Chronic lymphocytic leukaemia (CLL)

A guide for people with CLL and their support network

Leukaemia Foundation®

This booklet has been written to help you and your support people understand more about chronic lymphocytic leukaemia (CLL).

It is inclusive of small lymphocytic lymphoma (SLL). This booklet has a list of contents, useful resources and a glossary. Your treatment team can answer further questions. You can also call our Blood Cancer Support Coordinators on 1800 620 420.

You will meet many healthcare professionals working as a team to provide you with the best available treatment. You will need to have a regular GP throughout your treatment. In this booklet when we refer to 'your treatment team' we usually mean haematologist and haematology nurses.

There is some information about treatments in this booklet, but it does not recommend any particular treatment. You must discuss your circumstances and treatment options with your haematologist.

The Leukaemia Foundation acknowledges the traditional owners of country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

The Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

Booklets for Aboriginal and Torres Strait Islander patients and their families can be found on our website.

Access the Leukaemia Foundation online support service for practical and emotional information and resources.

Access CLL Your guide to best cancer care here

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CLL in brief

About CLL

Chronic lymphocytic leukaemia (CLL) starts in the bone marrow, where too many abnormal white blood cells are made. In CLL the abnormal white cells are mainly found in the bone marrow and the bloodstream. If the abnormal white cells are mainly found in the lymph nodes this is diagnosed as a type of non-Hodgkin lymphoma called small lymphocytic lymphoma (SLL). CLL and SLL are considered the same disease and are treated in the same way. When this booklet refers to CLL it is inclusive of SLL.

In CLL the abnormal white blood cells are called lymphocytes. Usually, lymphocytes help protect against infection and disease. In people with CLL, lymphocytes are abnormal and do not work properly. They build up in the bone marrow limiting space to make enough healthy blood cells. These healthy cells include red cells, white cells or platelets and they are very important to how the body functions.

The abnormal lymphocytes can build up in organs including the lymph nodes (glands), liver, spleen, and other parts of the body.

Symptoms of CLL include:

- Tiredness
- Weakness
- Dizziness
- Weight loss
- Fever
- Infections
- Night sweats
- Easy bruising
- Swollen lymph nodes
- Abdominal discomfort

Often, people have no obvious symptoms of CLL at diagnosis.

Approximately one-third of all CLL patients will live for years without symptoms.

CLL is diagnosed through blood tests.

You may require a CT scan and a bone marrow biopsy.

There is often a genetic abnormality in the cancerous lymphocytes.

In most cases we don’t know what causes CLL.

There is no way to prevent CLL and you can’t catch it or pass it on.

Who gets CLL?

2400
number of Australians diagnosed each year

84%
of people diagnosed are over 60

71
average age at diagnosis

Second opinion

If you are unsure about your diagnosis or treatment, you are entitled to seek a second opinion. This may be at the same hospital or clinic, or at a different location. “Your guide to best cancer care” is a resource to help to guide you, your family and friends through the blood cancer experience. There are specific guides for each type of blood cancer. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP, or a counsellor.

Access CLL Your guide to best cancer care here.

What's the prognosis?

A prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. CLL is divided into stages. Your haematologist will work out and let you know your stage. Your haematologist will consider many factors regarding your prognosis.

Some of these are:

- Your lymphocyte count (and how long it takes to double)
- Which chromosomes or genes are affected
- Stage of CLL
- Your overall health
- Your age

Your prognosis might change if your CLL comes back after treatment or changes to a different type of cancer.

All about blood

What is blood?

Blood travels through the heart and blood vessels, carrying oxygen, nutrients and waste products. It's made up of cells and plasma. Plasma is the straw coloured liquid part of the blood that carries blood cells and other substances around your body. The main types of blood cells are red and white cells. Platelets are talked about like blood cells, but they are fragments of blood cells.

Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives the blood its red colour and carries oxygen from the lungs to all parts of the body. Most blood cells in your total blood volume (40-45%) are red blood cells. They carry oxygen for the body to produce energy.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs. They form part of the immune system. White blood cells are necessary to protect us against and fight off infection.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They stick together when you are bleeding to help your blood clot, a process called coagulation.

Where and how is blood made?

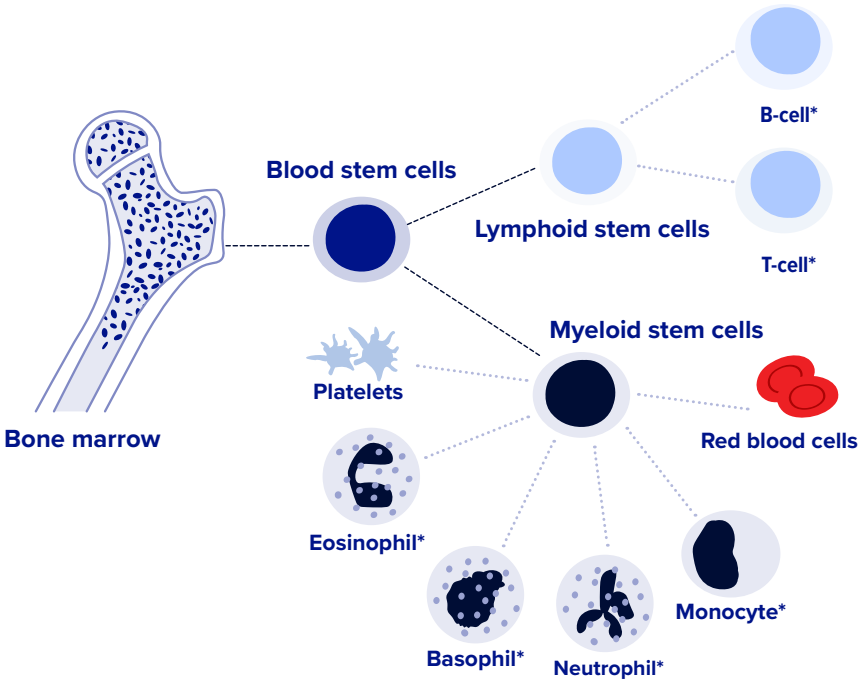
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called haemopoiesis.

In children, haemopoiesis takes place in the long bones, like the thigh bone (femur). In adults, it's mostly in the spine (vertebrae), hips, ribs, skull and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

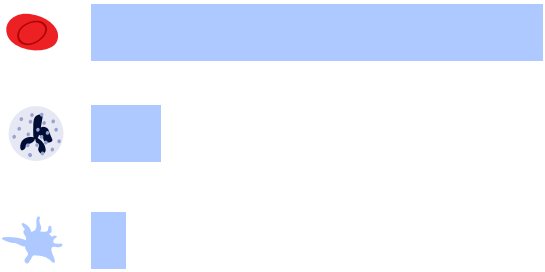
Think of blood production like a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. At the bottom of the family tree are red blood cells, white blood cells*, and platelets.



Growth factors

All normal blood cells live a short time:



red blood cells for 80-100 days

neutrophils 8-14 days

platelets 4-5 days

They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood, called growth factors, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the laboratory (synthesised) and given to people to help treat blood disorders.

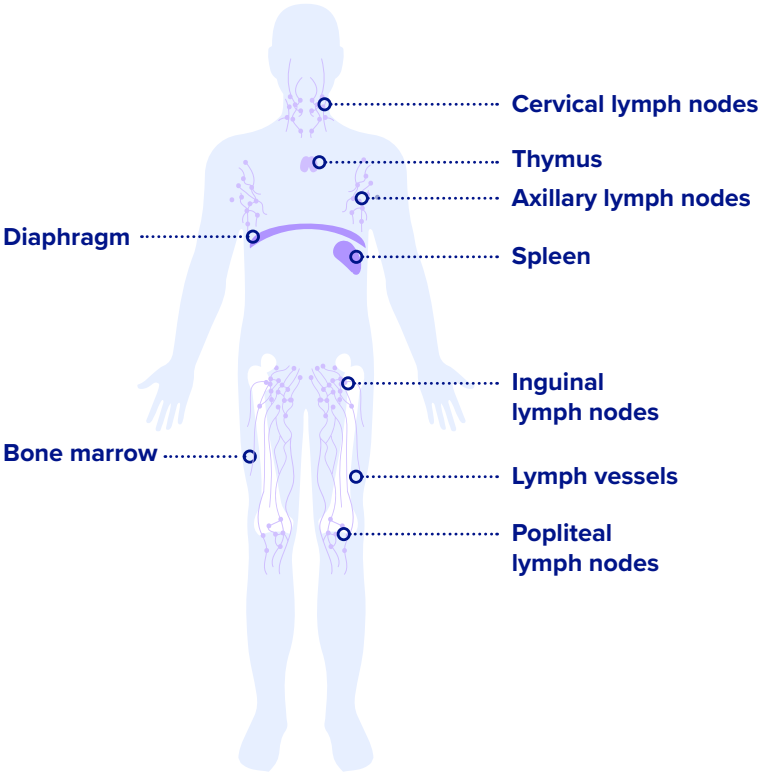
All about the lymphatic system

The lymphatic system plays various roles in your immune system and helps defend our bodies against infection and disease. It's a network of small tubes called lymphatic vessels. These carry lymph around the body. It also drains lymph fluid that's leaked from blood vessels into your body's tissues and returns it to the blood.

The lymphatic system is made up of:

- Lymphatic vessels
- Lymph nodes (also called lymph glands)
- White blood cells (lymphocytes)

Lymph nodes are small filters. They filter bacteria from the lymph fluid. Lymphocytes (white blood cells) inside the lymph nodes attack and kill bacteria. Your neck, armpits, and groin area all contain groups of lymph nodes. There are also some along the lymphatic pathways in your chest and belly.



Lymphatic tissue is also found in:

- The spleen (an organ on the left side of the abdomen)
- The thymus (a gland behind the breast bone)
- Tonsils and adenoids (glands in the throat)
- Bone marrow
- The stomach and gut
- The skin

These are all part of the lymphatic system and perform similar roles to lymph nodes.

About leukaemia

Leukaemia is the name of a group of cancers that start in the bone marrow. Leukaemia begins in developing blood cells, which have had an abnormal (cancerous) change. They multiply in an uncontrolled way and do not mature how they are supposed to. Because they have not matured properly, these cells can't function normally.

Types of leukaemia

There are quite a few different types and subtypes of leukaemia. Leukaemia can be either acute or chronic. The terms 'acute' and 'chronic' refer to how quickly the disease develops and progresses. Acute diseases tend to develop and progress very quickly. Whereas chronic diseases develop and progress over a long time. Chronic lymphocytic leukaemia (CLL) is a chronic type and usually progresses slowly over years.

What is chronic leukaemia?

In chronic leukaemia the bone marrow makes too many mature abnormal white blood cells. These abnormal cells are called leukaemic cells. The leukaemic cells build up in the bone marrow and spill into the bloodstream. Sometimes leukaemia spreads from the blood to other organs such as the spleen or liver.

All about CLL

What is CLL?

Chronic lymphocytic leukaemia (CLL) is a slow-growing leukaemia. It starts in B lymphocytes in the bone marrow and over time these cells divide and multiply in the bone marrow, then spill over into the blood. People with CLL have too many abnormal B lymphocytes.

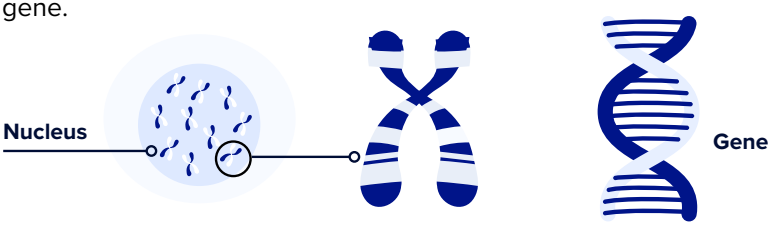
Normal B-cells fight bacterial, fungal and viral infections by:

- Making proteins called antibodies that lock onto the surface of an invading cell. This makes it a target to be killed by other white blood cells.
- Killing bacteria, viruses and fungi directly.
- Recognising previous infections and killing them quickly.

In CLL, the abnormal B-lymphocytes can’t function normally.

How does CLL develop?

CLL affects how normal blood cells are made in your bone marrow. Normally lymphoid stem cells mature into healthy blood cells. Inside cells there are coded instructions that control how the cell should act. Chromosomes inside cells are long strands of deoxyribonucleic acid (DNA). Each section of DNA that holds the cell's instructions is called a gene.



Cell

The nucleus controls the processes of the cell.

Chromosome

Chromosomes are thread-like structures made up of DNA tightly coiled many times around proteins called histones.

DNA

Deoxyribonucleic acid is a self-replicating material present in nearly all living organisms as the main part of chromosomes. It is the carrier of genetic information.

In CLL, the DNA in stem cells in the bone marrow is damaged. The DNA damage is called an acquired mutation. Each damaged stem cell divides and creates a clone. A clone is a group of identical cells all with the same mutation. This is why CLL is sometimes called clonal. The bone marrow makes too many abnormal lymphocytes.
The abnormal lymphocytes crowd the bone marrow and it can't make enough:

Red blood cells (RBCs) 

Normal white blood cells (WBCs) 

Platelets 

This means that people with CLL often have very active bone marrow, producing many cells. But there are a low number of healthy blood cells in the bloodstream. Low numbers of blood cells are called cytopenias.

Is CLL cancer?

CLL is a form of blood cancer. It is slow growing (also called indolent) and some people may not require treatment for a long time. But CLL can get worse over time. As more leukaemic cells fill up the bone marrow, fewer healthy blood cells can be made.

CLL can change (transform) into a different type of cancer, which is faster growing. CLL can transform into:

Diffuse large B-cell lymphoma or into Hodgkin lymphoma. This is called Richter's transformation which affects up to 7% of people with CLL.

Prolymphocytic leukaemia which affects up to 2% of people with CLL.

Monoclonal B-lymphocytosis (MBL)

Some people have a blood condition called monoclonal B-lymphocytosis (MBL). In MBL the B-cells contain the proteins seen in CLL. MBL isn't leukaemia as there are not enough abnormal B-cells in the blood.

Depending on the B-cell count MBL is called High count MBL, or Low count MBL.

Each year 1-2% of people with a high-count MBL will develop CLL. It is sometimes called 'pre-CLL'. People with this condition will have regular blood tests and follow-ups with their GP, but do not need treatment.

Causes of CLL

In most cases, there is no specific cause of CLL. Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them from causing problems in the body. But the longer we live, the more chance we have of getting mutations that can escape these safeguards. That's why CLL is more common in older people. All CLL changes have gene mutations.

CLL behaves differently in people depending on which genes are affected. More than half the people diagnosed with CLL also have chromosome changes. These also vary from person to person.
Why a particular person at a particular time gets CLL is not really known. But some things (risk factors) give people a higher risk of developing CLL.

Known CLL risk factors

Ageing: the risk of developing genetic mutations increases with age.

Exposure to Agent Orange: a herbicide used for defoliation during the Vietnam war.

Family: people who have a parent, sibling or child with CLL.

Gender: CLL is more common in men than in women.

Ethnicity: more common in people of European origin.

Symptoms of CLL

Many people with CLL have no symptoms at all. It may be picked up during a routine blood test. Some visit their general practitioner (GP) because they have symptoms.

You may have general symptoms, such as:

- Fatigue (extreme tiredness not relieved by rest)
- Weight loss without trying
- Fever
- Chills
- Drenching night sweats

Low blood counts

Many symptoms of CLL are because of low normal blood cell counts. You may have low numbers of red blood cells, white blood cells or platelets, or a combination of these. Anaemia is caused by low red blood cells. Red blood cells carry oxygen around your body. You may have a low number of a type of white blood cells called neutrophils. This is called neutropenia. White blood cells support your immunity. Thrombocytopenia is a low platelet count. Platelets help control bleeding and help wounds to heal. You may have symptoms from each because all your blood cells may be low (which is called pancytopenia).

Anaemia

Cause

Low RBCs or Hb

You might notice

Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat.

Neutropenia

Cause

Low WBCs (neutrophils)

You might notice

More frequent or severe infections eg. chest or skin, fevers, shivering, chills, low blood pressure, mouth ulcers.

Thrombocytopenia

Cause

Low platelets

You might notice

Easy bruising and bleeding e.g. nosebleed, cuts that keep bleeding, coughing up blood, petechiae - tiny unraised red blood spots under the skin, often starting on the legs.

Pancytopenia

Cause

All three blood cell types are low

You might notice

A mix of symptoms from all three conditions

Enlarged spleen

Your spleen is an organ located in the top left of your abdomen (stomach), near your rib cage. It acts like a sponge for blood cells. It stores blood cells but can also make them. If your spleen starts making too many blood cells it may swell up. When the spleen is swollen (enlarged), it is called splenomegaly.

Symptoms of splenomegaly are:

- Feeling of fullness in your abdomen
- Discomfort or pain in the left upper side of your abdomen
- Feeling rapidly full when eating

Swollen lymph nodes

If the CLL has spread to your lymph nodes you may have small, hard lumps. These are swollen lymph nodes, they may be in your armpits, on either side of your neck, and/or in your groin. They're usually painless. There are also lymph nodes in your chest and abdomen. They might swell but can only be seen with scans. Swollen lymph nodes are called lymphadenopathy.

How is CLL diagnosed?

Your haematologist will diagnose CLL by talking with you about how you are feeling and looking at samples of your blood. You may need other tests, like a scan or a bone marrow biopsy. Some symptoms of CLL, like feeling tired, are part of many conditions.

Medical history and physical exam

Your treatment team will take a full medical history:

- Past and present illnesses
- Health problems
- Infections
- Bruising and bleeding
- Details of any medications you have taken, are taking or intend to take. These include prescribed and over the counter medications.
- Do a physical examination, to check your general health and any signs of CLL.

Full blood count

You will be asked to have a simple blood test called a full blood count (FBC). This test measures the number of red cells, white cells and platelets in circulation. Your treatment team will give you a referral and tell you where to go to have it done. They will also tell you if you need to fast (not eat or drink) for a certain amount of time before you have the blood test. A pathologist (blood specialist) will look at the blood cells under a microscope.

Blood chemistry tests

Blood chemistry tests measure the levels of different chemicals in your body. These blood tests will often be taken at the same time as your FBC.

Substance Tested	What it indicates
Creatinine	Kidney function
Electrolytes	Kidney function
Blood urea nitrogen (BUN)	Kidney function
Calcium	Bone destruction
Lactate dehydrogenase (LDH)	Blood cell damage
Beta-2 microglobulin	Level of lymphoma in the body

Some blood tests taken may include:

- Hepatitis and HIV tests: hepatitis B can become active again due to cancer or some of its treatments. HIV and hepatitis C may affect your treatment.
- Antibody testing: depending on the type of CLL you have and treatments you have received, you may have low or high levels of antibodies. Low antibody levels may increase your risk of infection.

All these tests help to rule out other health problems and to confirm your diagnosis.

Staging tests

Bone marrow biopsy

Your treatment team may request a bone marrow biopsy to check if the leukaemia is in your bone marrow. This procedure is performed either in hospital, at your haematologist's rooms, in a day procedure unit or an outpatient clinic. It's a good idea to bring a support person with you. They can help you home if you are instructed not to drive afterwards.

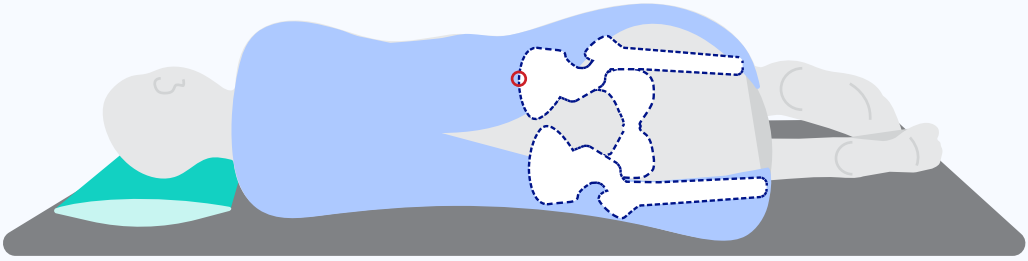
What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a needle to enter the bone marrow at the back of the hip (iliac crest). This is an area where the bone is usually close to the skin and can be easily accessed. A small amount of liquid bone marrow (aspirate) is usually taken and placed onto slides and into blood tubes. The liquid bone marrow is sent to the laboratory for examination and other specialised tests. Usually a small piece of the bone marrow (trephine) is also taken and examined in the laboratory.

Is a bone marrow biopsy painful?

A bone marrow biopsy can cause discomfort and/or pain. Local anaesthetic is injected into the skin and on the bone before the procedure to numb the area. You may also be given a form of pain preventer that you breathe in. On occasions a small dose of intravenous sedative may be required to manage discomfort. This is in the hospital setting, where you will be closely monitored.

The bone marrow is taken from the back of the hip bone, not from the spine.



What to expect after

You should try to rest for the day. If you have had sedation, then you must not drive a car or work for 24 hours, so you will need someone to take you home. If you have any pain or discomfort, take paracetamol as per the recommended dose. The dressing must remain in place for 24 hours after the procedure, or as advised by your treatment team.

You will have to wait several days for the results of the bone marrow biopsy.

Special testing

Your haematologist might request additional tests on your bone marrow biopsy. These tests help your haematologist work out your treatment options.

Cytogenetic tests

Cytogenetic tests are a genetic test performed on the bone marrow. The results provide information about the genetic make-up of your cells. These tests examine the structure of chromosomes (DNA) in your bone marrow cells. This determines if there are any gene mutations. These results help your haematologist diagnose which type of CLL you have, and your treatment plan.

Flow cytometry

Flow cytometry looks for proteins on the surface of a cell. Dye is applied to thousands of cells. This helps to work out the types and the number of abnormal cells.

FISH

Fluorescent in-situ hybridisation (or FISH) is a specialised cytogenetic test. It uses dyes to highlight parts of chromosomes to check if they are abnormal.

Molecular tests

Molecular genetic tests such as polymerase chain reaction (PCR) or next generation sequencing (NGS) look directly at the genetic sequence/code and help your haematologist work out which type of CLL you have. It may take a few weeks for these test results.

- Polymerase chain reaction (PCR) – also called quantitative reverse transcriptase PCR (QPCR). This test evaluates DNA to look for known/specific gene mutations/sequence. It is often done at the same time as cytogenetics/FISH. This test is used to monitor your response once treatment starts.

- Next generation sequencing (NGS) – looks for multiple gene mutations across multiple samples at the same time. It can detect unknown mutations/sequence. It is often done at the same time as cytogenetics/FISH.

HLA testing

Human leukocyte antigen (HLA) testing is also called tissue typing or histocompatibility testing. It tests which HLA genes someone has inherited. If you are eligible for an allogeneic stem cell transplant your doctor will request HLA testing. This will be compared to the HLA type of possible donors to see if they match.

You can read more about stem cell transplants later in this booklet, or in our booklet, 'Allogeneic Stem Cell Transplants'.

Direct antiglobulin test (direct Coombs test)

Sometimes CLL affects the immune system by making abnormal antibodies. This happens when it mistakes red blood cells as abnormal. The direct antiglobulin test checks if these antibodies are attached to red blood cells. This can result in a condition called autoimmune haemolytic anaemia. This is where the immune system breaks down red blood cells faster than they are replaced.

Lymph node biopsy

In some cases you may need to have a swollen lymph node, or part of, taken out to be checked under a microscope. This minor surgery is done under anaesthetic in a day surgery and leaves a small wound with a few stitches to be removed about a week later.

Imaging tests

A computed tomography (CT) scan, magnetic resonance imaging (MRI) and positron emission tomography (PET) scan show where CLL is in your body. It can identify if the CLL is in your spleen and lymph nodes. These imaging tests are done in a radiology department and you are able to go home the same day. You will be given detailed instructions on how to prepare for each scan.

CT scans

CT scans use x-rays and a computer to create detailed images of the inside of your body. They can find tiny changes in tissue density (thickness). You may have a dye called contrast, which is given as a drink or intravenously before your scan. During the scan you lie flat and still on a cushioned table which moves slowly through the CT machine. The CT scanner takes images as the contrast moves through your body.

PET scan

A PET scan is an imaging test that shows the metabolic function of your tissues and organs. It can show both normal and abnormal function. This provides the potential to find disease in its earliest stages. A PET scan may be used to stage your CLL in correlation with symptoms and biopsy results.

Before a PET scan you will be given a small and safe dose of radioactive material. This is called a radiotracer, it is attached to glucose and is in the form of an injection. The radiotracer injection is given to you intravenously. You will sit in a chair for about an hour while the radiotracer is absorbed by your organs and tissues. Diseased cells in your body absorb more of the radiotracer than healthy ones do. These are called ‘hot spots’. During the scan you lie flat on a cushioned table that slides in and out of the PET scanner. The PET scanner detects the ‘hot spots’ and produces images of the affected tissue. You may have a PET scan during and after treatment.

MRI scans

Magnetic resonance imaging (MRI) uses a very strong magnet to make 3D images. It is particularly useful for looking at parts of the body like the spinal cord and brain. MRI scans can sometimes show soft tissue more clearly than CT scans. Before the MRI you might have an injection of a dye (contrast) intravenously. This helps to show your soft tissue clearly. The scanner makes a very loud clanging noise, so you will wear headphones to protect your hearing.

Heart tests

Some treatments for CLL can cause heart problems. Before you start treatment you might have an echocardiogram or heart scan. The test takes pictures of your heart to check how well it pumps blood.

Other tests

You might need more blood tests and imaging tests to monitor your CLL and treatment. The results of your first blood and bone marrow tests provide a baseline of your disease and general health. Your treatment team can then compare later test results against the baseline to track how you are going.

Multidisciplinary team meetings

When your test results are available your case may be presented at a multidisciplinary team (MDT) meeting. An MDT meeting generally includes:

- Haematologists
- Radiologists (imaging experts)
- Radiation oncologists (radiotherapy experts)
- Pathologists

The pathologist reviews the blood and biopsy for accurate diagnosis of the CLL. A repeat biopsy may be advised or additional tests ordered on the existing biopsy. The radiologists will review the imaging scans to help clarify the stage. All the information will be checked. The haematologists and radiation oncologists will suggest the best treatment plan.

This process ensures that diagnosis and staging are accurate. Multiple expert discussion of your case ensures up-to-date treatment recommendations. Cases may be re-presented to monitor treatment response or at relapse.

What happens next?

After diagnosis

When your test results have been reviewed you will meet with your haematologist. Your CLL diagnosis including the stage, and your treatment plan will be discussed. It is natural to feel scared, confused or sad. You will be given a lot of information, this can be overwhelming. You may feel relieved and reassured that your symptoms have been explained. Ask your haematologist if you need further details and for some written information. It is helpful to bring someone with you to the appointment. A second pair of ears, someone to take notes and ask questions for clarification.

Disease staging

The stage of your CLL helps with prognosis and treatment planning. There are two staging systems used: the Rai and the Binet systems. The Binet system is most often used in Australia. Lymph tissues include your lymph nodes, spleen and liver. These are called lymphoid areas. When your haematologist works out your stage, they'll look at how many lymphoid areas are affected, along with your blood counts.

Binet stage A (Rai stage 0)

< 3 lymphoid areas involved. High lymphocyte count.
Risk: Low
Likely treatment: watch and wait

Binet stage B (Rai stages I to III)

3 or more lymphoid areas involved. High lymphocyte count.
Risk: Intermediate
Likely treatment: supportive care, some treatment

Binet stage C (Rai stages III to IV)

Bone marrow failure. Low red blood cell count +/-, low platelet count
Risk: High
Likely treatment: treatment

Treatment plan

Your haematologist will recommend treatment based on:

- The stage of your CLL.
- Whether you have symptoms of CLL (e.g. fevers or weight loss).
- Your blood counts.
- Your genetic changes.
- Whether your lymph nodes or spleen are larger than normal.
- Your age and your general health.
- Your wishes.

Your treatment plan may include one or more the following:

1. Active observation (watch and wait) involves regular check-ups but no treatment.
2. Supportive care controls symptoms of CLL, like thrombocytopenia (low platelets).
3. Standard drug therapies, such as chemotherapy or targeted therapy.
4. Involvement in a clinical trial.
5. Stem cell transplantation to replace your bone marrow cells with new, healthy cells.

Your treatment team will explain the treatments, their benefits, and possible side effects. You will be asked to sign a consent form, to agree to the treatment after you have thought about the options.

Watch and wait/active observation

Many people don't need to start treatment as they have minimal changes in blood counts and no symptoms. This approach is called 'watch and wait' it is suitable for people with stage A (low risk) CLL. Your haematologist may recommend regular check-ups to keep an eye on your health and blood tests and monitoring by your GP as active follow-up.

Frequency of blood tests and check-ups will depend on any changes in your blood counts and your overall health. Studies have compared watch and wait to early treatment for people with low-risk CLL and found no benefits of early treatment. The benefit of watch and wait is that you will not have unwanted side effects of medications. If you do need treatment in the future it means there are more options. In some cases CLL can be managed with watch-and-wait for years before it progresses.

Many people with CLL on watch and wait feel like they should be doing something. There are some actions people can take:

Learn as much as you can about your CLL

Know the signs and symptoms that may mean your CLL has progressed

Join a CLL **support group**

Keep up to date with immunisations (avoid live vaccines). Plan a vaccination schedule with your treatment team (CLL is an immune compromising disease)

Attend all appointments and have blood tests as recommended by your haematologist

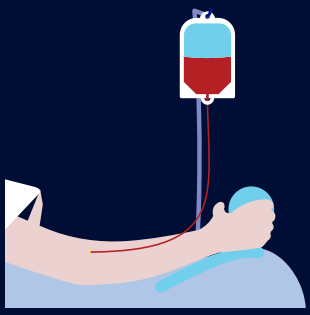
Regular moderate **exercise or movement**

Regular screening for other cancers (second cancers are more common in people with CLL)

Eat well (find more information here

Supportive care

Supportive care prevents and treats symptoms and side effects. It includes emotional and social support too. The goal is to improve symptoms of your CLL, but it doesn't treat the disease itself. People with stage B and C (intermediate-high risk) CLL may have supportive care alongside treatment.



Blood transfusions

You will have regular blood tests to monitor your haemoglobin. Your haemoglobin carries oxygen throughout the body. If your haemoglobin is low and you have fatigue, weakness, shortness of breath and dizziness you may have anaemia. Your treatment team will assess if you need a red blood cell transfusion. Transfusions are usually given by a nurse in an outpatient department.

The nurse will use your central venous access device (CVAD) or will insert a cannula into a vein in your arm or hand. Each bag of blood will take 60-120 minutes to transfuse.

Platelet transfusions

If you have symptoms of low platelets (thrombocytopenia), you may need a platelet transfusion. This is similar to a red blood cell transfusion, but you will be given a bag of platelets instead. A platelet transfusion usually takes 30 minutes. There are oral medications that can increase your blood clotting, these may be prescribed by your treatment team.

Growth factors

Growth factors are chemicals in your blood that help the bone marrow produce different types of blood cells. Some growth factors can be made in the laboratory. They are used to boost low blood counts.
Neutrophils are white blood cells that help fight infections. A growth factor called granulocyte colony stimulating factor (G-CSF) makes the bone marrow produce more neutrophils. GCSF is commonly given to people having chemotherapy. Growth factors are usually given as an injection under the skin (subcutaneous). A family member or friend can be taught to give the injections. The injections can be given at a local medical centre or outpatient department if preferred.

Some people experience flu-like symptoms while using G-CSF including mild to severe bone pain, fevers and chills and headaches.

Antibiotics

When your white blood cell count is low you have a higher risk of infection. If you develop signs or symptoms of infection, it is important you are treated as soon as possible. Your treatment team will prescribe antibiotics. You will continue on antibiotics until the infection resolves and your white blood cell count recovers.

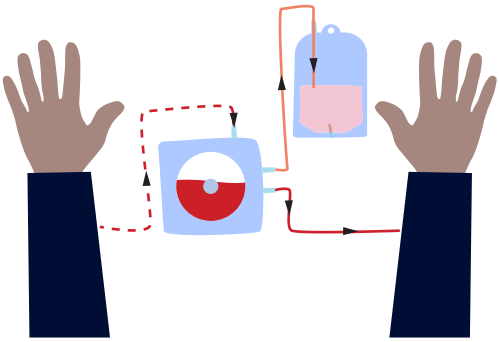
Antimicrobial, antifungal and antiviral medicines

You may be given antimicrobial, antifungal and/or antiviral medicines. If you're low in certain cell types, you have a higher risk of fungal or viral infections. These types of medicines will be taken to prevent infection. This is called prophylaxis, or you might hear the drugs referred to as prophylactics. They will usually be in tablet form and your treatment team will tell you how often and for how long you need to take them.

Vaccines

Vaccines are important for people with CLL because you have a higher risk of infection. Vaccines help prevent infections. Inactivated vaccines are the safest and you should not have any live vaccines. You will need to check with your treatment team for the best timing.

Apheresis



Very rarely, people with CLL have an extremely high white blood cell count (called hyperleukocytosis). People with extremely high white blood cell counts may need a procedure called apheresis. It removes abnormal white blood cells from your blood. This is called Leukapheresis or white blood cell depletion/ reduction. The blood is drawn from a cannula (plastic needle) placed in a vein in one arm, or a lumen on a central venous access device (CVAD). The machine spins the blood very quickly and removes the part that contains the white blood cells. The rest of the blood is returned via another cannula or lumen of a CVAD. This is a continuous process.

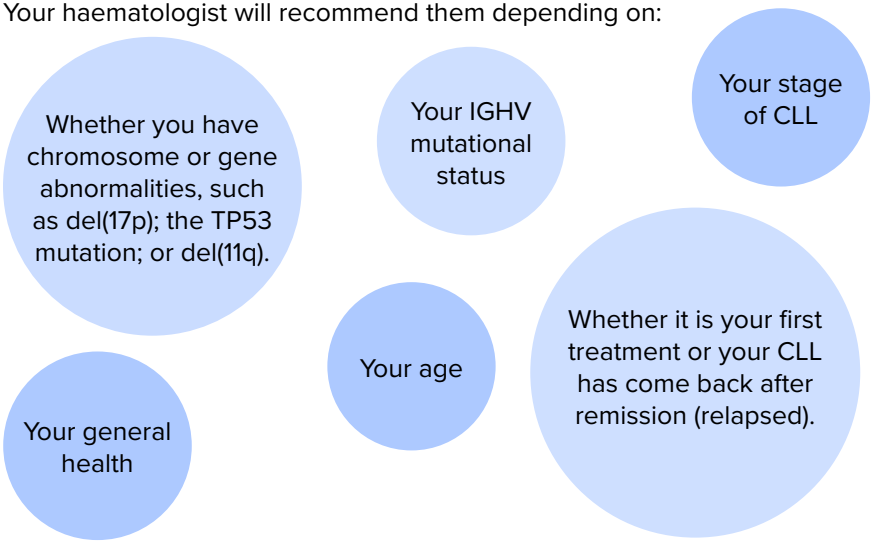
Treatment phases

The first treatment you receive for CLL is called first line treatment. Its goal is remission. For intermediate-risk or high-risk CLL, this may include chemotherapy and/or immunotherapy. Where chemotherapy and immunotherapy are both given, it's called chemo-immunotherapy. You may be given one drug or a combination of drugs. Your haematologist will choose which treatment you have depending on a few factors. Including any gene and chromosome changes you have. There are also treatments for people whose CLL is hard to treat (resistant or refractory), or where it has relapsed (come back) after they've been in remission. If further treatment or a clinical trial is not an option, the treatment goal might change. Your haematologist will speak to you about the best options.

Standard drug therapies

Your treatment team might use the term 'standard of care' or 'standard therapy'. This is a treatment that is commonly used by medical experts for a certain type of disease. Standard drug therapies for CLL include chemotherapy, immunotherapy, and targeted therapies. Some of these therapies will be given intravenously (IV) and some are tablets which you can take at home. You'll have IV treatments in a clinic, outpatient ward, or as an inpatient in hospital.

Your haematologist will recommend them depending on:



Very infrequently in CLL an allogeneic bone marrow transplant may be required (you can read more about stem cell transplants later in this booklet).

Targeted therapy

Targeted therapies directly target the mutations/changes specific to blood cancer cells. They also slow down the growth or speed up the rate at which the blood cancer cells die. These treatments cause less damage to normal cells than chemotherapy. Targeted therapies may be given by themselves or given with chemotherapy. Targeted therapies are used in highly specific circumstances and are expensive. In some cases they may only be available on a clinical trial. These treatments are complex, and your doctor will discuss the best options available for you.

Cancer growth inhibitors

Cancer growth inhibitors are a type of targeted therapy. They block signals to cancer cells to stop them from growing or surviving. There a few types of inhibitors used to treat CLL:

Bruton's tyrosine kinase inhibitors (BTKi's):

- Bruton's tyrosine kinase (BTK) protein is essential to the growth of B-cells.
- BTKi's block the B-cell receptor (BCR) on CLL cells.
- When this receptor is blocked the CLL cells die.
- Acalabrutinib, ibrutinib, and zanubrutinib are oral BTKi's.

B-cell leukaemia/lymphoma-2 (BCL2) inhibitors:

- BCL2 is a type of protein CLL cells make.
- BCL2 inhibitors block the protein and the CLL cells die.
- Venetoclax is an oral BCL2 inhibitor.

Phosphoinositide 3-kinase (PI3K) inhibitors:

- Phosphoinositide 3-kinase is a protein important to the growth and survival of cells.
- PI3K inhibitors block the PI3K protein in CLL cells and slow down growth.
- Idelalisib is an oral PI3K inhibitor.

Side effects from targeted therapies tend to be different to chemo side effects. If you're having more than one type of drug, you may have a few different side effects at different times. Your treatment team will talk to you about what you might expect.

Side effects of cancer growth inhibitors may include:

- Diarrhoea
- Nausea
- Constipation
- Fatigue
- Shortness of breath
- Feet and hand swelling
- Body aches and pains
- Headache
- Stomach pain
- Rash
- Low blood counts
- Infection
- An irregular heart rhythm called atrial fibrillation
- High blood pressure
- Bleeding

Intravenous access for treatments

Some CLL treatments are given directly into a vein (intravenously, IV). Your bloodstream can be accessed through the peripheral veins in your arms or through a central vein in your chest. Some treatments can only be given through a line into a central vein. Your treatment team will discuss intravenous access with you before you start treatment.

Peripheral intravenous cannula

A cannula is a short, thin plastic tube with an inner thin needle. Your nurse will insert the cannula into a vein, removing the inner needle so only the thin plastic tube remains in the vein. Usually, cannulas are inserted into your lower arm or the back of your hand. The cannula is held in place with a dressing. Your treatment is given through intravenous lines connected to the cannula. These lines are often connected to a pump. Having a cannula inserted may cause discomfort but once it is in place you should have no pain. It can stay in for a few days or be removed after your treatment.

Peripherally inserted central catheter (PICC)

A PICC is a long, thin silicone tube. A specialist nurse, doctor or radiologist will insert it in an outpatient department. The tip of the PICC is inserted into a vein in your upper arm, then threaded into a large vein in your chest. The other end of the PICC is visible on top of your skin on your upper arm. There may be one, two, or three tubes (lumens) visible.

Treatment is given through the lumens. The PICC will be secured with a dressing. PICCs can stay in for up to two years. Sometimes PICCs are called central venous access devices (CVADs).

Port

A port is a type of central venous access device (CVAD) that is surgically implanted under the skin in your upper chest. It has a small dome shaped body with a silicone pad in the middle, this is attached to a tube (catheter). The tip of the catheter is inserted into a large vein and sits just above the heart. You can feel the port under your skin but it does not have external tubes. Your nurse will access the port by inserting a short needle into the silicone pad, this is held in place with a dressing. The needle is replaced every 7 days or removed after treatment, before you go home. Ports can stay in for years. Ports are also called infusaports or portacaths.

Other central lines

A central line is a long, thin silicone tube. **It is a type of CVAD.** There are different types of central lines, Hickman® line, central venous catheter (CVC). The tip of the tube sits in a large vein above your heart. The other end comes out of your chest and has one, two, or three tubes (called lumens). It is secured with a dressing. Treatment is given through the lumens. A central line can stay in for years.

Monoclonal antibodies (MAB) or Immunotherapies

Immunotherapy is sometimes called biologic therapy. It is a targeted therapy that uses part of your immune system to fight blood cancer cells. Immunotherapies are given intravenously (IV) or in tablet form.

Monoclonal antibodies are a type of immunotherapy. They work by attaching to specific cancer cell proteins to tell your immune system to destroy those cells. They also slow down cancer cell growth. Monoclonal antibodies may be given to people who are not suited to some chemo treatment due to its side effects. These may be given in combination with either chemotherapy or other targeted therapies.

Monoclonal anti-CD20 antibody is used to treat CLL.

CD20 is a protein found on the surface of B-cells, it is found on the cell surface of some CLL subtypes. **This is termed CD20 positive.**

The monoclonal anti-CD20 antibody connects to this protein on the CLL cell.

It destroys the cell by damaging the antibody, causing the cell to die.

Rituximab and Obinutuzumab are monoclonal antibodies that target the CD20 protein. They are mostly given IV.

Side effects from monoclonal antibodies tend to be different to chemo side effects. If you're having more than one type of drug, you may have a few different side effects at different times. Your treatment team will talk to you about what you might expect.

Infusion related reactions (appear during or soon after infusion) of monoclonal antibodies may include:

- Itching
- Chills and/or fever
- Nausea
- Fatigue
- Shortness of breath/cough
- Facial swelling
- Lightheaded
- Chest pain
- Rash/hives
- Headache

Side effects (appear within days-weeks) of monoclonal antibodies may include:

- Body aches and pains
- Headache
- Constipation
- Diarrhoea
- Rash
- Low blood counts
- Infection
- Shortness of breath/cough
- An irregular heart rhythm called atrial fibrillation
- Bleeding

You can find more information on our website.

Chemotherapy

Chemotherapy (chemo) is cytotoxic, or 'cell killing', medication that stops cancer cells growing. They work by killing cancer cells, or by stopping them from dividing, replicating, and reproducing. Chemo does damage normal cells, but these cells can repair and recover. Chemo treats disease and is often called disease modifying treatment. Chemo can be given as a tablet, injection, or intravenous (IV) drip. The type of chemo given depends on the type of CLL. It is common to be on more than one chemo at a time. Some people have chemo alongside other therapies like immunotherapy, or radiation therapy. You can take chemo tablets at home, or you might have injections or IV chemo in an outpatient ward/clinic, or as an inpatient in hospital. Chemo is given in cycles of treatment days. This means that you will have treatment for a certain number of days, followed by a set number of rest days. The number of treatment days and the number of cycles can be different due to the chemo or the cancer being treated.

Your haematologist will recommend chemo depending on:

- Your type of CLL
- Your overall health
- Your age
- Your wishes

Chemotherapy side effects

Chemotherapy kills cells that multiply quickly, like the cells that cause CLL. It also damages fast-growing normal cells, like hair cells and the cells in your mouth, gut and bone marrow. You get chemo side effects because of the damage to normal cells.

Everyone gets different side effects with chemo. You may have no side effects, or one or more of them, and they may change over time. Your treatment team will have medicines and suggestions to help manage side effects.

Which side effects you have and how severe they are depend on:

- Your type of CLL
- The type of chemotherapy you are given
- Your overall health and wellbeing

You can find more information on chemo side effects and how to manage them on our website.

Changes in blood counts

Chemo affects the ability of your bone marrow to produce enough blood cells. Your red blood cells, white blood cells and platelets will usually drop within a week of treatment. They should then increase before your next cycle of chemo.

Low red blood cells cause anaemia. You may feel tired, short of breath, and look pale. Take it easy and contact your treatment team if you have any concerns. You might need a transfusion.

If your platelets are low you can bruise and bleed more easily.
When your white blood cell count is too low you are at higher risk of developing an infection. It is important that you follow the advice of your treatment team immediately if you have signs of an infection.

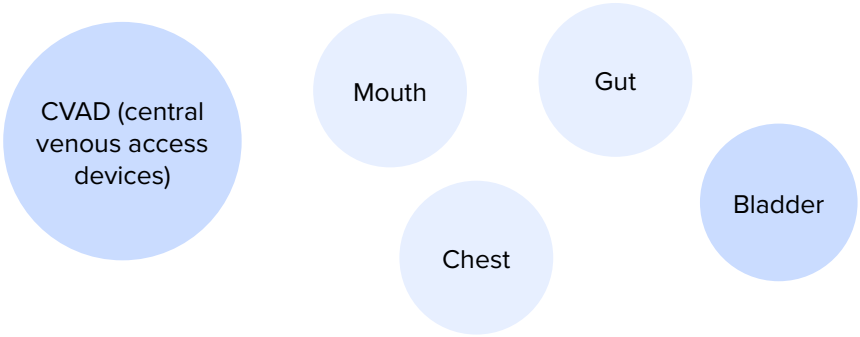
Risk of infection

When white cells (neutrophils) are low this increases the risk of developing an infection. A person with a low neutrophil count is described as being neutropenic. The lower the neutrophil count and the longer it is low increases the chance of developing an infection. If you develop a fever (rise in your body temperature) while neutropenic you have 'febrile neutropenia'.

It is important that you follow the advice of your treatment team if you:

- Have a temperature.
- Are feeling hot, cold or shivery.
- Develop a cough, pain or soreness.

Infections can develop anywhere, common sites of infection include:



Causes of infections include bacteria, viruses and fungi. You may be prescribed preventive antibiotics, anti-viral and anti-fungal medication.

Things you can do to prevent infection:

- Regular hand washing.
- Daily showering.
- Regular mouth care.
- Avoid people with suspected colds, flu and other viruses.
- Avoid close contacts and people with chicken pox, measles or other viruses.
- Avoid people who have had a live vaccines such as polio.
- Avoid places with large numbers of people.
- Wear a mask.
- Avoiding garden soil and potting mix.
- Washing your hands after handling animals.
- Discuss vaccinations with your treatment team.

You can find more information on infection prevention our website.

Feeling sick - nausea and vomiting

Nausea (feeling sick) and vomiting are common side effects, you will be given medicine to prevent or manage them. If you feel nauseous, even with medicine to help, contact your treating team to ensure it is managed so you can continue to eat and drink. If you are finding it difficult to eat, are eating less than usual and/or losing weight, talk to your treatment team. They can arrange for you to see a dietitian for some advice.

Sense of taste and smell

Changes to your sense of taste and smell can stop you from enjoying food and drinks that you used to love. You might have a metallic taste in your mouth. These changes will pass when your treatment ends.

Mouth problems - mucositis

Your mouth or throat might become sore, or you might get ulcers. This is called mucositis. It is very important to keep your mouth clean by using an alcohol-free mouthwash, salty water or sodium bicarbonate in water.

Bowel changes

Chemo can damage the lining of your bowel, this can cause cramping, wind, bloating and/or diarrhoea. You will be given medication to help. Tell your treatment team if you have diarrhoea, are constipated (painful or difficulty when passing faeces), and if you have haemorrhoids. Your treatment team can give you tips on food choices.

You can read more about diet and nutrition later in this booklet and on our website.

Feeling tired and weak (fatigue), even after resting

Most people feel tired following chemo. It can be frustrating if you're used to keeping busy.

You can find more on how to manage fatigue later in this booklet and on our website.

Chemo brain

You may find it difficult to concentrate ('foggy brain') or have trouble remembering things. It can take up to a year after treatment finishes to recover. There are no medicines to help with chemo brain and in some cases changes can be permanent. You can set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.

Bone, joint or muscle aches and pains

Whilst having chemo you may have muscle aches, headaches, back pain, painful and/or swollen joints. Talk to your treatment team about any pain you are experiencing, they will advise you on what medications to take. It is important that your pain is managed so you can move to perform everyday activities.

Hair loss (alopecia) and thinning

The thought of losing your hair is scary. Hair thinning or loss is a very common side effect of chemo. You might lose your head hair, your eyebrows, and your eyelashes, but it's only temporary. Hair starts to fall out a few weeks after you start treatment and tends to grow back three to six months after it finishes. You might find your scalp is itchy and/or tender as you lose your hair, but this will pass. There are some great wraps, turbans, wigs and beanies available. Your nurse can give you information on where to find them.

Tingling or numbness in fingers and toes (peripheral neuropathy)

Some chemo drugs can affect your nerves, usually in your hands or feet. This is called peripheral neuropathy. Symptoms can start any time during treatment. It might be hard to do up buttons or to grip things. Tell your treatment team if you feel tingling, numbness, burning or pins and needles in your fingers or toes.

Sun sensitivity

Some chemo drugs make you more prone to sunburn. You can go outside, but you will need to avoid direct sunlight. Stay in the shade when possible, wear sun protective clothing and apply sunscreen.

Tumour lysis syndrome

When chemo kills a large number of CLL cells, the cells break apart and release their contents into the blood. This can cause irregular heart beats and puts stress on the kidneys, which try to rid the body of these substances. Tumour lysis syndrome is a medical emergency. It can happen during induction (the first phase of) chemo. You will be given fluids and medicines to help prevent it.

Early menopause

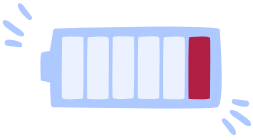
Some cancer treatments can affect the normal functioning of the ovaries. This can lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in this situation can be sudden and distressing. Hormone changes can lead to many of the classic symptoms of menopause including:

- Menstrual changes
- Hot flushes
- Sweating
- Dry skin
- Vaginal dryness and itchiness
- Headache
- Aches and pains
- Decreased sexual drive
- Anxiety and depressive symptoms

It is important you discuss any changes to your periods with your treatment team. They may refer you to a gynaecologist or clinic for symptom management.

"Manage pain – this affects concentration and energy"

Top tips from people with blood cancer



Managing chemo side effects

Low red blood cells (anaemia)

What might help

You may be given a blood transfusion or recommended supplements.

Low platelets

What might help

- Avoid sharp objects in your mouth like chop bones or potato chips.
- Be careful not to cut or injure yourself.
- Use a soft toothbrush.
- Use an electric razor.
- Wear gloves and closed shoes in the garden.

Low white blood cells (neutrophils) – risk of infection

What might help

- Wash your hands regularly.
- Avoid touching your face.
- Clean surfaces and objects you use often.
- Talk to your treatment team about vaccinations.
- Avoid crowds.
- Keep away from people who are sick and might be contagious (colds, flu, chicken pox).
- Eat food that has been properly prepared and freshly cooked.
- Don't clean up pet faeces.
- Wear gloves in the garden.
- Don't swim in public pools, lakes or rivers.

Feeling sick – nausea and vomiting

What might help

- Eat smaller meals more often during the day.
- Try cool or cold food like jelly.
- Let someone else cook for you.
- Drink ginger ale or soda water.
- Avoid strong smells.
- You'll be given medicine to help.

Change to taste

What might help

- Add a little more sugar to sweet foods.
- Add a bit more salt to savoury foods.
- If you have a metallic taste, try rinsing your mouth out.

Mouth problems – mucositis

What might help

- Use a soft toothbrush and mild toothpaste.
- Brush every time you eat.
- Use salty water, sodium bicarbonate in water or alcohol-free mouthwash.
- Continue to floss but stop if your gums bleed.

Bowel changes

What might help

- Drink plenty of fluids.
- Get some diet advice from your treatment team.
- If you're constipated, don't strain.
- If you have haemorrhoids don't push on them, tell your treatment team, you'll be given medicine to help.

Fatigue

What might help

- See page 53 of this booklet.
- Rest or nap when needed.
- Take regular gentle exercise.

Bone, joint or muscle aches and pains

What might help

- Take medication as prescribed by your treatment team.
- Track your pain, including location and how well pain medication is working.
- Drink plenty of fluids.
- Maintain bone strength through a healthy diet and exercise.
- Rest when needed.
- Breathing and relaxation techniques.
- Use assistive devices if needed, like handrails and walkers.

Chemo brain

What might help

- Keep a notebook or notes app handy to write things down.
- Ask your pharmacist to Webster pack your medications.
- Take regular gentle exercise.
- Socialise – tell your loved ones what's going on/what you're experiencing.

Hair loss and thinning

What might help

- Prepare your family and friends.
- Use a soft hairbrush and a mild baby shampoo.
- Pat your hair dry gently with a towel.
- Cut your hair shorter or have it shaved when you start chemo.
- Use an electric shaver.
- Avoid using heat or chemicals – don't dye or blow dry your hair.
- Use sunscreen on your scalp.

Sun sensitivity

What might help

- Cover up with long sleeves and pants when in the sun/ outdoors.
- Wear sunglasses and a hat or beanie to protect your eyes and scalp.
- Talk to your nurse about which sunscreens are best to use.
- Avoid sun exposure during high UV times of the day.

Corticosteroids

During treatment it is likely you will be given drugs called corticosteroids or steroids. Common steroids are prednisolone and dexamethasone. They can be given as a tablet and/or intravenously (IV). They can help:

- Some chemo destroy cancer cells
- Prevent/treat nausea and vomiting
- Reduce the risk of allergic reaction to some chemo drugs

Some common corticosteroid side effects include:

Difficulty sleeping	Take in the morning after breakfast.
Upset stomach	Take with food or milk.
High blood sugar levels	Diabetics should increase checks and talk to their treatment team about adjusting insulin.
Mood changes	Ask your treatment team to refer you to a counsellor.
Increased appetite and weight gain	Ask your treatment team to refer you to a dietitian.
Swelling due to retaining fluid	Keep an eye on swelling and let your treatment team know if it gets worse.

Radiation therapy (radiotherapy)

Radiation therapy, also called radiotherapy, is a type of treatment that uses high energy X-rays to kill cancer cells. Radiotherapy is a local therapy because it only destroys cancer cells in the area it treats.

A few people with CLL may have radiation therapy if CLL cells have built up. This might happen in the spleen. CLL is sensitive to radiotherapy so low doses are used.

Total body irradiation (TBI) is sometimes used for people with CLL before an allogeneic stem cell transplant. This is because it can treat areas of your body like your brain and spinal cord, of which chemotherapy may not effectively reach. It is also very effective at suppressing your immune system, allowing the donor's stem cells to grow.

To find out more about TBI and allogeneic stem cell transplant go to our website

Before you start

You will meet with the radiation oncologist (specialist in treating people with radiotherapy), treatment options and goals will be discussed, and you may have a physical examination. Next you'll have a simulation session. This will scan and position you for your radiotherapy treatments. Using these scans your dose of radiation will be calculated. You may have a dot tattooed on your skin, this helps guide treatment.

During treatment

Treatment is usually 15-30 minutes per treatment. Most of this time the treatment team will be setting you up for treatment. Once set up you will be alone in the treatment room. Your treatment team will be able to hear and see you. If you feel nervous you might like to bring along some music.

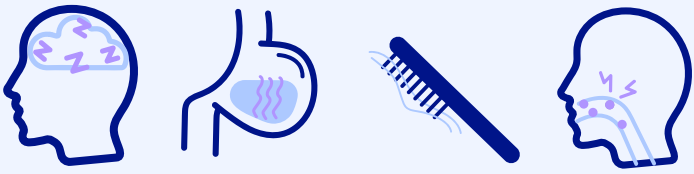
Any important structures like your heart and lungs will be shielded, so they are not affected by the treatment. You will be positioned like you were at simulation. The radiation machine moves around you to deliver the treatment and makes a buzzing sound. The radiation beam is only on for a couple of minutes. It is important to stay still throughout the treatment. You do not see or feel anything during the treatment and it is painless. You may have short, one or two treatments, or a longer course of radiotherapy. Longer courses are usually given in small doses, called fractions. Treatments are usually weekdays, Monday to Friday, over several weeks.

Side effects

Radiation therapy side effects vary from person to person and are dependent on the area treated. Some are short term, and some can last beyond treatment.

Side effects include:

- Fatigue – extreme tiredness not relieved by rest. **You can read more about it on page 54.**
- Skin changes – your skin may become red, dry, warm or sore where you are treated. Stay out of the sun. Skin changes will be worst just after your treatment ends. They will usually start to heal four to six weeks after you finish radiotherapy.
- Mouth pain or soreness.
- Feeling sick (nausea and/or vomiting).
- Bowel changes – wind, diarrhoea, bloating, cramping.
- Hair loss – only in the area where you're having radiation.



Radiotherapy follow up

After your course of radiotherapy finishes, you may have scans. Then you'll see your radiation oncologist to discuss how your treatment went.

Surgery

You will have day surgery to have a central venous access device (CVAD) or a port inserted. You may also need day surgery for a lymph node biopsy.

Stem cell transplantation

A stem cell transplant is where your stem cells are replaced with new stem cells after high dose chemotherapy and/or radiotherapy. The aim is to destroy the stem cells in your bone marrow and any disease in your body. The stem cells are then replaced with healthy stem cells. Stem cell transplant, bone marrow transplant and haemopoietic cell transplant (HCT) describe the same process.

A stem cell transplant may be used if the blood cancer gets worse or does not respond to treatment, or the type of blood cancer is known to recur. This treatment is not available for everyone because there are very serious side effects, including a risk of dying. There are two types of stem cell transplants, autologous (au-tol-o-gous) and allogeneic (al-o-gen-e-ic). Allogeneic stem cell transplants may be used to treat CLL.

Autologous stem cell transplant

An autologous stem cell transplant is where the persons own stem cells are collected. The stem cells are collected through either a peripheral blood stem cell collection using an apheresis machine or from the bone marrow. The stem cells are stored and returned to you after receiving high dose chemotherapy. The stem cells travel to the bone marrow and begin to rebuild your blood and immune system.

Allogeneic (donor) stem cell transplant

The stem cells transplanted in an allogeneic transplant are from a donor. Usually, a brother or sister with the same tissue type as you. A blood test can see if they are the same tissue type, a HLA matched donor. The stem cells can also come from a volunteer donor who is not related but are a HLA match.

In an allogeneic stem cell transplant the donated stem cells create a new immune system. The new immune system destroys any blood cancer cells left after the high dose chemo. The healthy donated stem cells also rebuild your blood.

Stem cell transplant side effects include:

- Low blood counts.
- All the same side effects as chemo, but more severe.
- Graft-versus-host disease (GvHD) for allogeneic transplants, where the new immune system attacks normal cells.

These side effects can go on for years after the stem cell transplant.

You can find out more about stem cell transplants in our booklets 'Autologous stem cell transplants' and 'Allogeneic stem cell transplants' and on our website.

Autologous stem cell transplants booklet

Stem cell transplants

Allogenic stem cell transplants booklet

Chimeric Antigen Receptor (CAR) T-cell therapy

CAR T-cell therapy is a type of immunotherapy and gene therapy. It involves changing the genetic make-up of some of your own normal T-cells (immune cells). This is so they recognise proteins on the surface of lymphoma cells and attempt to kill them. T-cells are taken from the blood using the procedure called apheresis. Apheresis is used to collect normal T-cells from the blood which are then sent off to a specialised laboratory to have their genes changed. The genetically modified T-cells have 'chimeric antigen receptors' (CAR) on the surface of the cells. The changed T-cells are called chimeric antigen receptor (CAR) T-cells. They are then given back to the person via IV infusion to kill the cancer cells.

You can find more information about CAR-T Cell Therapy on our website.

Clinical trials

Clinical trials, or research studies, test new treatments. Your haematologist may suggest you join a clinical trial. Results from clinical trials compare new or combination therapy to current treatments. Results also report any side effects of the new treatment. Many clinical trials are randomised. This means some patients receive the new treatment and others the current treatment. Clinical trials provide important information about how treatments can be improved. In Australia some clinical trials may provide access to expensive new treatments not available on the Pharmaceutical Benefits Scheme (PBS).

For a clinical trial you will need to:

Understand the risks and benefits of the trial.

Understand how your treatment will be different compared to current treatment.

Ask any questions you have before deciding whether to participate in the trial.

Give your informed consent to participate in the clinical trial.

Clinical trials are run through hospitals and clinics. A clinical trial nurse will be part of your treatment team.
Clinical trial participation is purely voluntary.

You can search current clinical trials at the following websites.

Australian Cancer Trials: **australiancancertrials.gov.au**

ANZ Clinical Trials Registry: **anzctr.org.au**

ClinTrial Refer: **clintrialrefer.org**

Complementary therapies

Complementary and alternative medicines are not standard medical treatments. Some people find that they help with side effects and symptoms. No complementary or alternative treatment on its own can treat blood cancer. Tell your treatment team what complementary or alternative medicines you plan to take.

To find out more, visit Cancer Australia.

“Meditate” and “Use breathing techniques.”

Top tips from people with blood cancer

Visit ‘A mindful moment’ to ground and calm yourself.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue (CRF). It can be hard to describe to people who haven't felt it. It's more than being tired, its different to normal everyday tiredness, and is often not resolved with sleep or rest. You will feel tired, but you may also feel weak and be sleepy, drowsy, impatient or confused. It's hard when you have no get-up and-go, however, for most people fatigue should improve after you finish treatment.

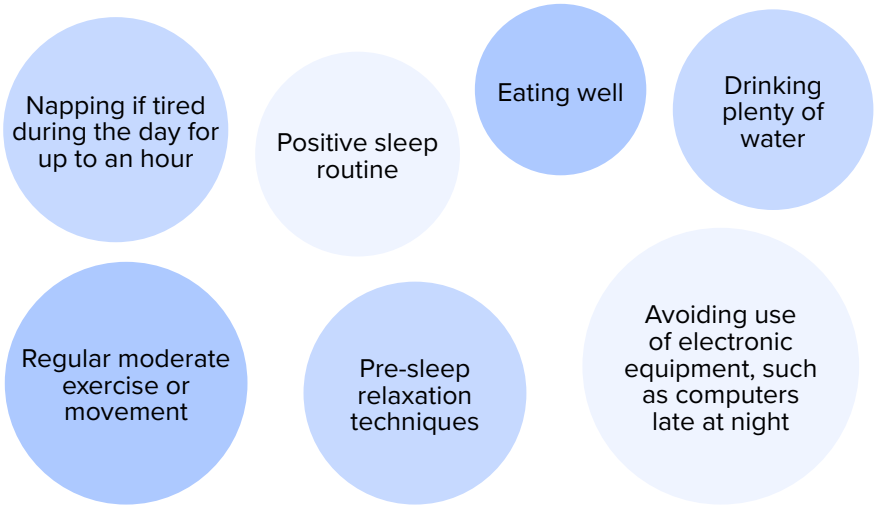
"Cancer-related fatigue (CRF) is not the same as being tired."

Top tips from people with blood cancer

Tips for managing fatigue

Fatigue is a side effect of your blood cancer or treatment. Managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treatment team about it, they may suggest a referral to a psychologist who specialises in sleep management. It's particularly important to explain how you feel to your carers and support people. You will need to let them know your priorities and discuss how they can help.

Tips to manage fatigue include:



“Recognise your limits, physical/cognitive/emotional/social.”

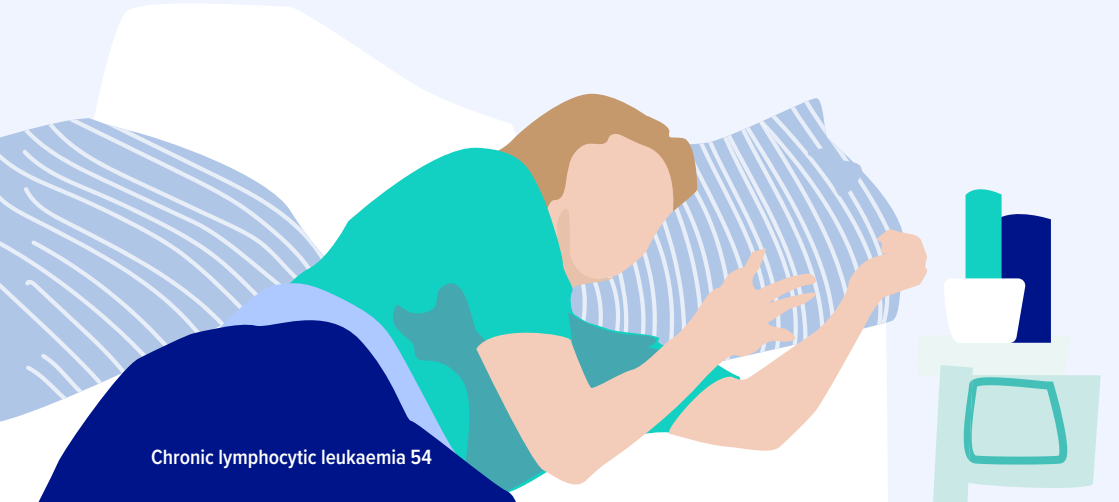
Top tips from people with blood cancer

While you’re managing your fatigue, you can jot down what time of day you have most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to, or play music, read, catch up with friends and family. These things might seem difficult, but they will help distract you from the fatigue.

“Know when you are at your most productive and do important tasks then.”

Top tips from people with blood cancer

Go to our online ‘Cancer-related fatigue’ learn module or website to find out more.



Fertility decisions

Some types of treatment may affect your fertility, which is your ability to conceive a baby. It is important to talk to your treatment team about future fertility before you start treatment. If you are planning on having a child, there are steps you can take.

Make sure you understand:

- The fertility preservation processes.
- The risks and side effects of fertility treatments.
- Success rates.
- Any costs involved.

The impact of all of these factors vary to the individual so be sure to find the right information and advice for you.

For men

Chemo can stop or lower your sperm production. It can reduce your sperm's ability to move. This can be temporary or permanent. It also affects the hormone testosterone.
The best way to preserve your fertility before treatment is by freezing a semen sample, which contains sperm. This is called sperm cryopreservation.

For women

Chemo can reduce your number of available eggs (ova) and can affect your hormones. There are several fertility cryopreservation (freezing) options for women. Egg and embryo freezing are common, less so ovarian tissue freezing. For some young women and their families, it may not be possible to pursue fertility options prior to cancer treatment.

Having the opportunity for discussion about your future fertility is important.

Fertility Society of Australia: fertilitysociety.com.au

Practical matters

Navigating the health system

The Australian health system may seem large, complicated and stressful especially when you are also living with a blood cancer. Knowing a bit about how our health system works and who are key people in your care can make navigating the system much easier.

Key people in your health team

Haematologist – A specialist doctor trained in diseases of the blood including blood cancer who leads a team of doctors in your care.

Radiation oncologist – A doctor who specialises in treating cancer using radiotherapy.

Cancer care coordinator (CCC)/Cancer nurse consultant (CNC) – Specialist cancer nurses who coordinate patient care and provide referrals to allied health professionals if needed.

Cancer nurse – A nurse in an outpatient clinic or cancer ward who supports, educates and gives you your chemo treatment.

Occupational therapist – A health professional who helps maintain or improve your quality of life using different techniques and equipment. Occupational Therapists help develop, recover, improve and/or maintain the skills needed for daily living, community participation and vocational pursuits.

Palliative care physician – A doctor who specialises in controlling symptoms and improving quality of life in people with terminal illnesses and chronic health conditions.

Pharmacist – A health professional who prepares, dispenses medicines (drugs), and support your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian – A university-qualified professional with ongoing training and education who helps to support your recovery and manage challenges in your diet. Dietitians provide you with personal support to help with your health and wellbeing. They provide expert nutrition and dietary advice, advice to understand how to improve your nutritional health, and help to understand how nutrition affects the body.

Social worker – A health professional who specialises in emotional support, counselling, and advice about practical and financial matters.

Physiotherapist/Exercise physiologist – A health professional who specialises in treating and rehabilitating patients through physical means.

Psychologist – A health professional who specialises in providing emotional support and difficulties such as anxiety, distress, and depression.

Record your important contact details

	Contact name	Phone number and/or email	Comments
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo day unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			
Occupational therapist			
Physiotherapist			

You can find out more about navigating the healthcare system as a cancer patient and the wide range of health professionals here.

The new normal – what is it?

Life is not the same as it was before a blood cancer diagnosis. Frequent appointments and regular follow up can be tiring and stressful. Everyday life changes for you and the people around you. Things that were once important don't matter as much. Things that weren't important before now take greater priority.

In essence, a 'new normal' is about living with your blood cancer, creating and maintaining as good a life as possible. Changes you may face include:

- Physical/mental/spiritual
- Emotional/relationships/identity/sexuality
- Financial, ability to work/return to productivity

It is important to seek information and support. Accepting help to manage challenges that arise throughout your cancer experience isn't always easy. Having this support can enable you to have a high quality of life while living with a blood cancer. It is also important to remember that dealing with the diagnosis and treatment of blood cancer is a big life change and everyone handles it differently.

You can find out more about living well with blood cancer on our website.

Go to our online learn module, 'Transition to a new normal' to learn more.

Body image

You may not always look like a patient with cancer. Your physical appearance may improve. In the meantime, do things that make you feel good about yourself. This might include enjoying time with friends, regular exercise and relaxing.

Look Good...Feel Better is a free community service for people with cancer. The program focuses on how to manage the appearance related side effects of cancer treatment. You can visit their website **lgfb.org.au** or call **1800 650 960**.

Diet and nutrition

Being underweight or malnourished can have a negative effect on your quality of life. Poor appetite and weight loss are associated with symptoms such as weakness, fatigue, pain, and difficulty sleeping.

A high-energy diet is encouraged to meet the changing metabolic demands of your body. During chemo treatment you may experience complications that affect your nutrition. You may take drugs called corticosteroids, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema).

General nutrition recommendations for people receiving cancer treatment:

Maintain a healthy weight. For many people, this means avoiding weight loss by getting enough calories every day. For people who are obese, this may mean losing weight, get advice from your treatment team.

Get essential nutrients. These include protein, carbohydrates, fats, vitamins, minerals and water.

You can make an appointment to see a hospital dietitian as an outpatient or ask to see one if you are an inpatient. Your treatment team may refer you to a dietitian. Community dietitians are also available. Your GP can arrange this through a care plan if your private health insurance doesn't cover it.

You can find more information about eating well on our website.

"Eat well" and "Use a meal service to stay nourished without having to cook each day."
Top tips from people with blood cancer

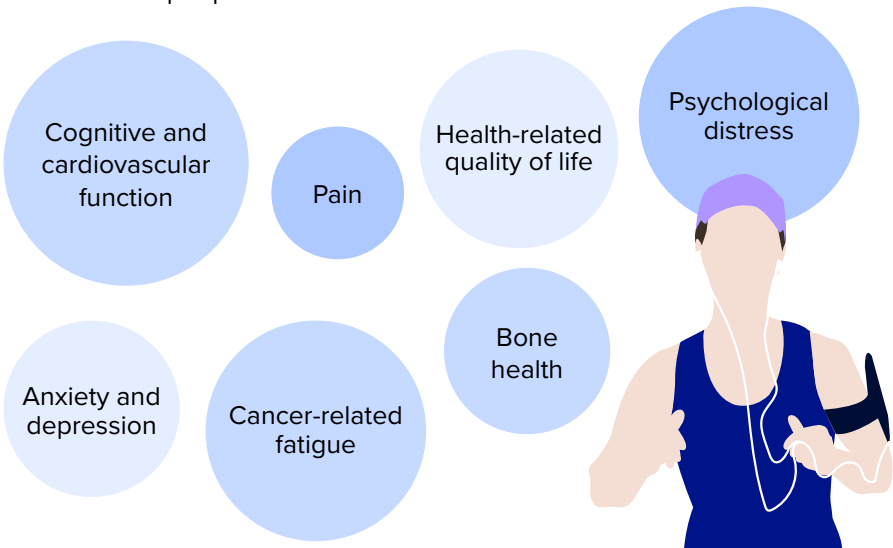
"Need to practise and build up skills over time – multi-tasking/moving/travel/work."
Top tips from people with blood cancer

Physical activity

It is common to experience a physical and/or psychological drop in function. This is called deconditioning. Having cancer doesn't mean you can't be physically active. Avoid inactivity and sedentary behaviour as much as possible.

What are the benefits of exercise/physical activity?

Strong evidence has shown that exercise and physical activity improves outcomes for people with cancer for:



"Doing something is better than nothing"

Top tips from people with blood cancer

Exercise can be tailored to the individual around activities of daily living. Before you start an exercise program speak with your treatment team. Check to make sure it is safe to do so and to see who is best placed to help you.

Information on exercise with cancer can be found on the Clinical Oncology Society of Australia (COSA) website: cosa.org.au

Specific information for older people on exercising with chronic illness and some advice about healthy eating is available from the Australian Government. 'Chose Health, Be Active – a physical activity guide for older Australians'.

Mental health and emotional wellbeing

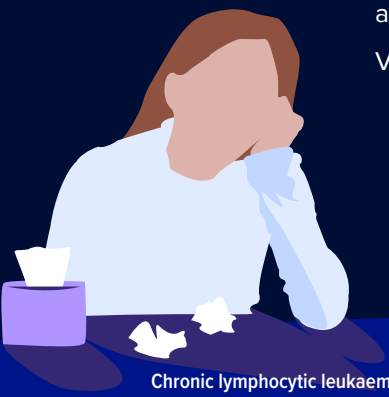
Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings. It is not uncommon to feel low, depressed, or anxious. Feeling sad is a normal response to a cancer diagnosis as is worrying about the future. **Feelings can be challenging and may include:**

- Anxiety
- Grief
- Guilt
- Uncertainty
- Anger
- Spiritual distress
- Fear
- Feeling isolated or lonely

Worrying about treatment, its success and side effects can impact your mental health. Changes in your physical, lifestyle, and family dynamics can also impact your wellbeing. Seeking help from your treatment team is important. They and/or your GP can refer you to someone who can help, such as **a psychologist who specialises in blood cancer.**

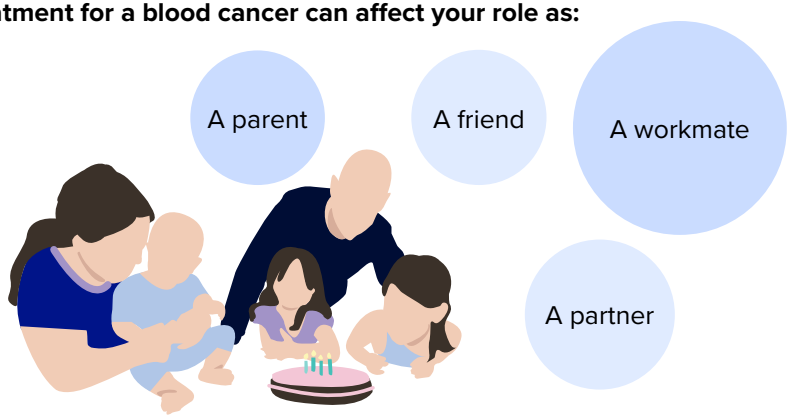
The Leukaemia Foundation's Blood Cancer Support Coordinators can also help you to work through what you are feeling and provide information on who might assist you in your local area.

Visit **leukaemia.org.au** or call **1800 620 420.**



Relationships, carers, family and friends

Treatment for a blood cancer can affect your role as:



You and the people in your life will cope in different ways. Encourage open communication between yourself, family and friends. Effective communication with family, children, friends, and carers is essential. Being clear with others about what you want and need allows them to be of greater support. Together you can work as a team to manage and solve problems as they arise. There are resources and other organisations that can assist with support and information.

The Leukaemia Foundation's Blood cancer support coordinators can assist you, your carer or family in identifying who can help with different issues and how to contact them (1800 620 420 or support@leukaemia.org.au).

For information for carers go to our online 'Carers' learn module.

Carers Australia: carersaustralia.com.au

Carer Gateway (Australian Government): carergateway.gov.au

Canteen: canteen.org.au

Redkite: redkite.org.au

Relationships Australia: relationships.org.au

Sexuality and sexual activity

It is likely the experience of the treatment will have some impact on how you feel about yourself. Hair loss, skin changes, weight gain or weight loss and fatigue can all interfere with feeling attractive. You may experience a decrease in libido, which is your body's sexual urge or desire. It may take some time for things to return to 'normal'. It is safe to have sex as soon as you feel like it, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant for some time after treatment. Some of the treatments given can harm the developing baby. You will need to use a suitable form of contraception. Condoms (with a spermicidal gel) provide good contraceptive protection. This also protects against infection or irritation.

Always use barrier protection/condoms to protect your partner if you are having chemotherapy or immunotherapy.

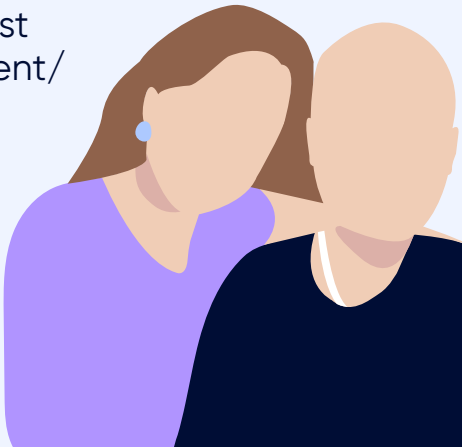
Partners are sometimes afraid that sex might harm the patient. This is unlikely, as long as the partner is free from infections and the sex is gentle. This is especially important if your platelet count is low. If you experience vaginal dryness and irritation the use of lubricants is helpful.

If you have questions or concerns about sexual activity and contraception talk to your treatment team. You may ask for a referral to a doctor or health professional who specialises in sexuality.

Find out more about sexual health during and after a blood cancer diagnosis here.

"Pay attention to emotional fatigue in relationships – adjust expectation/social commitment/ hours of care given"

Top tips from people with blood cancer



Work, finances and legal matters

Finances

People with blood cancer often report a negative impact on their financial situation during treatment. Monthly costs can increase for items such as travel, childcare and, taking time off work for appointments.
Your household income may reduce due to you or your carer having to stop work, or reduce hours permanently or temporarily.

A financial stocktake

A good first step is to run a quick 'financial stocktake'. First, assess what income you can expect or what financial resources you have available.
Possibilities may include:

Are you or your partner able to work part-time?

Do you have sick leave or long service leave?

Do you have income protection or trauma insurance, either as a stand-alone policy or part of a life insurance policy, or through a superannuation policy?

Do you have money in the bank or a line of credit against your mortgage which you can access?

The second step is to check on important expenses which need paying in the immediate future. Put together a brief budget if you don't have one.

To find out more visit our website.

Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources.

The Leukaemia Foundation's Blood cancer support coordinators can help point you in the right direction (1800 620 420 or support@leukaemia.org.au).

A few key other options to consider are:

Centrelink

If you expect your income to reduce, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you could receive relief payments. If you have employment to return to, this will affect the basis of your benefit. Your partner may also be eligible for a Carer Payment or Carer Allowance, so be sure to enquire about this.

Centrelink online account (sign in through myGov for instructions): centrelink.gov.au

Financial institutions

It is important that you let organisations know as soon as possible if you think you will have financial difficulties. Banks and other financial organisations have special arrangements for customers in financial hardship because of ill health.

Other sources of help

Discuss your financial circumstances with a social worker or your private insurer. They may be able to assist with advice on deferring payments.

- Many providers have hardship support programs (like energy providers).
- State governments have hardship programs available.
- It may be possible to access some money from your superannuation fund to help with emergency payments.

Don't forget to check if your superannuation has income replacement insurance. If you are not sure, give their helpline a call.

To find out more go to:
Money smart: moneysmart.gov.au
National Debt Helpline: ndh.org.au or phone 1800 007 007

Getting back to work

The decision about when to return to work is a very personal one. It will depend on how well you are feeling, the type of work you do, and your personal and financial circumstances.

On return to work some people may go back part-time, increasing their hours when they feel up to it. Discuss timeframes for returning to work with your doctor.

"Make a plan with your workplace"

Top tips from people with blood cancer

Find out more about returning to work or study on our website.

Discover more on our online learn module, 'Return to work'.

Legal matters

This information applies to all members of the community, not just those who have a blood cancer or their carer. The best time to get your affairs in order is when you are in good health. Here are some of the most common legal documents you should have and where to get help.

Enduring Power of Attorney/Enduring Guardian

There may be circumstances when a person loses the capacity to make decisions. You can sign a legal document which allows you to choose a trusted person to make decisions on your behalf.

An Enduring Power of Attorney (EPOA) is a document that allows your trusted person the power to sign documents on your behalf. They also can make personal and administrative decisions, and if you choose, financial decisions.

An Enduring Guardian (EG) is a trusted person who can make decisions on your behalf regarding your health including medical treatment, care and protection (even if this decision is against your wishes).
An Enduring Guardian (EG) requires another legal document.
To find out more visit the Australian Guardianship and Administration council at agac.org.au

Wills

It is very important to have specialist legal advice when preparing your Will. Intestacy is the condition of your estate if you die without a valid Will. Intestacy laws set out the way in which an estate will be distributed when there's no Will. This process is very specific and may not reflect your personal wishes. You will need to determine who will be responsible for your dependents in the event of your death. Even if your affairs are very simple and your immediate family will receive your assets, you need a Will. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document that states your wishes about medical treatments. It indicates those you may or may not wish to receive in the event of a serious illness or accident. Although lengthy, it is simple to complete as it consists of a series of optional questions. There are also sections where you make comments in your own words. While this form can be completed on your own, you may wish to discuss it with your family.
A doctor must sign the form to certify that you understand the contents of the document.
Advance Care Planning Australia: advancecareplanning.org.au or phone 1300 208 582.

Getting help

Help with legal matters is available from several sources including solicitors, trustee companies, the Public Trustee in your state, and the Australian Guardianship and Administration Council.

To find out more about putting your personal affairs in order, visit our website.

And our online learn module, 'Financial and legal matters'.

More information and help

Glossary

You can find any **bold** terms in the definitions also defined in this glossary.

Anaemia – a lower-than-normal number of red blood cells in the blood. It causes tiredness, paleness and sometimes shortness of breath.

Baseline – a first measurement of a condition taken early on, used to compare over time, to look for changes.

Blast cells – immature blood cells normally in the bone marrow in small numbers.

Bone marrow – soft, sponge-like tissue in the centre of most bones. It contains stem cells that make all blood cells.

Bone marrow biopsy – also called a bone marrow aspirate and trephine or BMAT. The removal of a small sample of bone marrow. This is sent to the lab for a pathologist to look at under a microscope.

Biotherapy – a type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.

Bone marrow aspirate – a procedure that takes a sample of bone marrow fluid.

Bone marrow transplant – also called a stem cell transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).

Bone marrow trephine – a sample of bone marrow tissue.

Cancer – diseases where some of the body's cells become faulty, begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.

Chemotherapy – the use of drugs to treat cancer.

Chromosome – part of a cell that contains genetic information.

Coagulation – process of changing from a liquid blood to a solid. Also called clotting. Platelets help with coagulation.

Cytogenetic tests – the study of the structure of chromosomes. These tests are carried out on samples of blood and bone marrow. The results help with diagnosis and getting the most appropriate treatment.

Cytopenia – where there is a lower-than-normal number of a type of blood cell in the blood.

Dysplasia – also called dysplastic cells. A change in size, shape and arrangement of normal cells seen under a microscope.

Erythrocytes – also called red blood cells. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.

Full blood count – also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the haemoglobin and haematocrit in the blood.

Growth factors – proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.

Haematocrit – the amount of blood that is made up of red blood cells.

Haematologist – a doctor who specialises in diagnosing and treating blood disorders.

Haemoglobin – a protein inside red blood cells that carries oxygen around the body.

Haemopoiesis – the formation of new blood cells.

Immune system – the body's defence system against infection and disease.

Immunotherapy – sometimes called biological therapy, is a type of cancer treatment that works by boosting a person's own immune system to fight the cancer.

Leukocytes – also called white blood cells that are made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system. Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Megakaryocytes – very large bone marrow cells that break apart to form platelets.

Mutation – a harmful change in 'normal' DNA (the building blocks of all cells).

Neutropenia – a lower-than-normal number of neutrophils in the blood. It increases the risk of infection.

Neutrophils – the most common type of white blood cell. They help fight infection.

Pancytopenia – where there are lower-than-normal numbers of a type of all blood cells and platelets in the blood.

Pathology – the study of diseases to understand their nature and their cause. A specialist in this field is called a pathologist. In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph tissue.

Petechiae – tiny, unraised, round red spots under the skin caused by bleeding.

Platelets – also called thrombocytes. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.

Prognosis – an estimate of the likely course and outcome of a disease.

Purpura – bleeding and bruising under the skin.

Radiotherapy (radiation therapy) – uses high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells or injure them so they can't grow or multiply.

Red blood cell – also called an erythrocyte or RBC. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.

Relapse – return of the original disease after it has improved for a time.

Remission – where the signs and symptoms of cancer decrease or disappear. Remission can be partial (a reduction in some or many symptoms) or complete (all symptoms have disappeared). Remission is not the same as a cure. Even in complete remission cancer cells may still be in the body.

Rigor – also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.

Stem cells – young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce red blood cells, white blood cells and platelets.

Stem cell transplant – also called a SCT or bone marrow transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).

Thrombocytes – also called platelets. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.

Thrombocytopenia – a lower-than-normal number of platelets in the blood. It causes bruising and bleeding.

White blood cells – also called leukocytes or WBCs. Blood cells made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system. Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Useful websites

Leukaemia Foundation

Australian Cancer Trials

eviQ Cancer Treatments Online

Pharmaceutical Benefits Scheme

ClinTrial Refer

Question builder

Who will be my main contacts?
How do I best contact them?

What can I do to avoid infections?

Can I have a flu shot and other vaccinations?

Is it safe to take my supplements and/or vitamins?

Can I eat normally?
Is there anything I need to avoid or special diets that will help me?

Can I exercise and what is the best frequency and type for me?

Are there any clinical trials for my type of CLL and am I eligible?

Could this treatment affect my sex life?
If so, how and for how long?

Will my treatment send me into menopause?

Where can I or my loved ones get any other support?

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.

The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us.

Email: info@leukaemia.org.au
Phone: 1800 620 420

Achieving excellence in blood cancer supportive care

At the Leukaemia Foundation, patient safety and quality care are at the heart of everything we do.

We are proud to have voluntarily achieved accreditation against the National Safety and Quality Primary and Community Healthcare Standards.

This significant milestone underscores our unwavering commitment to providing the highest standard of care for people living with blood cancer, reflecting our dedication as a not-for-profit organisation to support patients and their families throughout their experience with blood cancer.

Why are these standards important?

Patient safety: They ensure that healthcare providers have the systems in place to prevent and manage risks, ensuring patient safety.

Quality assurance: These standards promote continuous improvement in care delivery, helping organisations maintain high-quality services.

Equity in healthcare: They emphasise the importance of delivering culturally safe and inclusive care, ensuring that all patients, regardless of their background, receive the care they need.

Consumer engagement: The standards encourage healthcare providers to engage with patients and communities, placing their needs at the centre of care.

Visit https://www.safetyandquality.gov.au for more information.