diseases, including blood cancers.

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.

Lymphocytes: A type of white blood cell that has a key role to play in fighting infection.

Targeted therapies: Targeted therapy drugs target certain parts of the cancer cells that make them different from other cells.

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

Relapse: When disease returns following a stable/remission phase.

Notes/Questions

Notes/Questions

Notes/Questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave their time and expertise to contribute to previous editions of this booklet.

LEUKAEMIA ADVISERS

Dr Niamh Appleby, Consultant Haematologist
Fidelma Hackett, Haematology Advanced Nurse Practitioner
Melissa Martin, Haematology Clinical Nurse Specialist

This edition has also been reviewed by the National Cancer Control Programme's Chronic Lymphocytic Leukaemia Clinical Advisory Group (NCCP CLL-CAG)

CONTRIBUTOR

Aoife McCormack, Daffodil Cancer Nurse

EDITOR

Deborah Colgan

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

- 2025 *British Society for Haematology Guideline for the treatment of chronic lymphocytic leukaemia*, R Walewska, TA Eyre, A Bloor, et al. *British Journal of Haematology* 2025; 207(6): 2296–2313 (2025)
- *National Cancer Strategy 2017–2026*, National Cancer Control Programme (published 2017, updated 2024)
- *Cancer in Ireland 1994–2022*, National Cancer Registry of Ireland (2024)
- *Cancer Nursing: Principles and Practice*, CH Yarbro, d Wujcik, B Holmes Gobel. Jones & Bartlett Learning, 8th edition (2018)

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2006. Revised 2012, 2017, 2026

Next revision: 2028

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! Visit www.cancer.ie if you want to get involved.

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

Did you like this booklet?

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



Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre