

Chronic lymphocytic leukaemia (CLL)

A guide for people with CLL and their support people

This booklet has been written to help you and your support people understand more about chronic lymphocytic leukaemia, commonly called *CLL*. For all intents and purposes, it is the same disease as small lymphocytic lymphoma or *SLL*.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with CLL. Maybe you are discussing different treatment options with your treatment team or maybe you have started treatment. Whatever point you are at, this booklet will answer some of your questions and it may raise others, which you can jot down and discuss with your haematologist or nurse.

If you don't feel like reading this booklet from cover to cover, take a look at the list of contents and choose which parts to read now. You can come back to read other parts later. You may need more information, so towards the back of the booklet there is a list of useful resources. Your doctor or nurse might also give you some further reading. You can always call the Leukaemia Foundation's Blood Cancer Support Coordinators to find out how we can help you.

You will meet many different types of healthcare professionals who work as a team to provide you with the best treatment available. The people you'll most often see will be haematologists and haematology nurses, and you'll need a regular GP, but you'll also meet pathologists and allied health professionals, like dietitians. In this booklet, when we refer to 'your treatment team' we usually mean your haematologist and haematology nurses.

You will come across quite a few medical terms in this booklet. They are words that your treatment team will probably use and that you may not have heard before. They will be happy to explain any terms you don't understand, so never be afraid to ask. Many of these words are defined in the text or in the Glossary at the end of this booklet.

Although we provide some information about treatments, this booklet does not recommend any particular form of treatment and you must discuss your circumstances and best treatment options with your haematologist.

We hope you find this information useful. We'd love to hear any feedback so we can make sure we best meet your information needs.

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.

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CLL in brief

About CLL

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) represent cancers that starts in the bone marrow, where blood cells are made.

A small number of people with CLL may be diagnosed with a type of non-Hodgkin lymphoma called *small lymphocytic lymphoma (SLL)*. CLL and SLL are considered the same disease, the only difference being where the cancer primarily occurs.

Both CLL and SLL are characterised by small and mature lymphocytes present in the bone marrow, lymphoid tissue, and peripheral blood. When most of the cancer cells are located in the bloodstream and the bone marrow, the disease is referred to as CLL, although the lymph nodes and spleen are often involved.

When the cancer cells are located mostly in the lymph nodes, rather than the bone marrow, the disease is called SLL. It's diagnosed and treated the same way as CLL.

In CLL/SLL the bone marrow makes too many unhealthy white blood cells called *lymphocytes*. Under normal conditions lymphocytes produce immunoglobulins (also called antibodies) that help protect our bodies against infection and disease. In people with CLL/SLL, lymphocytes undergo a cancerous change. They don't work as they should. They crowd the bone marrow so that it can't make enough healthy blood cells. When healthy blood cells (red cells, white cells or platelets) are low, the body can't function as it should.

The abnormal lymphocytes also spill out of the bone marrow into the bloodstream. They can build up in organs including the lymph nodes (glands), liver, spleen, and other parts of the body.

CLL is the more frequent presentation of this type of cancer.

Symptoms of CLL may include tiredness, weakness, dizziness, weight loss, fever, infections, night sweats, easy bruising, swollen lymph nodes, and abdominal discomfort.

Often, people with CLL have no obvious symptoms of the disease at diagnosis. Approximately one-third of all CLL patients will live for years without symptoms.

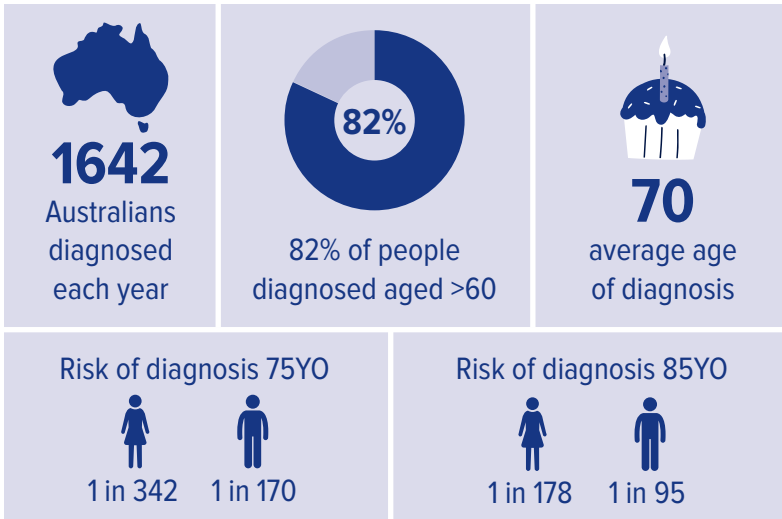
CLL and SLL are diagnosed using blood tests. You may require a CT scan and a bone marrow biopsy too.

In most cases we don't know what causes CLL/SLL. There is often a genetic abnormality in the cancerous lymphocytes that give them an advantage over normal cells. There is no way to prevent CLL/SLL and you can't catch it or pass it on.



Scan to learn more about how the Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

Who gets CLL



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 when you are diagnosed.

Your haematologist will consider many factors regarding your prognosis. Some of these are the stage of your CLL, which chromosomes or genes are affected, your lymphocyte count (and how long it takes to double), your age, and your overall health. 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 to all parts of the body, carrying oxygen and nutrients and removing 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.

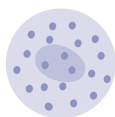
The main types of blood cells are red and white. Platelets are talked about like blood cells, but they are *fragments* of blood cells.

Platelets
Support blood clotting
to stop bleeding



Red Blood Cells

Carry oxygen for the body to produce energy



White Blood Cells

Form part of the immune system

Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives 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.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They help your blood clot or stick together; a process called coagulation. They help stop bleeding when you have an injury.

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs
Leukopenia	Low WBCs	More frequent or severe infections
Thrombocytopenia	Low platelets	Bruising and bleeding, like nosebleeds
Pancytopenia	All three types low	A mix of symptoms from all three conditions

Where and how is blood made?

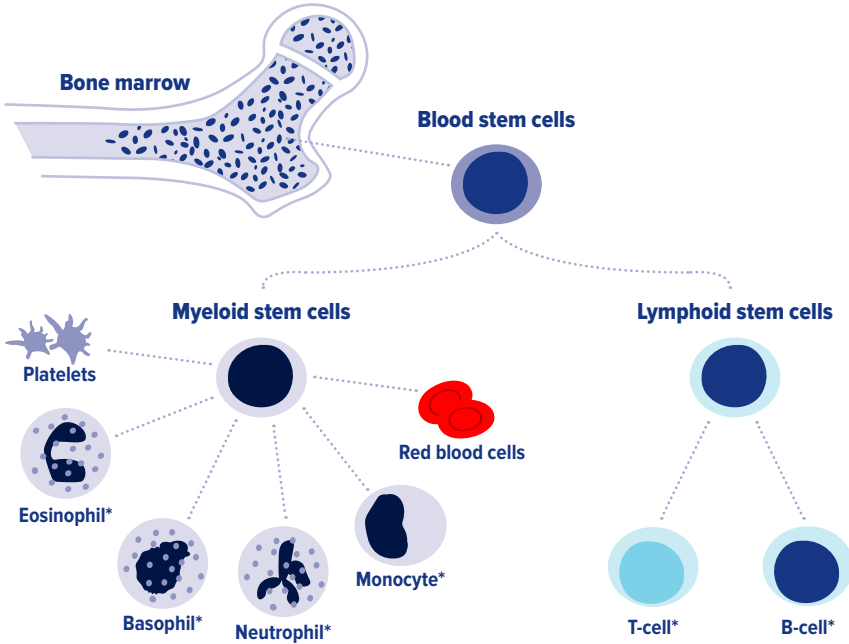
Bone marrow

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

In children, haematopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and 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 as 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, and 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.

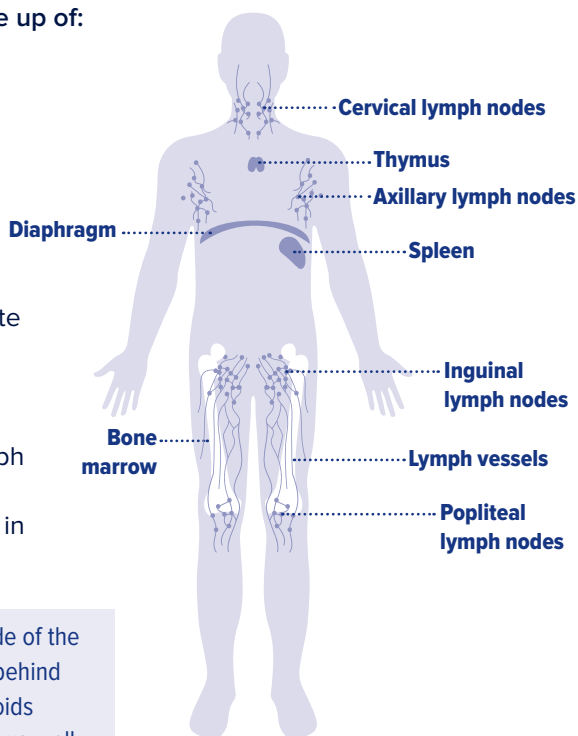
All about the lymphatic system

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.



The spleen (an organ on the left side of the abdomen), thymus (a gland found behind the breast bone), tonsils and adenoids (glands in the throat), and bone marrow all contain lymphatic tissue and are part of the lymphatic system. These tissues perform similar roles to lymph nodes, but in different parts of the body. There is also lymphatic tissue in the stomach, gut, and skin.

All 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 a *malignant change*. This means they multiply more than they should and don't mature the way 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 is a chronic type.

The bone marrow contains stem cells. They divide and grow into immature blood cells called blast cells. These immature blood cells become white blood cells, red blood cells, and platelets, which are eventually released into the bloodstream.

What is chronic leukaemia?

In people with chronic leukaemia, the bone marrow makes too many mature but abnormal white blood cells over time. These abnormal cells are called leukaemic cells.

The leukaemic cells build up in the bone marrow. They often spill out into the bloodstream. Sometimes leukaemia spreads from the blood to other organs such as the spleen or liver.

All about CLL

What is CLL?

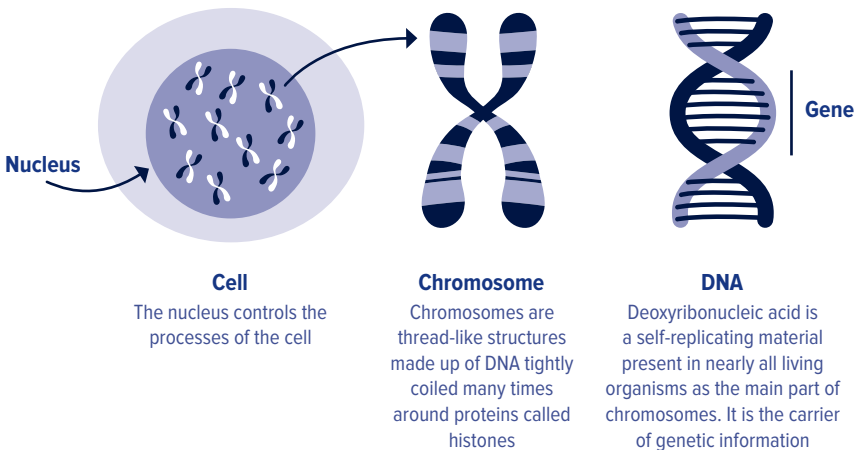
Chronic lymphocytic leukaemia is a slow-growing leukaemia. It starts in B lymphocytes in the bone marrow and over time these cells divide and proliferate (multiply) in the bone marrow, then spill over into the blood. People with CLL have too many B lymphocytes.

Normal B-cells fight bacteria and viruses (invaders) by making proteins called antibodies that fight infection. They lock onto the surface of an invading cell. This makes it a target to be killed by other immune cells. In CLL, the abnormal B-cells can't function as they are meant to.

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 DNA (deoxyribonucleic acid). Each section of DNA that holds the cell's instructions is called a *gene*.



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. They crowd the bone marrow. Because the bone marrow can't function properly, it can't make enough red blood cells, normal white blood cells and platelets.

This means that people with CLL often have very active bone marrow, producing many cells, but a low number of healthy blood cells circulating in the bloodstream. Low numbers of blood cells are called *cytopenias*. One type of cytopenia is *anaemia*, which is where someone has low red blood cells.

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 lymphocyte cells fill up the bone marrow, so 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 (up to 2%).

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. The gene changes vary between people with CLL. 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 some people a higher risk of developing CLL.

Known risk factors

- **Ageing**, because the risk of developing genetic mutations increases with age.
- Exposure to **Agent Orange**, a herbicide used during the Vietnam war.
- People who have a **parent, sister, brother or child with CLL** have a higher risk.

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 troubling symptoms.

You may have general symptoms, such as:

- fatigue (extreme tiredness not relieved by rest)
- weight loss
- fever
- chills
- drenching night sweats.

Low blood counts

Many symptoms of CLL are because of low normal blood cell counts. Your bone marrow can't make enough healthy cells. You may have lower-than-normal 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 of these groups because all your blood cell types can be low due to CLL (which is called *pancytopenia*).

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat.

Neutropenia	Low WBCs (neutrophils)	More frequent or severe infections, e.g. chest or skin, fevers, shivering, chills, low blood pressure, mouth ulcers.
Thrombocytopenia	Low platelets	Easy bruising and bleeding, e.g. nosebleeds, cuts that keep bleeding, coughing up blood, petechiae – tiny, unraised red blood spots under the skin, often starting on legs.
Pancytopenia	All three blood cell types are low	A mix of symptoms from all three conditions.



Petechiae

Enlarged spleen

Your spleen is an organ located in the top left of your abdomen, 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.

If you have splenomegaly you may feel fullness, discomfort or pain in the left upper side of your abdomen and you may feel rapidly full when eating.

Swollen lymph nodes

If the CLL has spread to your lymph nodes, or your diagnosis is SLL, you may feel small, hard lumps in your armpits, on either side of your neck, and/or in your groin. They're usually painless. There are internal lymph nodes too, in your chest and belly. 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, if you have symptoms. Some symptoms of CLL, like feeling tired, are part of many conditions.

Medical history and physical exam

First, your treatment team (usually your GP) will take a full medical history. They'll ask you to talk about past and present illnesses, health problems, infections, bruising, and bleeding. They'll also need details of any old and new medicines you're taking, including prescribed and any over the counter medications you take regularly.

Your doctor will also do a physical examination, to check your general health and your whole body for any signs of CLL, like swollen lymph nodes.

Full blood count

You'll 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 haematopathologist (a 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 be taken at the same time as your FBC. Some substances that will be tested for CLL will be:

Substance tested	What it indicates
Creatinine	Kidney function
Electrolytes	Kidney function
Blood urea nitrogen (BUN)	Kidney function
Calcium	Bone destruction
Uric acid	Cell breakdown
Lactate dehydrogenase (LDH)	Blood cell damage

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

Bone marrow biopsy

This test is more complex than a blood test, but it won't involve a hospital stay. It will be done in your haematologist's rooms or in a day procedure clinic or outpatient ward in a hospital. It's a good idea to bring a support person with you to keep you company while you wait and to help you home, as you won't be able to drive.

What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a sharp needle to enter the bone marrow, usually in the hip bone towards the lower end of the back. A small amount of liquid bone marrow is usually taken and placed onto slides that are examined in the laboratory. The liquid bone marrow is also sent for additional specialised tests. Usually, a small piece of the bone marrow is also taken and examined in the laboratory.

Is a bone marrow biopsy painful?

Having a bone marrow biopsy is sometimes painful. With the use of local anaesthetic, before the bone marrow needle is inserted, this pain is usually well tolerated. You may be given a form of pain preventer that you breathe in, or a small dose of sedative (given under appropriate hospital conditions) to assist in managing the discomfort.

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. You may not have any pain but if you do, take a paracetamol tablet. You can take off the dressing and shower 24 hours after the test, or as advised by your treatment team.

You may have to wait a few days for the results of the bone marrow biopsy.

Lymph node biopsy

Very few people may need to have a swollen lymph node 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 a week later.

Molecular genetic tests

Molecular genetic tests, such as gene sequencing, look directly at the genetic sequence/code and help your haematologist work out the best course of treatment for your cancer. It may take a few weeks for these test results to come through.

Gene sequencing

Next generation gene sequencing uses DNA to look for specific gene mutations. This test is very sensitive and can detect low levels of cancer cells in the blood. It is often done at the same time

as cytogenetics/FISH/SNP array and it also checks for the tumor suppressor gene TP53 and to look at the immunoglobulin variable heavy chain (IGHV) mutational status.

This test is used regularly after treatment starts to monitor your response.

Cytogenetic tests

Cytogenetic tests, which include the SNP array (single nucleotide polymorphism) on the bone marrow, are one type of genetic test. The results give your treatment team information about the genetic make-up of your cells. They look at the structure of chromosomes in bone marrow cells to see if there is any gain, loss or switching of genetic material between chromosomes. Your haematologist will use the results to help work out which type of CLL you have and to plan your treatment.

FISH

Fluorescent in-situ hybridisation (or FISH) is a type of cytogenetic test your treatment team might mention. It can be done using either a blood or a bone marrow sample. The pathologist uses dyes or gene probes to highlight parts of chromosomes to check if they are abnormal.

Flow cytometry

Flow cytometry looks for proteins on the surface of a cell by adding dyes that bind to specific proteins. Leukaemia blasts often have abnormal combinations of proteins on their surface. This abnormal combination is called a leukaemia-associated immunophenotype and can be used to tell the difference between a leukaemic cell and a healthy, normal bone marrow cell at diagnosis. In flow cytometry, dye is applied to thousands of cells and can be used to detect very small amounts of leukaemia, present after chemotherapy, that are not able to be seen when looking at the bone marrow down the microscope.

Direct antiglobulin test (direct Coombs test)

Sometimes CLL affects the immune system by making abnormal antibodies. These antibodies attack normal blood cells. The direct antiglobulin test checks whether red blood cell antibodies are attached to red blood cells. If they are, it's called *autoimmune haemolytic anaemia*. The test will also show the type of antibody.

HLA testing

HLA testing looks for human leukocyte antigen. The test is also called *tissue typing* or *histocompatibility testing*. It tests which HLA genes someone has inherited. People eligible for stem cell transplants and their donors will be HLA tested to see if they are matches. You can read more about stem cell transplants later in this booklet and in our booklet, *Understanding Allogeneic Stem Cell Transplants*.

Other tests

You might need more blood and imaging tests when you are diagnosed and throughout your treatment. CT, MRI or PET scans look for signs of leukaemia in parts of your body, like your spleen and your lymph nodes.

Other conditions

There are other conditions that are similar to CLL that your haematologist will rule out during diagnosis.

Monoclonal B-lymphocytosis (MBL)

Some people have a blood condition called monoclonal B-lymphocytosis (MBL). In MBL, the B-cells have the CLL immunophenotype. This means that the MBL B-cells contain the proteins seen in CLL. However, MBL isn't leukaemia as there are not enough abnormal B-cells in the blood. There is low-count MBL and high-count MBL depending on the B-cell count. One or two per cent of people per year with a high-count MBL will develop CLL, so you might hear it called 'pre-CLL'. People with this condition will have regular follow-ups with their GP to check their bloods, but don't need treatment.

What happens next?

After diagnosis

When all your test results have been reviewed, you'll meet with your haematologist to discuss your CLL stage, and treatment goals and options. It's natural to feel scared, confused or sad. You'll hear a lot of information and it can be overwhelming. Don't be afraid to ask your haematologist to repeat things and for some written information. It's helpful to bring someone along to the appointment as a second pair of ears and to take notes.

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.

Stage	Findings	Risk	Likely treatment
Binet stage A (Rai stage 0)	<3 lymphoid areas involved. High lymphocyte count.	Low	Watch and wait
Binet stage B (Rai stages I to II)	3 or more lymphoid areas involved. High lymphocyte count.	Intermediate	Supportive care Some treatment
Binet stage C (Rai stages III to IV)	Bone marrow failure. Low red blood cell count +/- low platelet count.	High	Treatment

Heart tests

Some medicines for CLL can cause heart problems. Before you start treatment, you might have an echocardiogram or a multigated acquisition scan (MUGA). Both tests take pictures of your heart to check how well it pumps blood.

Venous access for treatments

CLL treatments are given directly into a vein (*intravenously*, or via *IV*). There are two broad ways to provide access to your bloodstream: through the peripheral veins in your arms or through a central vein in your chest. **People with CLL rarely need a central vein access device such as a port or central line.** Your treatment team will discuss them with you before you start treatment so you can understand which is best for you.

Peripheral intravenous cannula

This is the most common way to access a peripheral vein. A cannula is a short, thin plastic tube. It has a thin needle that your nurse will put into a vein in your lower arm or the back of your hand. It will be held in place with a dressing. The cannula is connected to the lines that give you your treatment, often through a pump. Having a cannula inserted may hurt a little, but once it's in place you'll have no pain. It can stay in for a few days or be removed right after your treatment.

PICC line

A PICC line is a long, thin silicone tube. It's put into a vein above where your elbow bends. A specialist nurse will insert it in an outpatient ward or a clinic. One end is fed up a vein in your arm into a large vein in your chest. The other end comes out around your elbow and can have one, two, or three tubes (*lumens*). Treatment is given through the lumens. The PICC line will be taped

with a dressing so it doesn't move. PICC lines can stay in for up to two years. Sometimes PICCs are called *central venous access devices* (CVADs).

Port

A port is a small medical device that is implanted under the skin in your chest, just above your heart. It's a thin, flexible silicone tube with a silicone disk on the end. The disk is the 'port'. When it heals, you can see and feel the port under your skin, but there are no external tubes. Ports are also called *infusaports* or *portacaths*.

Central line

A central line is a long, thin silicone tube. It's also called a *Hickman® line*, a *central venous catheter* (CVC), or a *central venous access device* (CVAD). One end of the tube sits in a large vein above your heart. The other end, which is capped, comes out of your chest.

Treatments and side effects

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.

There are a few kinds of treatment for CLL (and SLL). Your treatment plan may include one or more of them.

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 only

Many people don't need to start any treatment as they don't have any symptoms. Your haematologist may recommend regular check-ups to keep an eye on your health. Your GP may monitor your CLL with blood tests as part of your active follow-up. How often, will depend on any changes in your blood counts and your general health. This is called 'watch and wait'. It's suitable for people with stage A (low risk) CLL.

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 CLL may have supportive care alongside treatment.**

Blood transfusions

If you notice symptoms of anaemia, tell your treatment team. You may need a blood transfusion.

Blood transfusions are slow injections of blood into a vein (intravenously, or IV). Transfusions are usually given by a nurse in a clinic or in an outpatient ward of a hospital. The nurse will use your CVAD to insert a 'drip' (cannula). The cannula connects to a bag of blood (called packed red blood cells). 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 of packed red blood cells. Additionally, an oral medication that increases blood clotting may be given.

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 lab. They are used to boost low blood counts.

In Australia, white blood cell growth factors are given. Neutrophils are white blood cells that help fight infections. A growth factor called *granulocyte colony stimulating factor* (also known as G-CSF) makes the bone marrow produce more neutrophils. This is predominantly used when people are being treated with chemotherapy.

Growth factors don't usually cause any major side effects, but some people may have chills, headaches, and bone pain after an injection.

Antibiotics

When your white blood cell count is low you have a higher risk of getting infections. If you do, it's important to be treated as soon as possible. If you develop signs or symptoms of infection, your treatment team will probably prescribe antibiotics; either in tablet form or given via a 'drip' straight into your bloodstream (IV).

Antifungal and antiviral medicines

When you start chemo or if you are preparing for a stem cell transplant, you may be given antifungal and/or antiviral medicines. Because you are low in certain blood cell types, you have a higher risk of fungal or viral infections. These types of medicines prevent infection. This is called *prophylaxis*, or you might hear the drugs referred to as *prophylactics*. Usually, they will 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. Only some vaccines are safe and these are called *inactivated* vaccines. You will need to check with your treatment team when to have them. You should not have any *live* vaccines, so before getting a vaccine always ensure that it is not live.

Apheresis

Very rarely, people with CLL have an extremely high white blood cell count (called *hyperleukocytosis*). They may need a procedure called *apheresis*. It removes abnormal white blood cells from the blood. It's done in an outpatient ward. Apheresis lowers white blood cells right away.

Treatment phases

Most treatment for CLL is called *first-line therapy*. This is the first treatment you receive. Its goal is remission. For people with 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 medicines 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. Most of these therapies will be given via drip (IV), although some are tablets which you can take at home. You'll have IV therapy in a clinic, outpatient ward, or as an inpatient in hospital.

There are a few chemo and other drugs available to treat CLL. Your haematologist will recommend them depending on:

- your stage of CLL
- whether you have chromosome or gene abnormalities, such as del(17p); the TP53 mutation; or del(11q)
- your IGHV mutational status

- your overall health
- your age
- whether it is your first treatment or your CLL has come back after remission (relapsed), and
- very infrequently in CLL an allogeneic bone marrow transplant may be required. *You can read more about stem cell transplants later in this booklet.*

Chemotherapy

Chemotherapy medications (also called *chemo*), sometimes also called cytotoxic (which means ‘cell killing’) medications, make cancer cells stop growing. They either kill the cells or stop them from dividing, replicating, and reproducing. They also damage normal cells, but these cells can repair and recover.

Unlike supportive care, which treats symptoms, chemo treats the actual disease. Because of this, it’s often called *disease modifying* treatment.

Chemo can be given as tablets, injections, or infusions via a drip (IV). The type of chemo given depends on the type of cancer. You can take some chemo tablets at home and may have injections or IV chemo in a clinic, outpatient ward, or as an inpatient in hospital.

Intravenous 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. Chemo cycle times depend on the drug. The number of treatment days and the number of cycles can be different due to the drug or the disease being treated.

For people with CLL with del(17p) or the TP53 mutation chemo doesn’t work as well. For this reason your doctor may recommend a clinical trial or other novel agent approaches to treatment. The most common treatment for CLL is a combination chemotherapy protocol, given in cycles over a period determined by your

treatment team. Some people may be prescribed another chemotherapy protocol in common use in Australia where a chemotherapy drug is given orally in combination with a monoclonal antibody.

Emerging treatments for CLL are in development and your treatment team will be able to advise you on what your options are and the treatment that would be best for you.

Immunotherapies

Immunotherapies are sometimes called *biologic therapies*. They use a part of your immune system to fight cancer. In this case, antibodies are created in a lab. In your body, antibodies fight infection by targeting parts of cancer cells to change how they grow. Immunotherapies are given via drip (IV) or in tablet form.

Monoclonal antibodies

Monoclonal antibodies are a type of immunotherapy. The types of monoclonal antibodies used for CLL are also targeted therapies. They work by attaching to B-cells to tell the immune system to destroy those cells. They also make cancer cells grow more slowly. Monoclonal antibodies may be given to people who are not suited to some chemo treatment due to its side effects. These are given in combination with either chemotherapy or a novel agent therapy.

Targeted therapies

Targeted therapies target specific substances on the surface of leukaemic cells, or inside the leukaemic cells, and cause far less harm to normal cells. They can act by switching genes on or off, or by sending substances straight to the leukaemic cells to kill them or stop them growing.

B-cell receptor (BCR) inhibitors target proteins called B-cell receptors on CLL cells. These receptors control the growth of CLL

cells. When they are switched off, the cells die. These drugs are given when CLL relapses and are preferred for people with del(17p) or the TP53 mutation.

BCL2 is a type of protein CLL cells make. The protein prevents the leukaemic cells from dying. BCL2 inhibitors block the protein. This kills the cells. These drugs are given to people when CLL relapses and are preferred for people with del(17p) or the TP53 mutation.

Treatment side effects

Chemotherapy, immunotherapy, and targeted therapies all come with side effects. Everyone gets different side effects. You may have no side effects, or one or more of them, and they may change over time.

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

- your medicines
- your overall health and wellbeing.

Chemotherapy side effects

Chemotherapy kills cells that multiply quickly, like leukaemic cells. It also damages fast-growing normal cells. These include hair cells and cells that make up the tissues in your mouth, gut, and bone marrow. You may get chemo side effects because of the damage to the normal cells.



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

Immunotherapy and targeted therapies

Side effects from immunotherapy and 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.

CLL chemo side effects

Changes in blood counts

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 treatment.

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

If your platelets are low, you can bruise and bleed more easily.

Your white blood cell count (neutrophils) will drop within a week of your treatment. This puts you at a higher risk of developing an infection. If you develop a fever, you should seek immediate medical advice.

You may need a red cell or platelet transfusion or injections to boost your neutrophils.

Feeling sick - nausea and vomiting

Nausea (feeling sick to your stomach) and vomiting are common side effects, but you will be given medicine to prevent or manage them. If you do feel nauseous, even with medicine to help, do not hesitate to contact your treating team to ensure it is managed and you can continue eating and drinking.

Keep an eye on your weight if you are eating less than usual. If you find it difficult to eat, 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 make you not enjoy 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

You might have cramping, wind, bloating, diarrhoea, or constipation. You will be given medication to help. Tell your treatment team if you are constipated or if it's painful or hard to pass faeces, and if you have haemorrhoids, don't strain. Sometimes making a few changes to what you eat can help too. 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 information 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. Set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.

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, although it's less common with CLL drugs.** 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 as you lose your hair, but this will pass. There are some great wraps, turbans, and beanies available. Your nurse can give you information on where to find them, and about where to get wigs.

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*. **Chemo-induced peripheral neuropathy is unlikely in people being treated for CLL.** Symptoms can start any time during treatment. Tell your treatment team if you feel tingling, numbness, burning, or pins and needles in your fingers or toes. It might be hard to do up buttons or to grip things.

Sun sensitivity

Some chemo drugs make you more prone to sunburn. You can go outside, but avoid direct sunlight.

Tumour lysis syndrome

Some patients who commence anti-CLL therapy may experience rapid leukaemia cell death with the attendant risk of kidney and heart problems. Ask your doctor if you are at risk of this and what measures are being taken to monitor and manage the problem.

Managing chemo side effects

Potential side effects	What might help
Low platelets	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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
Mouth problems – mucositis	<ul style="list-style-type: none">• use a soft toothbrush and mild toothpaste• brush every time after you eat• use salty water, sodium bicarbonate in water, or alcohol-free mouthwash• continue to floss but stop if your gums bleed

Bowel changes	<ul style="list-style-type: none"> • drink plenty of fluids • get some dietary advice from your treatment team • if you're constipated, don't strain • if you have haemorrhoids, do not push on them • tell your treatment team, you'll be given medicine to help
Fatigue	<ul style="list-style-type: none"> • see later in this booklet for more info • rest or nap when needed • take regular gentle exercise
Chemo brain	<ul style="list-style-type: none"> • keep a notebook handy to write things down • ask your pharmacist to Webber-pak your medications • take regular gentle exercise • socialise – tell your loved ones what's going on
Hair loss and thinning	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • cover up with long sleeves and long pants • wear sunglasses and a hat or beanie to protect your scalp • talk to your nurse about which sunscreens are best to use • avoid sun exposure at high UV times of the day
Tumour lysis syndrome	<ul style="list-style-type: none"> • take medication to lower uric acid build up • have intravenous and oral hydration • monitor with frequent blood tests

Corticosteroids

During treatment you may be given drugs called *corticosteroids*, or *steroids* for short. Steroids are drugs that act like your body's own hormones. They can help treat many types of cancer, and they can keep you from having nausea and vomiting after a round of chemo. They can also prevent allergic reactions to other drugs and blood products. Common steroids are prednisolone and dexamethasone. They can be given in tablet form and/or via drip (IV).

Steroid side effects and how to deal with them:

- 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)

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. People preparing for stem cell transplantation will also have total body irradiation, which is radiation therapy to the whole body.

Before you start radiotherapy, you'll meet with the radiation oncologist (who specialises in treating people with radiotherapy).

You'll discuss treatment options and goals, and you may have a physical examination.

Next, you'll have a *simulation session*. You'll have scans and your radiation oncologist and radiation therapists will work out what position you will be in for all your radiotherapy treatments. They'll also work out your dose of radiation. You may end up with small tattooed dots on your skin, which help guide the treatment.

Surgery

You will have day surgery if you have a central line or a port inserted for access. You may also need day surgery for a lymph node biopsy.

Stem cell transplantation

Stem cell transplants (also called a bone marrow transplant, or a hemopoietic cell transplant or HCT) are available if required for younger or very fit older people with CLL. This treatment has very serious side effects. Your haematologist will determine if you need and can have a stem cell transplant.

Stem cell transplants involve very high doses of chemotherapy. The aim is to completely destroy the abnormal stem cells in your bone marrow. These cells are then replaced with healthy stem cells.

The healthy stem cells are donated. The donor is usually a brother or sister who has the same tissue type as yours. They just need a blood test to see if they are a match to you. If they are, they are called HLA matched donors. This procedure is called an allogeneic (donor) stem cell transplant. Extremely rarely, the stem cells can come from someone who is not related.

The goal of stem cell treatment is twofold. First, to create an immune response called a graft-versus-leukaemia (GVL) effect. The donated stem cells make their own immune cells and these create

a new immune system. These immune cells kill any cancer cells that are left after you've had high-dose chemotherapy.

Second, to restore normal blood cell growth with healthy donated stem cells after 'conditioning' chemo destroys your abnormal cancerous stem cells.

Stem cell transplant side effects include:

- low blood counts
- all the same side effects as chemo, but more severe
- graft-versus-host disease (GVHD).

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



You can find out more about stem cell transplants in our booklet *Allogeneic Stem Cell Transplants* and on our website.

Clinical trials

Clinical trials (also called *research studies*) test new treatments and often provide early access to promising therapies that aren't routinely available. Results from the new agent (or combination of agents) are compared against current (or standard) treatments to see if the new treatment works better. They also check for the new treatment's side effects. Many clinical trials are randomised, which means some patients receive the new treatment and others the current standard of care treatment.

Clinical trials provide important information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that aren't available on Australia's PBS.

Your haematologist may suggest you join a clinical trial. Before you can start, you will need to give informed consent. This shows that you understand the risks and benefits of the trial treatment.

Clinical trials are run through hospitals and clinics, just like other treatments. You will have a clinical trial nurse as part of your treatment team.

Clinical trial participation is purely voluntary. If you are offered a clinical trial, make sure you understand how your treatment will be different compared to what is generally given (standard of care treatments). Be sure to ask any questions you have before deciding whether to participate.

You can search current clinical trials at:

Australian Cancer Trials australiancancertrials.gov.au

ANZ Clinical Trials Registry: anzctr.org.au and

ClinTrial: clintrial.org.au

Second opinion

If you feel unsure about your diagnosis or treatment, you are entitled to seek a second opinion from an independent doctor. This may be at the same hospital or clinic, or at a different location. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP, or a counsellor for advice.

Complementary therapies

Complementary and alternative medicines (CAM) also known as integrated therapies are not standard medical treatments.

These therapies should 'complement' or be done alongside medical treatment after consultation with your treatment team.

No complementary or alternative treatment on its own can treat CLL. They may help with some symptoms or side effects.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called *cancer-related fatigue*. 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 also 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.

Tips for managing fatigue

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

A positive sleep routine, pre-sleep relaxation techniques, napping if tired during the day for up to an hour, regular moderate exercise or movement, eating well, drinking plenty of water, and avoiding use of electronic equipment, such as computers late at night, can be very helpful in improving sleep and reducing fatigue.

While you're managing your fatigue, jot down what time of day you have the 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.

Fertility decisions

It may seem funny reading about fertility here, given the average age of most CLL patients. But some young people do get CLL, while others may have younger partners. 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
- success rates
- the risks
- side effects of fertility treatments, and
- any costs.

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. Tell your treatment team right away if you are pregnant or think you may be.

There are several mainstream 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.

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 supports your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian - A university-qualified professional with ongoing training and education programs, who helps to support your recovery and manage challenges in your diet.

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

Physiotherapist/Exercise physiologist - Health professionals who specialise 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 here:

	Contact name	Phone	Comment
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo Day Unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			

Useful website: <https://patients.cancer.nsw.gov.au/diagnosis/navigating-the-health-system>

The new normal – what is it?

For many people, the start of treatment signals changes to life that include the day-to-day managing of a multitude of new activities and changes around treating and monitoring of your blood cancer. Frequent appointments with your health care team and regular follow up can be tiring and stressful for all.

Life is not exactly the same as it was before the blood cancer diagnosis. Everyday life changes for you and the people around you. Things that were once important may no longer be so, or 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 your new normal to live as good a life as possible while facing changes such as and not limited to:

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

Seeking information, tools, and support, and accepting help to manage challenges that arise throughout a person's cancer experience is very important. Having this support can enable individuals to have a high quality of life throughout their blood cancer journey. 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 and is affected differently.

Diet and nutrition

During treatment, nutritional goals are designed to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/ muscle) and to minimise side effects, such as decreased appetite, nausea, diarrhoea, dry mouth, and taste changes.

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

It is likely you will be encouraged to eat a high-energy diet to meet the changing metabolic demands of your body during this time. During chemo treatment, you may experience complications that negatively affect your nutrition and hence your overall wellbeing, such as mucositis (ulcers in the mouth/throat and/or stomach).

You may be given drugs called corticosteroids, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema) in your limbs, abdomen, and face.

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. It's important to get advice from your health care team before you try to lose weight during treatment.
- **Get essential nutrients.** These include protein, carbohydrates, fats, 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 treating team may refer you to a dietitian. Community dietitians are also available, and your GP can arrange this through a care plan if your private health insurance doesn't cover it.

Exercise

With any blood cancer treatment, it is common to experience deconditioning; a physical and/or psychological drop in function. Having cancer doesn't mean you can't be physically active.

People with blood cancer should attempt to avoid inactivity and sedentary behaviour as much as possible and return to normal daily activities as soon as possible following diagnosis.

What are the benefits of exercise/physical activity?

Strong evidence is available to show that exercise and physical activity improves outcomes for people with cancer across a range of dimensions including:

- cancer-related fatigue, pain, psychological distress, anxiety, depression
- in-bone health, cognitive, and cardiovascular function
- health-related quality of life.

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

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

Mental health and emotions

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings and 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, and feeling isolated or lonely. Worrying about treatment, its success and side effects, or changes in your physical, lifestyle, and family dynamics can also impact your mental health.

Seeking help from your healthcare 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.

Relationships/carers/family and friends

Undergoing treatment for a blood cancer can affect your role as a parent, partner, friend, and workmate, to name a few. You and all the people in your life will cope differently. Be open with your communication and encourage family and friends to be open with you.

Communicating effectively with family, children, friends, and a carer 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 many allied healthcare staff and not-for-profit organisations that can assist with support and information. The Leukaemia Foundation is one of them and can assist you, your carer or family in identifying who can help with different issues and how to contact them.

Carers Australia: carersaustralia.com.au

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

Canteen: canteen.org.au

Redkite: redkite.org.au

Work/finances/legal matters

Finances

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

A financial stocktake

When you become aware that you may lose your income or suffer a reduced income as a result of the ill health of you or an immediate family member, the first step should be 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 policy?
- Do you have money in the bank or a line of credit against your mortgage which can be drawn against?

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

Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources. Your local Leukaemia Foundation Blood Cancer Support Coordinator can help point you in the right direction.

A few key other options to consider are:

Centrelink

If you expect to lose all or most of your income or your partner's income, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you may receive some 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

If you are unable to make your regular payments on your mortgage as a result of serious ill health, it is important that you let the relevant organisations know as soon as possible. Most banks and other financial organisations have special arrangements for customers in financial hardship as a result of ill health.

Other sources of help

Do not hesitate to discuss your financial circumstances with your treatment centre social worker or your private insurer. They may be able to assist with advice on deferring payments. Some of your household accounts may also have hardship support programs (like energy providers). 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 as one of its features. If you are not sure, give their helpline a call.

Moneysmart: moneysmart.gov.au

National Debt Helpline: ndh.org.au or phone 1800 007 007

Legal matters

This information applies equally 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 we consider 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 for themselves. 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, make personal, administrative and, if you choose, financial decisions.

An *Enduring Guardian (EG)* is another document where your trusted person can make decisions on your behalf regarding your health matters such as medical treatment, care, and protection, even if this decision overrides your wishes.

Australian Guardianship and Administration council: agac.org.au

Wills

It is very important to have specialist legal advice when preparing your Will. There are many questions and options your legal adviser will discuss with you which may not be immediately apparent. This is particularly important when you have dependent family members and you need to determine who will be responsible for them in the event of your death.

If you die without leaving a valid Will, you leave what is known as 'intestacy'. Although you may feel your affairs are very simple

and your immediate family will receive your assets, this is not necessarily true. Should you die intestate, distribution of your estate will be determined by a formula set down in legislation. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident. Although this is a lengthy document, it is simple to complete as it mainly 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, and you are also required to have a doctor 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
- Australian Guardianship and Administration Council

More information & help

Glossary

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

active disease	Where the disease is still present during treatment, or where it has relapsed.
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.
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.
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, bone marrow 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.
bone marrow aspirate	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 <i>clotting</i> . Platelets help with coagulation.
complete remission	Also called remission . Where there is no evidence of disease after you've had treatment.
complete response	Where there is no sign of disease for a defined period after treatment ends, blood counts are normal, and no signs or symptoms.
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	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 . Immunotherapy is currently approved in Australia for some types of cancers and is also being trialled for other cancers.
leukaemia	Cancer that begins in blood-forming tissue, such as the bone marrow . It causes large numbers of abnormal blood cells to be made and to enter the bloodstream.
leukocytes	Also called white blood cells. These blood cells 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).
lymphocytes	A type of white blood cell that plays a role in the immune system.
measurable residual disease	Where, after treatment, you still have a very small number of leukaemic cells in the bone marrow. They can't be seen under a microscope but can be seen using other tests, like flow cytometry.
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.
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.
progressive disease	In CLL, where there are new enlarged lymph nodes or a newly enlarged spleen or there is an increase by at least half in lymphocyte count or spleen size, or transformation to another condition such as Richter syndrome.
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.
resistant or refractory disease	Where the disease is not responding to treatment.
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 <i>partial</i> (a reduction in some or many symptoms) or <i>complete</i> (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.
spinal tap	Also called lumbar puncture. A procedure to take fluid from the spine in the lower back through a hollow needle, usually as part of diagnosis.
stable disease	Where the leukaemia is not getting worse or growing, but there has been no complete or partial response.
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:	leukaemia.org.au
Australian Cancer Trials:	australiancancertrials.gov.au
Australian New Zealand Clinical Trials Registry:	anzctr.org.au
eviQ Cancer Treatments Online:	eviq.org.au
Australian Red Cross Blood Service:	mytransfusion.com.au
Pharmaceutical Benefits Scheme:	pbs.gov.au
ClinTrial Refer:	clintrial.org.au
Lymphoma Australia:	lymphoma.org.au

Question builder

- Who will be my main contacts? How do I best contact you/ them?
- What can I do to avoid infections?
- Can I have the flu shot and other vaccinations?
- Is it safe to take my supplements 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 via email: info@leukaemia.org.au or phone us on **1800 620 420**.

**Leukaemia
Foundation[®]**

GPO BOX 9954, BRISBANE QLD 4001

1800 620 420

leukaemia.org.au

 The Leukaemia Foundation cares about our environment. Please recycle or dispose of thoughtfully.