



Leukaemia
Foundation

VISION TO CURE
MISSION TO CARE

CHRONIC LYMPHOCYTIC LEUKAEMIA

A guide for patients and families



1800 620 420



leukaemia.org.au

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The Leukaemia Foundation values feedback from people affected by CLL and the healthcare professionals working with them. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact us at **info@leukaemia.org.au**.

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INTRODUCTION

This booklet has been written to help you and your family understand more about chronic lymphocytic leukaemia (also known as CLL).

It is important to acknowledge that for many people CLL may never become a problem and they can continue to lead a normal life despite their diagnosis.

For others, especially where there is evidence of disease progression, CLL may represent a more serious condition. If you, or a loved one, have been diagnosed with CLL you may be feeling anxious or a little overwhelmed. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family.

Whatever point you are at, we hope the information in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms which you may not be familiar with. Their meaning is explained in the booklet and/or in the glossary of terms at the back of the booklet.

In some parts of the booklet we have provided additional information you may wish to read on selected topics. Some of you may require more information than is contained in this booklet, so we have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treating hospital.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your particular circumstances at all times with your treating doctor and team.

We hope you find this booklet useful in providing support and information. We would appreciate any feedback from you so we can continue to help you and your family in the future.

THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life.

It exists only because of the generous and ongoing support of the Australian community.

Each year, the Leukaemia Foundation helps more than 750 families from regional and rural Australia by providing free accommodation in our capital cities so they can access life-saving treatment at major hospitals.

Our transport service helps thousands get to and from medical appointments, driving more than one million kilometres each year to ensure people get the medicines they need to beat their blood cancer.

The Leukaemia Foundation also provides counselling, comprehensive information, education and support programs and financial assistance to help the 60,000 Australians who are currently living with a blood cancer.

The Leukaemia Foundation also funds researchers who are working tirelessly to discover safer and more effective treatments that will save lives and help people lead a better quality of life.

Supporters ensure the Leukaemia Foundation can continue to give those impacted by blood cancer a strong voice, advocating for change and ensuring all Australians who need them have easy access to the very best blood cancer treatments.



Leukaemia Foundation staff with health professional qualifications provide patients and their families with information and support across Australia.

Support Services

The Leukaemia Foundation has a team of highly trained and caring support staff with qualifications and experience in nursing or allied health who work across the country.

We can offer individual support and care to you and your family when it is needed.

Support Services may include:

Information

The Leukaemia Foundation has a range of booklets, DVDs, fact sheets and other resources that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from **leukaemia.org.au**.

Education & Support programs

The Leukaemia Foundation offers you and your family both CLL-specific and general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment and how to support your general health and wellbeing.

Emotional support

A diagnosis of CLL can have a dramatic impact on a person's life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation's support staff can provide you and your family with much needed support during this time.

Blood Buddies

This is a program for people newly diagnosed with CLL to be introduced to a trained 'Buddy' who has been living with CLL for at least two years, to share their experience, their learning, and to provide some support.



Telephone discussion forums

This service enables anyone throughout Australia who has or has been affected by CLL to share their experiences, provide tips, and receive education and support in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation support team who is a trained health professional.

Accommodation

Some people need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation's staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Leukaemia Foundation's fully furnished self-contained units and houses can provide a 'home away from home' for you and your family.

Transport

The Leukaemia Foundation also assists with transporting people to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

We are not alone on the journey with CLL – support is available and real, and there are many ways to connect with others, either by support group meetings, phone support, seminars run by the Leukaemia Foundation, written materials or internet forums.

I ask lots of questions on the Leukaemia Foundation's CLL telephone forums, seeking information I can't get anywhere else. It gives me some power over this disease which makes you feel quite impotent because you can't do anything about it. I want to be able to fight it.

Practical assistance

The urgency and lengthy duration of medical treatment can affect everyday life for you and your family and there may be practical things the Leukaemia Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

Advocacy

The Leukaemia Foundation is a source of support for you as you navigate the health system. While we do not provide treatment recommendations, we can support you while you weigh up your options. We may also provide information on other options such as special drug access programs, and available clinical trials.

Contacting us

The Leukaemia Foundation provides free services and support across Australia. Every person's experience of living with CLL is different. It's not always easy, but you don't have to do it alone.

Please call **1800 620 420** to speak to a support staff member or to find out more about the services the Leukaemia Foundation offers.

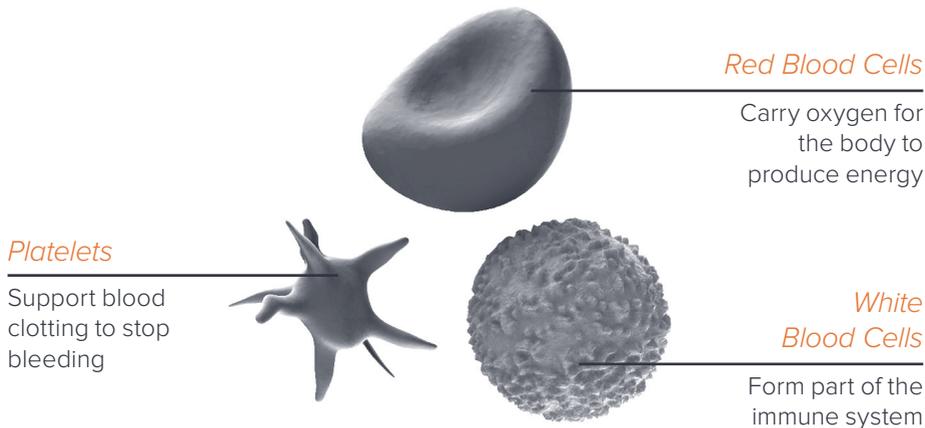
Alternatively, contact us via email by sending a message to **info@leukaemia.org.au** or visit **www.leukaemia.org.au**.

CLL

CLL is the most common type of leukaemia and is a form of blood cancer. Blood cancers occur in cells that originate in the bone marrow and are defined by the uncontrolled growth of faulty cells.

In CLL the majority of these cancerous cells are found in the blood in your circulatory system, but they can also be found in other areas of your body.

To understand CLL and its effects on our body, we first need to understand the cells involved and where they are formed. For this, we need to understand the bone marrow and the cells that are formed there – the blood cells.



Red Blood Cells

Carry oxygen for the body to produce energy

Platelets

Support blood clotting to stop bleeding

White Blood Cells

Form part of the immune system

GETTING TO KNOW YOUR BONE MARROW, STEM CELLS AND BLOOD

Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. Most of your blood cells are made in your bone marrow.

The process by which blood cells are made is called haematopoiesis. There are three main types of blood cells: red cells, white cells and platelets.

As an infant, haematopoiesis takes place at the centre of all bones. In later life, it is limited mainly to the hips, ribs and breast bone (sternum). Some of you may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest).

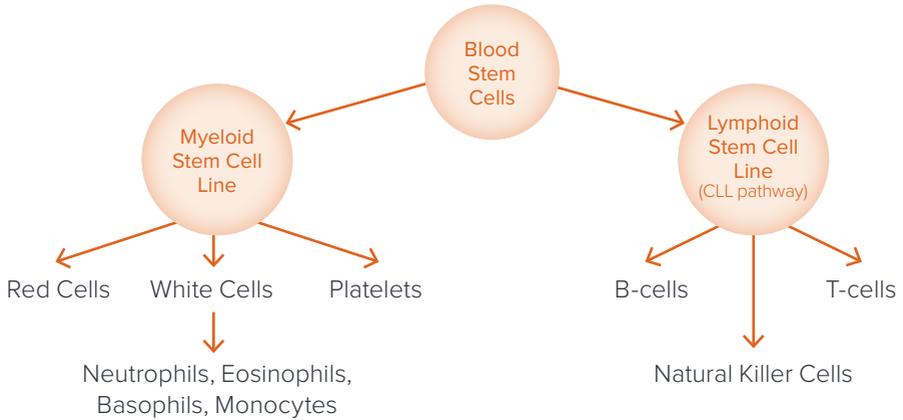
You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the stem cells. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans.

There are two main families of stem cells, which develop into the various types of blood cells.

Myeloid ('my-a-loid') stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.

Lymphoid ('lim-foid') stem cells develop into other types of white cells (lymphocytes) including T-cells, B-cells and Natural Killer Cells.

Blood cell formation:



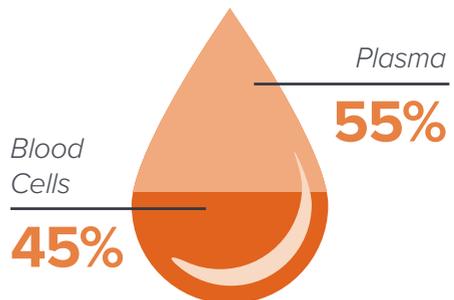
Growth factors and cytokines

All normal blood cells have a limited lifespan in the circulation and need to be replaced on a continual basis. This means that the bone marrow remains very active throughout your life. Natural chemicals circulating in your blood called growth factors (or cytokines) control this process of blood cell formation. Each of the different blood cells is produced from stem cells under the guidance of a different growth factor.

Some of the growth factors can now be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, granulocyte colony-stimulating factor (G-CSF) stimulates the production of certain white cells, including neutrophils, while erythropoietin (EPO) stimulates the production of red cells.

Blood

Blood consists of blood cells and plasma. Plasma is a straw-coloured fluid that blood cells use to travel around your body and also contains many important proteins and chemicals.



Blood cells

Red cells and haemoglobin

Red cells contain haemoglobin (Hb) which gives the blood its red colour and transports oxygen from your lungs to all parts of your body. Your body uses this oxygen to create energy.

Haematocrit

About 99% of all blood cells in circulation are red blood cells. The percentage of the blood that is occupied by red blood cells is called the haematocrit. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

Anaemia

Anaemia is a reduction in the number of red cells or low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you may feel rundown and weak. You may be pale and short of breath or you may tire easily because your body is not getting enough oxygen. In this situation, a red cell transfusion may be given to restore the red blood cell numbers and therefore the haemoglobin to more normal levels.

Normal ranges for adults:

	 Men	 Women
Haemoglobin (Hb)	130 – 170 g/L	120 – 160 g/L
Haematocrit (Hct)	40 – 52%	36 – 46%
White cell count (WBC)	3.7 – 11.0 × 10 ⁹ /L	
Neutrophils (neut)	2.0 – 7.5 × 10 ⁹ /L	
Platelets (Plt)	150 – 400 × 10 ⁹ /L	

White cells

White cells, also known as leukocytes, fight infection. The following is a list of some of the different types of white cells:

Neutrophils: mainly kill bacteria and remove damaged tissue. Neutrophils are often called the first line of defence when infections occur. They are often the first white blood cell at the site of infection and attempt to destroy the foreign pathogen before it becomes a problem to the body.

Eosinophils: mainly kill parasites.

Basophils: mainly work with neutrophils to fight infection.

Monocytes: mainly work with neutrophils and lymphocytes to fight infection; they also act as scavengers to remove dead tissue. These cells are known as monocytes when found in the blood, and called macrophages when they migrate into body tissue to help fight infection.

B-cells: mainly make antibodies which target micro-organisms, particularly bacteria.

T-cells: mainly kill viruses, parasites and cancer cells, and produce cytokines which can recruit other cells to make antibodies which target micro-organisms.

These white cells work together to fight infection and also have unique individual roles in the fight against infection.

Neutropenia

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than $1(1 \times 10^9/L)$, you are at an increased risk of developing more frequent and sometimes severe infections.

Platelets

Platelets are cellular fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding.

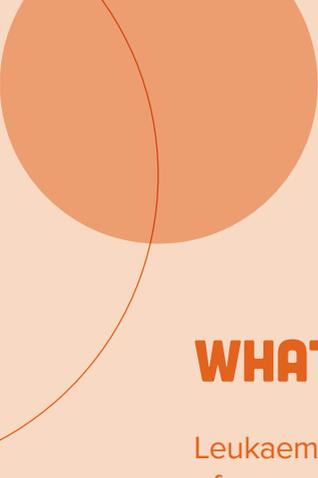
If a blood vessel is damaged (for example by a cut) the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding. They also release chemicals (called clotting factors) that are required for the formation of blood clots.



Thrombocytopenia

Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops too low, you are at an increased risk of bleeding and tend to bruise easily. Each treatment centre will have their own guidelines on the specific platelet count level when interventions may need to be taken. Platelet transfusions are sometimes given to return the platelet count to a safer level.

I have to be mindful with hygiene and I keep away from crowds. I've learnt to avoid touching my mouth, nose and eyes with my hands. I wash my hands frequently to decrease my chances of infection.



WHAT IS LEUKAEMIA?

Leukaemia is the general name given to a group of cancers that develop in the bone marrow. Under normal conditions the bone marrow contains a small number of immature blood cells, sometimes called blast cells. These immature blood cells mature and develop into red cells, white cells and platelets, which are eventually released into the blood stream.

Leukaemia originates in developing blood cells, which have undergone a malignant change. Instead of maturing properly these cells grow and multiply and interfere with normal blood cell production in the bone marrow. Most cases of leukaemia originate in developing white cells. In a small number of cases, leukaemia develops in other blood-forming cells, for example in developing red cells or developing platelets.

What are the different types of leukaemia?

There are several 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 leukaemias

Acute leukaemias develop and progress quickly and therefore need to be treated as soon as they are diagnosed. Acute leukaemias affect very immature blood cells, preventing them from maturing properly.

Chronic leukaemias

In chronic leukaemias there is an accumulation of more mature but abnormal white cells. Chronic leukaemias can occur at all ages but they are rarely seen in children.

Leukaemia can also be either myeloid or lymphoid. The terms myeloid and lymphoid refer to the types of cell lineage in which the leukaemia first started (see diagram on page 12).

Lymphoid leukaemias

When leukaemia starts somewhere in the myeloid cell line, it is called myeloid (myelocytic, myelogenous or granulocytic) leukaemia.

When leukaemia starts somewhere in the lymphoid cell line it is called lymphoblastic, lymphocytic, or lymphatic leukaemia.

Therefore, there are four main types of leukaemia:

1. acute myeloid leukaemia (AML)
2. acute lymphoblastic leukaemia (ALL)
3. chronic myeloid leukaemia (CML)
4. chronic lymphocytic leukaemia (CLL).

Both adults and children can develop leukaemia but certain types are more common in different age groups.

WHAT IS CLL?

Chronic lymphocytic leukaemia (CLL) is a type of slow-growing leukaemia that affects developing B-cells.

B-cells are specialised white blood cells which are an important component of the immune system and they protect our bodies against infection and disease in many ways. Some B-cells differentiate (mature) into plasma cells which produce immunoglobulins (also called antibodies) that help protect our bodies against infection and disease.

In people with CLL, lymphocytes undergo a malignant (cancerous) change and become leukaemic cells. For many people CLL remains stable for many months and years and has little, if any, impact on their lifestyle or general health. Around 30-50% of people diagnosed with CLL never require any treatment for their disease and can survive for many years despite their diagnosis. For others, the leukaemic cells

multiply in an uncontrolled way, live longer than they are supposed to and accumulate in the bone marrow, blood stream, lymph nodes (glands), spleen and other parts of the body.

CLL cells are abnormal and as such they are unable to function properly. Left untreated over time, an excess number of lymphocytes crowd the bone marrow and interfere with normal blood cell production. The bone marrow begins to produce inadequate numbers of red cells, normal white cells and platelets, making some people with CLL more susceptible to anaemia, recurrent infections and to bruising and bleeding easily. Circulating red cells and platelets can also be damaged by abnormal proteins made by the leukaemic cells.

CLL usually develops slowly and progresses slowly, over months and years. Most people have no symptoms of their disease when they are first diagnosed. In these cases, people often require no treatment for a long time (if at all), apart from regular checkups (often called 'watch and wait' or 'active monitoring') with their doctor to carefully monitor their health. Others may need to be treated soon after they are diagnosed.

HOW COMMON IS CLL AND WHO GETS IT?

Each year in Australia around 1400 people are diagnosed with CLL. While CLL is a relatively uncommon type of cancer, it is the most common type of leukaemia diagnosed in Australia and the western world.

The majority of people diagnosed with CLL (almost 80%) are over the age of 60. CLL is rare under the age of 40, with less than 10 children diagnosed with the disease in Australia since 1982 when records started. CLL is more common in men than women.

WHAT CAUSES CLL?

The cause of CLL is unknown and it does not develop as a consequence of someone's activities or their diet. It is not contagious and you cannot 'catch' CLL by being in contact with someone who has it.

There is increasing appreciation that there may be an inherited tendency to develop CLL in some patients. The risk for developing CLL in a first degree relative (i.e. father, mother, brother, sister or child) of a patient with CLL is approximately seven times higher than the population average. However, as the background risk of developing CLL is very low, the vast majority of family members will never develop CLL. At present, screening for CLL simply because of a positive family history is not recommended. It would be recommended to seek further advice if you had several (usually more than three) close family members who had CLL, and/or related blood cancers.

It could be that I'll never need treatment. I could be one of those lucky people and it (CLL) could be dormant forever.



Like other types of leukaemia, CLL is thought to arise from an acquired mutation (or change) in one or more of the special molecules of DNA (called 'genes') which control the growth and development of blood cells. This change (or changes) will result in abnormal growth. This change occurs in stem cells that produce your blood cells. This mutation is maintained when the affected stem cell divides and produces a series of 'clones': that is, a group of identical cells all with the same defect. As such CLL is regarded as a clonal blood stem cell disorder.

Why gene mutations occur in the first place remains unknown but there are likely to be a number of as yet unidentified factors involved. These acquired mutations in genes are gained during a person's lifetime, are not present at birth and are usually not passed on to the next generation.

WHAT ARE THE SYMPTOMS OF CLL?

Many people have no symptoms when they are first diagnosed. In these cases the disease may be diagnosed unexpectedly, for example during a routine blood test or physical examination. Other people may go to see their general practitioner (GP) because they have some troubling symptoms of their disease.

These may include the following:

Symptoms caused by a lack of normal white cells and normal antibodies:

- » frequent or repeated infections.

Symptoms of anaemia due to a lack of normal red cells:

- » persistent tiredness and fatigue
- » weakness
- » shortness of breath with minimal exercise
- » looking pale
- » feeling dizzy or lightheaded
- » chest pain (angina) or palpitations.

**Symptoms caused by
a lack of normal platelets:**

- » bleeding or bruising more easily for no apparent reason
- » frequent or severe nose bleeds or bleeding gums
- » the appearance of red or purple flat pinhead sized spots on the skin, especially on the legs initially. These are due to small superficial capillary bleeds known as petechiae ('pe-tee-chi-a').

**'B' symptoms (symptoms of simply
having CLL)**

- » weight loss, especially unintentional loss of >10% of body weight
- » fevers
- » night sweats
- » fatigue or poor energy.

CLL can also cause a painless swelling of the lymph nodes (glands) in your neck, under your arms or in your groin. This is usually a result of lymphocytes accumulating in these tissues.

The spleen may also be enlarged as it attempts to rid the body of the excess lymphocytes from the circulating blood. Symptoms of an enlarged spleen (splenomegaly) include feelings of discomfort, pain or fullness in the upper left-side of the abdomen. An enlarged spleen may also cause pressure on the stomach causing a feeling of fullness, indigestion and a loss of appetite. In some cases the liver may also be enlarged.

Some of the symptoms described above may also be seen in other illnesses, including viral infections. So, most people with these symptoms don't have leukaemia. However, it is important to see your doctor if you have any unusual symptoms, or symptoms that persist much longer than expected so you can be examined and investigated properly.



HOW IS CLL DIAGNOSED?

CLL is diagnosed by examining samples of your blood in the laboratory.

When you see your doctor about any of the symptoms mentioned, the first thing he or she will probably do is take your full medical history, asking questions about your general health and any illness or surgery you have had in the past, and give you a full physical examination.

The doctor will look and feel for any swelling of the glands in your neck, armpits and groin. Your abdomen and chest will also be examined for any signs of enlarged organs or fluid collection. The doctor will ask you about any other symptoms you might have and take some blood samples to check how well your bone marrow, liver and kidneys are functioning.

Which doctor?

If your blood test results are abnormal and your GP suspects you might have leukaemia, you will be referred to another specialist doctor called a haematologist or an oncologist for further tests and treatment.

A haematologist is a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system.



Full blood count

The first step in diagnosing CLL requires a simple blood test called a full blood count or full blood examination (FBC or FBE). It involves taking a sample of blood from a vein in your arm, and sending it to the laboratory for examination under the microscope. The number of red blood cells, white blood cells and platelets, and their size and shape, is noted as these can all be abnormal in CLL. In CLL, the lymphocyte count is abnormally high, and needs to be at least $5 \times 10^9/L$ for a diagnosis of CLL. Anaemia and thrombocytopenia (a lower than normal platelet count) are common in more advanced disease.

Bone marrow examination

A bone marrow examination (biopsy) is used in some cases to help confirm the diagnosis of CLL. It can also provide useful information about the likely course of the disease and to assess how well it is responding to treatment.

It involves taking a sample of bone marrow, usually from the back of the hip bone (iliac crest) and sending it to the laboratory for examination under the microscope. Bone marrow examinations are usually done if the disease has

progressed and requires treatment. The bone marrow examination may be done in the haematologist's rooms or clinic under local anaesthetic or, in selected cases, under a short general anaesthetic in a day procedure unit.

A mild sedative and a pain-killer are given beforehand and the skin is numbed using a local anaesthetic. This is given as an injection under the skin. The injection takes a minute or two, and you should feel only a mild stinging sensation. After allowing time for the local anaesthetic to work, a long needle is inserted through the skin and outer layer of bone into the bone marrow cavity. A syringe is attached to the end of the needle and a small sample of bone marrow fluid is drawn out – this is called a 'bone marrow aspirate'. A small core of bone marrow is then removed, which will provide more detailed information about the structure of the bone marrow and bone: this is known as a 'bone marrow trephine'.

If you receive a sedative or painkiller prior to your bone marrow tests you might feel a bit drowsy afterwards, so you should bring a family member or

friend who can take you home. A small dressing or plaster over the biopsy site can be removed the next day. There may be some mild bruising or discomfort, which is usually managed effectively with paracetamol. More serious complications such as bleeding or infection are very rare.

Immunophenotyping (*'im-u-no-feen-o-typing'*)

Immunophenotyping, or flow cytometry tests, are commonly used to confirm a suspected diagnosis of CLL. This technology uses special markers called antigens found on the surface of cells. These antigens act like flags identifying the abnormal characteristic of CLL.

Antigens are commonly referred to as 'cluster of differentiation' or CD antigens followed by a number. In CLL certain B-cell antigens like CD19, CD20, CD23 and CD5 and other surface markers are almost always expressed on the leukaemic cells. The presence of these markers is key in diagnosing CLL, and distinguishes it from other diseases.

Cytogenetic (*'cy-to-gen-etic'*) tests

Cytogenetic tests such as chromosomal analysis and fluorescent in situ hybridisation (FISH) tests provide information about the genetic makeup of the leukaemic cells: in other words, the structure and number of chromosomes present. These tests may be used to provide more information about the likely course of your disease and the best way to treat it. Whether you receive cytogenetic testing or not depends on your individual circumstance. Usually these tests are performed when CLL is progressing and treatment is being considered.

Chromosomes are the structures that carry genes. Genes are collections of DNA, our body's blueprint for life. Certain cytogenetic changes, such as missing, extra or abnormal chromosomes help to confirm the type of CLL you have, the likely course of your disease and the best way to treat it. These chromosomal changes are only found in the leukaemic cells. These changes are usually acquired over time and are not passed down from parent to child.

Immunoglobulin (antibody) levels

Blood samples may also be taken to measure the levels of antibodies in your blood. People with low levels of normal antibodies may be more susceptible to repeated infections and some may benefit from monthly intravenous immunoglobulin (antibody) treatment to reduce the frequency of infections.

Blood tests may be repeated at regular intervals to monitor your disease and look for the presence of any additional abnormalities that can be associated with CLL. When therapy for CLL commences, patients are monitored closely for treatment-related complications and to determine how their disease is responding to treatment.

Lymph node biopsy

Rarely, a lymph node biopsy is necessary to help confirm the diagnosis of CLL. This usually involves a small surgical procedure where an enlarged lymph node is removed. You will need a general anaesthetic for this and you will have a few stitches afterwards.

Once the lymph node is removed it is examined in the laboratory by a pathologist. A pathologist is a doctor who is specially trained to examine tissue specimens and cells to help diagnose diseases such as cancer.

Other tests

Once a diagnosis of CLL is made, further tests may be done to find out the stage, or extent of the disease in your body and the effect it is having on other organs. They include a combination of blood tests and imaging tests. These tests can also provide important information about your general health and how well your kidneys, liver and other vital organs are functioning. The results may be important in selecting the best treatment for you. They can also be used as a baseline and compared with later results to assess how well you are going.

Other blood tests

- » Kidney function tests
- » Liver function tests
- » Coagulation tests (to see if your blood is clotting properly)
- » Coombs test (direct antiglobulin test) to exclude autoimmune haemolytic anaemia, a rare complication of CLL where the body's own immune system can attack and destroy its own red blood cells.

Imaging tests

- » Chest x-ray (to detect a chest infection or any other abnormalities).
- » A CT (computerised axial tomography) scan may be ordered to see if your spleen or liver is enlarged. This is discussed further on the next page.

Computerised axial tomography (CT scan or CAT scan)

CT scans provide computer analysed, three dimensional (3D) images of cross sections of your body. This technology is able to detect tiny changes in tissue density which might indicate the presence of an infection or a tumour.

The CT scan does not hurt and it usually takes less than an hour to complete. While the scan is being done you have to lie flat and still on a cushioned table that moves slowly through the CT machine. The machine itself looks like a giant ring surrounding the table.

Sometimes a special dye is used to enhance the quality of the pictures taken. The dye may be swallowed or injected into a vein in your hand or arm before the scan. The CT scanner picks up the dye as it moves through the body, highlighting areas to be examined more closely.

Waiting around for tests can be both stressful and boring. Remember to ask beforehand how long the test will take and what to expect afterwards. You might like to take a book, some music, or a friend for company and support.

Testing for SLL and CLL

Small lymphocytic lymphoma (SLL)

A small proportion of people with CLL have the disease in their lymphatic system and/or bone marrow, and not in the blood. These patients are traditionally classified as having a form of non-Hodgkin lymphoma called small lymphocytic lymphoma (SLL). We now understand that this is actually the same disease as CLL, with the only difference being that the cells in SLL do not circulate in the blood. SLL is treated the same way as CLL, and behaves in an almost identical manner. A lymph node biopsy is usually required to confirm a SLL diagnosis.

'Pre-CLL' (Monoclonal B-lymphocytosis or MBL)

With the increasing use of advanced testing that can pick up a very small number of abnormal cells in the blood, we now know that approximately 5-7% of older people (over 60 years) will have a small population of CLL cells in their blood. These people are diagnosed incidentally and have no symptoms of leukaemia. Very few (approximately 1% per year) will develop real CLL. This state is known as 'monoclonal B-lymphocytosis' (MBL) and it is not regarded as cancer, although there is a risk of developing CLL in the long-term. People with this condition require periodic medical follow-up only.

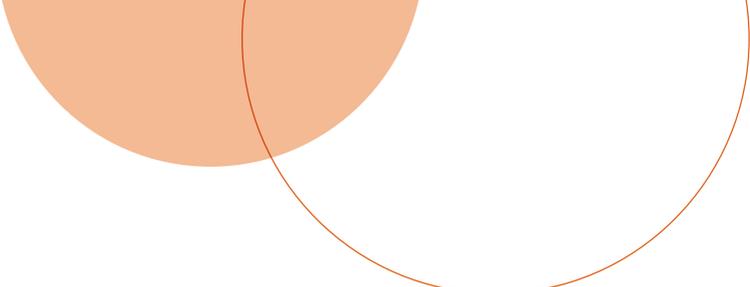
STAGING AND PROGNOSTIC FACTORS

Your doctor may want to document the stage of your disease (the extent that the disease has affected your body) and other factors that provide reliable information about the likely course of your disease (your prognosis), and whether or not treatment should begin.

Traditionally the Rai and Binet staging systems have been used to estimate prognosis in CLL. Using these systems, patients are assigned to one of three major subgroups (good, intermediate or poor prognosis) depending on the number of lymphoid areas affected by the disease (lymph nodes, spleen or liver), and the white cell (particularly lymphocytes), red cell and platelet counts in the circulating blood. Stage A is considered early stage disease and in nearly all cases people haven't got any symptoms and don't require treatment. People with stage B disease may occasionally require therapy, whereas stage C reflects more advanced disease which usually requires treatment.

Stage	Findings
Binet stage A <i>(equivalent to Rai stage 0)</i>	< 3 lymphoid areas involved High lymphocyte count
Binet stage B <i>(equivalent to Rai stage I to II)</i>	3 or more lymphoid areas involved High lymphocyte count
Binet stage C <i>(equivalent to Rai stage III to IV)</i>	Bone marrow failure: low red cell count (anaemia) +/- low platelet count (thrombocytopenia)

Learn about your disease and become a partner with your medical team, rather than a patient.



A prognosis is an estimate of the likely course of a disease. It provides some guide regarding the likelihood of your disease progressing, and the chances of controlling it for a given time. CLL is generally regarded as an incurable disease, but in many people the disease remains stable for long periods of time and may never require treatment. In some cases it progresses and when necessary it can often be treated effectively. The course of CLL can vary considerably between individuals.

As mentioned earlier, around 30-50% of people diagnosed with CLL never require any treatment for their disease and can survive for many years despite their diagnosis. In 25-30% of cases, CLL tends to progress gradually over time, eventually requiring treatment. In the remainder of cases CLL presents as an aggressive disease, and needs to be treated soon after it is diagnosed.

Over recent years, there has been significant progress in identifying factors (other than disease stage) that provide reliable information about an individual patient's prognosis and how quickly their disease is likely to progress.

These include certain cytogenetic changes in affected lymphocytes and immunoglobulin (antibody) genes (IgVH genes) which may be associated with a less favourable prognosis than others.

These factors (cytogenetic abnormalities or immunoglobulin gene rearrangements) are increasingly being used to help make therapeutic choices, particularly in younger people with CLL. We know that patients with certain deletions or mutations of a particular chromosome may not respond well to certain types of chemotherapy and will have their treatment regimen modified accordingly.

The rate at which the leukaemic cells are multiplying is also important. A fast (high) lymphocyte doubling time (< six months) where the amount of lymphocytes double in number may be associated with a poorer prognosis. This and other prognostic information may be used to decide when to start treatment, especially in younger patients and in patients with early stage disease.

Your doctor is the best person to give you an accurate prognosis regarding your disease, as he or she has the most information to make this assessment.

TREATING CLL

The treatment chosen for your disease will depend on several factors including the stage of your disease, whether or not you have symptoms of your disease, how quickly your disease is progressing, your age and your general health. Occasionally, treatment decisions may be influenced by other prognostic factors, which may put some people at a higher risk of disease progression than others, regardless of the stage of their disease. The principle aims of treatment are two-fold: to bring about a long-lasting remission and to prevent and reduce any symptoms of the disease.

Information gathered from hundreds of other people around the world who have had the same disease helps to guide your doctor in recommending the best treatment for you.

Remember that no two people are the same. In helping you to make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Standard therapy

Standard therapy refers to a type of treatment which is commonly used in particular types and stages of disease. It has been tried and tested (in clinical trials) and has proven to be safe and effective in a given situation.

Clinical trials

These trials (also called research studies) test new treatments or 'old' treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side-effects. Remember, any prescription medication you have ever taken is only available because people were prepared to test it on a clinical trial at some time. Clinical trials can give people access to new therapies not yet funded by governments.

If you are considering taking part in a clinical trial make sure you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor who can guide you in making the best decision for you.

Informed consent

Giving an informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you are happy that you have adequate information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you or some aspect of your care (data collection).

If you have any doubts or questions regarding any proposed procedure or treatment please do not hesitate to talk to the doctor or nurse again.

Before giving your informed consent, you may ask for a second opinion if you still feel uncertain.

Early stage CLL

Many people with CLL, particularly in the early stages of disease (Rai stage 0 and I, Binet stage A), have no symptoms of their disease and don't require any treatment. Instead the doctor may recommend an 'active monitoring' (sometimes called 'watch and wait') strategy involving regular check-ups and blood counts to carefully observe your health. This strategy may also be appropriate in more advanced stages of CLL, if your blood counts remain stable.

Treatment is usually only given when you start to have troubling symptoms of CLL, or when there are signs that your disease is starting to progress. Signs that your disease may be progressing include a significant increase in the number of lymphocytes in your blood (short lymphocyte doubling time), or rapidly-growing lymph nodes.

Advanced stage CLL

There is a general agreement that most people with advanced stage CLL (Rai stage III and IV, Binet stage B and C) need to be treated.

Treatment for CLL may involve the use of:

- » chemotherapy
- » monoclonal antibody therapy
- » targeted therapies
- » blood stem cell transplantation
- » experimental treatments with drugs not yet available for general use e.g. clinical trials or compassionate access programs.

Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells. Commonly, oral chemotherapy (such as chlorambucil or cyclophosphamide) is prescribed. For patients who may benefit from more intensive treatment, a combination of two or more chemotherapy drugs may be used, for example fludarabine and cyclophosphamide. These may also be given with monoclonal antibodies.

These combinations are often given through an injection into the vein. Your doctor will discuss which type of chemotherapy is best for you.

Each drug, in a combination of drugs, targets the cancer using different mechanisms, and also has different side-effects. Therefore, a combination may be more effective than a single drug in controlling your disease and the side-effects are kept to a minimum.

The names of the different regimens used are commonly derived from the first letters of each of the drugs given. Some examples of combinations of drugs used to treat CLL are listed below.

FC	Fludarabine and cyclophosphamide
FCR	Fludarabine, cyclophosphamide and rituximab (a monoclonal antibody)

Combinations of drugs are usually given in several cycles (or courses) with a rest period in between each cycle. This is to allow the body to recover from the side-effects of the drugs.

How is chemotherapy given?

There are many ways of giving chemotherapy. Some drugs are given in tablet form (orally). Others are given through a vein (intravenously or IV), usually in your arm or hand.

In most cases you don't need to be admitted to hospital for chemotherapy as it is usually given in the hospital's day treatment centre. Sometimes however, depending on the type of chemotherapy being given and your general health, you may need to be admitted to the ward for a short while.

Side-effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as cancer cells. It also causes damage to fast-growing normal cells, including hair cells, and cells in your mouth, gut and bone marrow. The side-effects of chemotherapy occur as a result of this damage.

Chemotherapy in tablet form is tolerated well by most people and side-effects tend to be few and mild. Intravenous chemotherapy can have more side-effects. The type and severity of these side-effects will vary from one person to another, depending on the type of chemotherapy used and how an individual responds to it.

There is no doubt that side-effects can be very unpleasant at times but it's good to remember that most of them are temporary and reversible. It is important that you report any side-effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

Effects on the bone marrow

Chemotherapy affects the bone marrow's ability to produce adequate numbers of blood cells. As a result, your blood count (the number of white cells, platelets and red cells circulating in your blood) will generally fall following treatment. The length of time it takes for your blood counts to fall and recover mainly depends on the type of chemotherapy given.

White cells

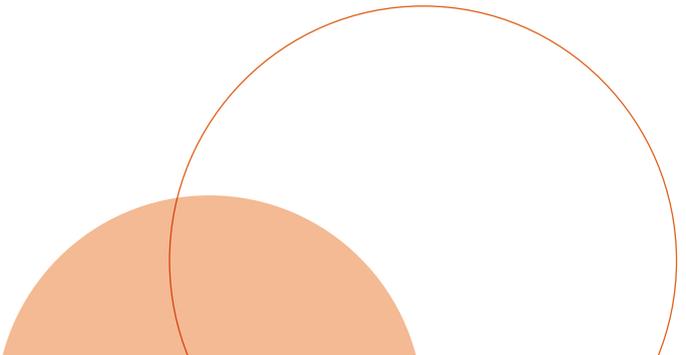
The point at which your white cell count is at its lowest is called the nadir, which usually occurs seven to ten days after chemotherapy. During this time you will be at a higher risk of developing an infection. At this stage you may be

neutropenic, which means that your neutrophil count is low. Neutrophils are important white cells that help us to fight infection. A blood test may be arranged for you during this time to check your blood count.

While your white blood cell count is low you should take sensible precautions to help prevent infection. These include avoiding crowds (for example shopping centres and movie theatres), avoiding close contact with people with contagious infections (for example colds, flu, chicken pox) and only eating food which has been properly prepared and cooked (avoid reheated food, soft cheeses and salad bars).

Your treatment centre may have its own special dietary guidelines and may recommend a specific 'neutropenic diet'.

Sometimes your doctor may decide to use a drug like G-CSF to help the recovery of your neutrophil count. This drug works by stimulating the bone marrow to increase the production





of neutrophils. G-CSF is given as an injection under the skin (subcutaneous). This is quite a simple procedure and the nurses can usually teach you or a family member (or friend) to do this at home.

Your doctor and nurse will advise you on how to reduce your risk of infection while your white cell count is low.

Platelets

Your platelet count may also be affected by your disease and by the chemotherapy you are receiving and you may become thrombocytopenic (a reduction in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as chop bones or potato chips as these can cut your gums. Using a soft toothbrush also helps to protect your gums, and an electric razor should be used instead of a razor blade. If your platelet count is very low, your doctor may prescribe a platelet transfusion to reduce the risk of bleeding until the platelet count recovers.

If you do develop an infection you may experience a fever, which may or may not be accompanied by an episode of shivering (a rigor) where you shake uncontrollably. Infections while you are neutropenic may be very serious and

need to be treated with antibiotics as soon as possible.

If you think you have an infection while receiving chemotherapy, you must notify your doctor immediately. If your doctor is not available (e.g. after hours or on a weekend), you must go to the nearest Emergency Department immediately.

Many medications provided for other symptoms or diseases may affect the blood's ability to clot properly and may need to be ceased while you are receiving chemotherapy. Medications in this category include non-steroidal anti-inflammatory drugs (e.g. aspirin, ibuprofen) and anticoagulants (e.g. warfarin, apixaban, rivaroxaban). Your haematologist will make recommendations on what medications need to be ceased during chemotherapy in consultation with your GP or other healthcare practitioners. If you are not sure if the drug is safe, please check with your doctor, nurse or pharmacist. A low platelet count may also result from idiopathic thrombocytopenia purpura (ITP), a rare complication of CLL where the immune system attacks and destroys the body's own platelets. Specific treatment may be required for this; your doctor will let you know if they are concerned.

Red cells

If your red blood cell count and haemoglobin level drop you will probably become anaemic, and you may feel more tired and lethargic than usual. If your haemoglobin level is very low, your doctor may prescribe a red cell (blood) transfusion.

Fatigue

Most people experience some degree of tiredness in the days and weeks following chemotherapy for CLL. Getting plenty of rest and doing a little light exercise each day may help you feel better during this time. Getting out into the fresh air and doing gentle exercise is important for your general wellbeing and it may help to reduce your fatigue. It is important to listen to your body and rest when you are tired. Fatigue is also a common side-effect of other CLL treatments and a symptom of CLL itself.

Other side-effects

Other possible side-effects of chemotherapy less commonly seen in the treatment of CLL include:

- » nausea and vomiting
- » changes in taste and smell
- » mucositis (sore mouth)
- » diarrhoea or constipation
- » hair loss is exceedingly rare with most forms of CLL treatment.

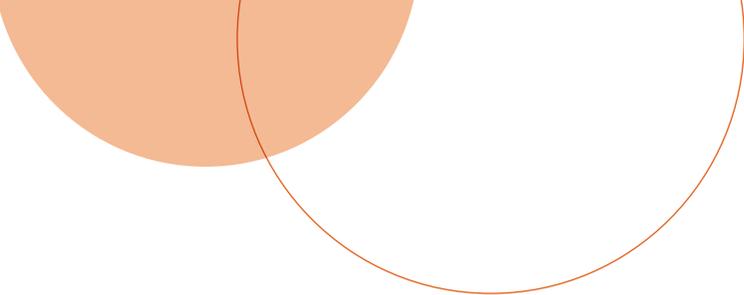
Steroids (corticosteroids)

Corticosteroids are hormones that are produced naturally by the body. They can also be made in the laboratory.

Corticosteroids are used to treat autoimmune haemolytic anaemia as well as ITP, both complications of CLL where abnormal proteins (antibodies) destroy healthy cells in the bloodstream and spleen. In autoimmune haemolytic anaemia there is a drop in the number of red cells in the blood and symptoms of anaemia may develop such as breathlessness, paleness and tiredness, and possibly a yellowing of the skin known as jaundice. In ITP the platelets are affected and if the platelet count falls to a very low level you may notice increased bruising or bleeding. If you develop any of these symptoms it is important for you contact your doctor as soon as possible so you can be treated properly.

Side-effects of corticosteroids

The types of side-effects seen with corticosteroids depend largely on how long they are used for and the dose given. If you are using them for a short time you may notice that your appetite increases or you may feel more restless than usual. Some people find it more difficult to get to sleep at night and sleeping tablets or other natural therapies are sometimes recommended. It may also



be helpful if the corticosteroids are taken early in the morning, so that the effects wear off by the time you go to bed.

Corticosteroids can cause a rise in the blood sugar. Diabetics may find they need more of their diabetes medication while they are taking these drugs and some people who are not normally diabetic may require treatment to keep their blood sugar at acceptable levels. It is important to keep a check on the blood sugar and keep a diary of the levels and the amount of diabetic medication being taken. Diabetics will already know how to do this and can seek additional assistance from their GP or, if appropriate, their endocrinologist. People whose blood sugar only goes up when they are on corticosteroids will be given information on diet and taught how to measure their blood sugar and adjust their medication.

Many of the side-effects of corticosteroids are temporary and should pass once you finish taking them.

Corticosteroids can impact your mental wellbeing. Feelings may be heightened and some people who have had a history of mental illness may have a recurrence of this.

If you have a history of mental illness, it is very important to share this with your doctor before taking corticosteroid treatment.

Long-term use, uncommon in CLL, may cause some other effects such as fluid retention and an increased susceptibility to infections. Aching joints such as the knees and hips have also been reported. Remember to tell your doctor and nurses about any side-effects you are having as they can usually suggest ways to help you.

Monoclonal antibody therapy

Monoclonal antibodies are antibodies produced in a laboratory that act against specific infectious agents, toxic inflammatory substances or cancer cells. More recently improved results have been achieved by combining chemotherapy with a monoclonal antibody like obinutuzumab, ofatumumab or rituximab.

Monoclonal antibodies work by binding to the B-cell antigens (e.g. CD20) found on the surface of the leukaemic cells. These help the person's own immune system to recognise these cells as foreign (or faulty) and kill them. Monoclonal antibodies are given as intravenous infusions, usually in the outpatient's department of the hospital.

Side-effects are common with the first dose but can generally be easily managed. They may include fever, chills and mild skin reactions. This therapy is usually given in combination with chemotherapy, or very occasionally with corticosteroids. There is an increased risk of infection among patients being treated with monoclonal antibodies.

Other targeted therapies

Promising new and experimental oral medications are being developed and are becoming available for use in Australia. Drugs used in these therapies target specific substances on the cancer cell and inhibit proliferation of B-cells (the blood cells affected in CLL). The Therapeutic Goods Administration (TGA) has approved the following drugs for use in Australia:

- » Ibrutinib
- » Idelalisib
- » Venetoclax.

These drugs are taken orally every day and can be used to treat adults with relapsed or refractory CLL who have received at least one prior therapy, generally intravenous chemotherapy. Sometimes doses need to be altered due to side-effects, so always talk to your treating specialist if you are experiencing any kind of side-effect.

It is important that you take your medications as directed. Adhering to your medication regimen is important in successfully treating your blood cancer and taking a break from your medication can be harmful. Let your treating specialist know if you have stopped taking your medication or you are taking it differently to how it is prescribed. Some of the medications you take for other symptoms or diseases may interact with targeted therapies and it is important that your treating haematologist is fully aware of all the prescribed and over-the-counter medications you are taking. Access to these new therapies may be restricted during this time.

If you are taking medications it is important to check with your pharmacist about interactions with other medications and foods, for example ibrutinib interacts with Seville oranges and grapefruit.

Remember that no two people are the same. In helping to make the best treatment decision about any side-effects you may experience, your doctor will consider the specific details of your situation. Do not be alarmed by this list of possible side-effects, as you may not experience any of them.

MANAGING SIDE-EFFECTS OF TREATMENTS

Potential side-effects	Potential remedies
Diarrhoea	<p>Avoid sorbitol, mannitol, maltitol (common ingredients in sugar free foods)</p> <p>Psyllium seed - which increases fibre</p> <p>Anti-diarrhoeal medications (e.g. loperamide) after discussion with your doctor</p> <p>Drink plenty of fluids</p>
Fatigue	<p>Check for anaemia</p> <p>Moderate regular exercise, yoga, meditation</p> <p>Take a daily nap if you need it</p> <p>Reduce stress</p>
Nausea and vomiting	<p>Anti-nausea drugs will usually be prescribed by your doctor to prevent nausea</p> <p>Record what you ate each time you felt sick, as some foods may cause an upset stomach more than others.</p>
Constipation	<p>Increase fruits and vegetables in diet</p> <p>Drink plenty of fluids, not alcohol</p> <p>Stool softeners/laxatives may be required</p> <p>Increase fibre intake</p> <p>20-30 min gentle exercise per day</p>
Bleeding/bruising	<p>Notify doctor/dentist if you need any operations or procedures</p> <p>Report irregular bleeding/bruising to your doctor</p>

Allogeneic stem cell transplantation (stem cell transplant or bone marrow transplant)

For a very small number of people with CLL a stem cell transplant may be done. Your age, fitness level and CLL prognostic factor would all be taken into consideration in determining if a transplant is the best option for you.

This procedure replaces the non-functioning bone marrow of the person with CLL with that of one from a healthy person, usually a brother or sister, although sometimes an unrelated donor may be used. In order to determine if a suitable donor is available, blood samples are taken from the patient and potential donors for compatibility testing in a procedure known as tissue typing. Unfortunately, suitable donors cannot be found for all patients. A highly matched donor decreases the risk of complications, but transplants with lower matches can still be performed.

The introduction of a new bone marrow will rebuild your body's blood and immune system. This can often induce a potential immune attack against the CLL cells, and may be curative. However, the risk is that the new immune system will recognise normal organs in the body as foreign and

attack them, causing Graft-versus-host disease which can be life-threatening or disabling. This is the reason why allogeneic stem cell transplantation is only considered in young patients with very aggressive disease. After allogeneic stem cell transplant, there is an increased risk of severe infection for many months.

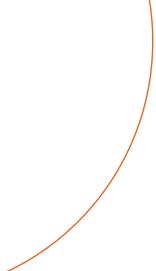
A transplant is usually only offered if your doctor feels it will be of most benefit to you.

Treatment for relapsed and resistant CLL

Finding out your CLL has come back (relapsed) or is resistant to standard treatment (refractory) can be devastating. It is important to remember there may still be several options for treating the disease and getting it back under control. These include corticosteroids, more chemotherapy, monoclonal antibody therapy, and in selected cases a stem cell transplant.

Promising, new and experimental treatments are being developed for CLL all the time. Some of these treatments are currently being used in clinical trials in Australia and other countries. Your doctor will discuss with you all of the treatment options suitable for you.

Clinical trials are an essential part of modern day medicine. Mostly these



drugs have been extensively evaluated for safety and trials set out to find exactly how effective the new agents are and which patients would most benefit from their use. Trials are strictly governed and patient care is paramount. You may like to consider participating in a trial if your haematologist suggests one to you.

Every drug you have ever taken has only been available to you because others have agreed to participate in clinical trials.

Palliative care

If a decision is made not to continue with anti-cancer treatments there are still many things that can be done to help you to stay as healthy and comfortable as possible. Palliative care aims to relieve any symptoms or pain you might be experiencing as a result of your disease or its treatment, rather than trying to cure or control it. You may still receive chemotherapy to relieve your symptoms even though you are in the care of the palliative care team.

SUPPORTIVE CARE

Supportive care plays an important role in the treatment of many people with CLL. This involves making every effort to improve your quality of life by relieving any symptoms you might have and by preventing and treating any complications that arise from your disease or treatment.

Blood transfusions, antibiotics and, in some cases, the use of growth factors which promote the production of blood cells in your bone marrow, are all important elements of supportive care.

Blood and platelet transfusions

If symptoms of anaemia are interfering with your normal daily activities, your doctor may recommend that you have a blood transfusion. Platelet transfusions are sometimes given to prevent or treat bleeding if your platelet count is very low.

You do not need to be admitted to hospital for a red blood cell or platelet transfusion and they are usually given in the outpatient department. Transfusions these days are considered safe and

they don't usually cause any serious complications. Nevertheless, you will be carefully monitored throughout the transfusion. You will need to call the nursing staff if you are feeling hot, cold and shivery or in any way unwell, as this might indicate that you are having a reaction to the transfusion. Steps can be taken to minimise these effects and ensure that they don't happen again.

Infections

Infections are a common complication of CLL and its treatment. Infections may be more common for several reasons, including lower levels of normally protective antibodies (hypogammaglobulinaemia) and inadequate numbers of normally functioning white cells circulating in the bloodstream. Infections can occur anywhere in the body. Common sites include the upper and lower respiratory tract (snius or chest infections), urinary tract (bladder infections) and skin. You may be prescribed preventive (prophylactic) antibiotics especially during and after particular types of treatment.

Some people are given monthly intravenous infusions of immunoglobulin to help fight infection.

Don't hesitate to contact your doctor or

hospital if you develop any of the following signs of infection so that you can be treated appropriately, with antibiotics and other drugs if necessary:

- » a temperature of 38°C and/or an episode of shivering (where you shake uncontrollably)
- » coughing or shortness of breath
- » a sore throat and/or a head cold
- » passing urine frequently or a stinging pain when passing urine
- » if you are feeling generally unwell.

You also need to be seen by a doctor if you:

- » cut or otherwise injure yourself severely
- » develop excessive bleeding (for example blood in your urine, stools, and/or sputum, bleeding gums or a persistent nose bleed) or start bruising easily
- » have any surgery planned by another medical practitioner, as advice may be required from your haematologist as to the best supportive treatment with red cells, platelets and antibiotics, to ensure your surgery is completed successfully without problems due to your disease.

Growth factors

As mentioned earlier, growth factors are natural chemicals in your blood that stimulate the bone marrow to produce different types of blood cells. Some of them can be made in the laboratory and used to help manage your CLL.

Granulocyte-colony stimulating factor (G-CSF) is an example of a growth factor which may be given to stimulate the bone marrow to produce more white cells, particularly neutrophils. These white cells help fight bacterial and fungal infections.

Growth factors are given as an injection under the skin (subcutaneous). They don't usually cause any major side-effects but some people experience fevers, chills, headaches and some bone pain. Your doctor may recommend you take paracetamol to relieve any discomfort you may be feeling.

Skin care and sun protection

People with CLL are at increased risk of developing skin cancer. It is important that you take care of your skin from the first day of CLL diagnosis with basic measures such as applying sun cream to exposed skin areas, and wearing long-sleeve

clothes and a hat if you are heading outdoors. This is especially important if you are having chemotherapy and radiotherapy. Your doctor may refer you to a skin specialist (dermatologist) for regular check-ups.

Nutrition

A healthy, varied and nutritious diet is important to help your body cope with your disease and treatment*. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietitian who can advise you on planning a balanced and nutritious diet.

If you are thinking about using herbs or vitamins it is very important to talk this over with your doctor first. Some of these substances can interfere with the effectiveness of chemotherapy or other treatment you are having.

* *There is a separate Leukaemia Foundation booklet called 'Eating Well'.*

Exercise

Blood Cancer Related Fatigue (BCRF) is tiredness or exhaustion that is directly related to blood cancer or blood cancer

treatment. Fatigue is the most common side-effect of all cancer, affecting 70 – 90% of people. It is not just a physical sensation, it can affect concentration levels and your ability to finish or even start complex tasks, which leads to frustration and distress.

‘Moderate’ activity and exercise has proven to be effective in easing BCRF and has many positive benefits for emotional and psychological wellbeing. Doing too much too soon can negatively impact energy levels, so it is important to seek advice from a health professional before undertaking exercise activities after your diagnosis.

Vaccination

Vaccinations are important to protect against infection. Vaccination against influenza and pneumococcal infection, as per Department of Health guidelines, should be considered in all patients with CLL.

Live vaccines (e.g. Zostavax to protect against shingles) are NOT recommended in patients with CLL.

Please discuss your vaccination schedule with your GP.

Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. Many people find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture and relaxation.

Complementary therapies should ‘complement’ or assist with recommended medical treatment for CLL. They should not be used instead of or as an alternative to medical treatment. It is important to realise that no complementary or alternative treatment alone has proven to be effective against CLL, and complementary medicines do not have to pass the same rigorous testing as prescribed medications to prove their effectiveness in treating disease or symptoms. Some complementary therapies may interfere with the way your body handles chemotherapy drugs, potentially making them less effective or more toxic. Please tell your doctor if you are on complementary therapies, including herbs, special diets and supplements.

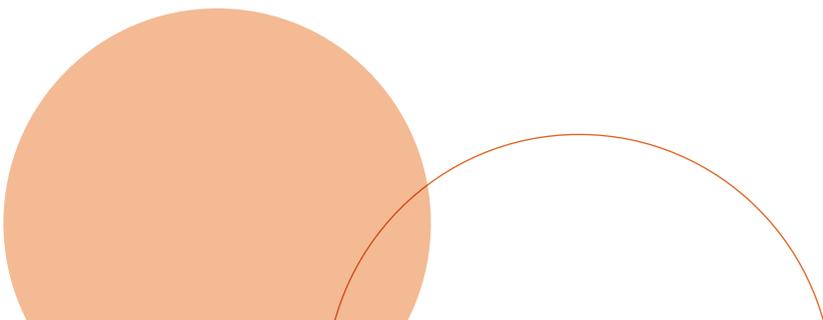
MAKING TREATMENT DECISIONS

Many people feel overwhelmed when they are diagnosed with CLL. In addition to this, waiting for test results and then having to make decisions about proceeding with the recommended treatment can be very stressful. Some people do not feel they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or that they are being rushed into making a decision. It is important you feel you have enough information about your illness and all of the treatment options available, so you can make your own decisions about which treatment to have.

Sometimes it is hard to remember everything the doctor has said. It helps to bring a family member or a friend along who can write down the answers to your questions, prompt you to ask others, be an extra set of ears or simply be there to support you.

Before going to see your doctor make a list of the questions you want to ask. It is handy to keep a notebook or some paper and a pen handy as many questions are thought of in the early hours of the morning.

Your treating doctor will spend time discussing with you and your family what he or she feels is the best option for you. Feel free to ask as many questions as you need to at any stage. You are involved in making important decisions regarding your wellbeing. You should feel that you have enough information to do this and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this is necessary.



BODY IMAGE

For some people, particularly for those with more advanced disease, it is likely that the diagnosis and treatment of CLL will have some impact on how they feel about themselves as a man or a woman and as a 'sexual being'. Hair loss, skin changes, and fatigue can all interfere with feeling attractive. Look Good...Feel Better is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments.

You might like to visit their website at lgfb.org.au or call them on **1800 650 960**.



INFORMATION AND SUPPORT

People cope with a diagnosis of CLL in different ways and there is no right or wrong or standard reaction. For some people the diagnosis can trigger any number of emotional responses ranging from denial to devastation. It is not uncommon to feel angry, helpless and confused. Naturally people fear for their own lives or that of a loved one. On the other hand, people who don't currently require treatment may wonder if they are sick at all.

It is worth remembering that information can often help to take away the fear of the unknown. It is best for patients and families to speak directly to their doctor regarding any questions they might have about their disease or treatment. It can also be helpful to talk to other health professionals including social workers or nurses who have been specially educated to take care of people with haematological diseases. Some people find it useful to talk with other patients and family members who understand the complexity of feelings and the kinds of issues that come up for people living with an illness of this nature.

There may be a CLL support group near you. You may wish to contact the Leukaemia Foundation for more information.

If you have a psychological or psychiatric condition please inform your doctor and don't hesitate to request additional support from a mental health professional.

Many people are concerned about the social and financial impact of the diagnosis and treatment on their families. Normal family routines are often disrupted and other members of the family may suddenly have to fulfil roles they are not familiar with, for example cooking, cleaning, doing the banking and taking care of children.

There is a variety of programs designed to help ease the emotional and financial strain created by cancer. The Leukaemia Foundation is here to provide you and your family with information and support to help you cope during this time. Contact details for the Leukaemia Foundation are provided on the back of this booklet.

USEFUL INTERNET ADDRESSES

Leukaemia Foundation

www.leukaemia.org.au

American Cancer Society

www.cancer.org

Bloodwise (UK)

www.bloodwise.org.uk

Cancer Council of Australia

www.cancer.org.au

Cancer Clinical Trials in Australia

www.australiancancertrials.gov.au

CLL Canada

www.clcanada.ca

CLL Support Association (UK)

www.clsupport.org.uk

CLL Global Research Foundation

www.clglobal.org

CLL Forum (discussion group for those with CLL)

www.clforum.com

Health Unlocked

www.healthunlocked.com

Leukemia & Lymphoma Society of America

www.lls.org

Look Good...Feel Better program

www.lgfb.org.au

National Cancer Institute (USA)

www.cancer.gov/cancerinfo

Patient Power

www.patientpower.info/chronic-lymphocytic-leukemia

GLOSSARY OF TERMS

Anaemia

A reduction in the haemoglobin level in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

Antiemetic

A drug which prevents or reduces feelings of sickness.

Antigen

A substance, usually on the surface of a foreign body such as a virus or bacteria that stimulates the cells of the body's immune system to react against it by producing antibodies.

Antibody

Naturally-produced substance in the blood, made by white blood cells called B-lymphocytes or B-cells. Antibodies target antigens on other substances such as bacteria, viruses and some cancer cells and cause their destruction.

Blood count

A routine blood test that measures the number and type of cells circulating in the blood. Also called a full blood count (FBC).

B-cell

A type of white (lymphocyte) cell normally involved in the production of antibodies to combat infection.

Bone marrow

The tissue found at the centre of many flat or big bones of the body. Active or red bone marrow contains stem cells from which all blood cells are made and in adults this is found mainly in the bones making up the axial skeleton – hips, ribs, spine, skull and breastbone (sternum). The other bones contain inactive or (yellow) fatty marrow, which, as its name suggests, consists mostly of fat cells.

Cancer

A malignant disease characterised by uncontrolled growth, division, accumulation and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer, in which case they are referred to as non-malignant or benign tumours.

Cannula

A plastic tube which can be inserted into a vein to allow fluid to enter the bloodstream.

Central venous access device

A line or tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needles.

Chemotherapy

Single drugs or combinations of drugs which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some common side-effects including hair loss and a sore mouth (mucositis). Nausea and vomiting are also common side-effects, but nowadays largely preventable with modern anti-nausea medication. Most side-effects from chemotherapy are temporary and reversible.

Computerised axial tomography (CT scan or CAT scan)

A specialised x-ray or imaging technique that produces a series of detailed three dimensional (3D) images of cross sections of the body.

Cytopenia

A deficiency of some cellular element of the blood.

Echocardiogram

A special ultrasound scan of the heart.

Electrocardiogram (ECG)

Recording of the electrical activity of the heart.

Growth factors and cytokines

A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood stem cell transplantation.

Haematologist

A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

Haemopoiesis

The process involved in blood cell formation.

Hairy cell leukaemia

A rare type of CLL in which abnormal B-lymphocytes accumulate in the bone marrow, liver and spleen. Under the microscope, these cells are seen to have tiny hair-like projections on their surface.

High dose therapy

The use of higher than normal doses of chemotherapy to kill off resistant and/or residual (leftover) cancer cells that have survived standard-dose therapy.

Hypogammaglobulinaemia

The term used to describe low immunoglobulins (IgA, IgG, IgM).

Immune system

The body's defence system against infection and disease.

Immunocompromised

When someone has decreased immune function.

Intravenous immunoglobulin (IVIg)

The pooled immunoglobulin (antibody) G (IgG), extracted from the plasma of many blood donors and may be provided to assist immunocompromised patients. IVIg's effects last between two weeks and three months.

Leukocytes

Another name for white blood cells.

Leukaemia

A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal blood cells. These cells take over the bone marrow often causing a fall in blood counts. If they spill out into the bloodstream however they can cause very high abnormal white cell counts.

Leukaemic blasts

Abnormal blast cells which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can accumulate in other organs.

Leukopheresis

A procedure that uses a special machine called a 'cell separator' to remove the excess white cells in the blood while returning the rest of the blood to the patient.

Lymphocytes

Specialised white blood cells involved in defending the body against disease and infection. There are different types of lymphocytes including: B-cells, T-cells and Natural Killer Cells.

Lymphocyte doubling time

The time it takes for lymphocyte counts to double.

Lymphocytosis

An abnormal increase in the number of lymphocytes in the circulating blood.

Lymphomas

General name given to cancers of the lymphatic system.

Malignancy

A term applied to tumours characterised by uncontrolled growth and division of cells (see cancer).

Minimal Residual Disease (MRD)

The name given to small numbers of leukaemic cells that remain in the patient during treatment, or after treatment when the patient is in remission. It is the major cause of relapse in cancer and leukaemia.

Mucositis

Inflammation of the lining of the mouth and throat, which also can extend to the lining of the whole of the gastrointestinal tract (stomach and intestines).

Neutropenia

A reduction in the number of circulating neutrophils, an important type of white blood cell. Neutropenia is associated with an increased risk of infection.

Neutropenic diet

A diet which seeks to reduce the amount of food introduced into the body that has high levels of bacteria.

Neutrophils

Neutrophils are the most common type of white blood cell. They are needed to mount an effective fight against infection, especially bacteria and fungi.

Oncologist

General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

Pathologist

A doctor who specialises in the laboratory diagnosis of disease, and how disease is affecting the organs of the body.

Peripherally inserted central venous catheter (PICC)

A type of central venous catheter which is inserted into a large vein in the arm.

Plasma cells

Activated B-cells that produce antibodies to help the body fight infection.

Prolymphocytic leukaemia (PLL)

A rare type of chronic lymphocytic leukaemia in which abnormal lymphocytes known as prolymphocytes are found in the bone marrow and bloodstream.

Prognosis

An estimate of the likely course of a disease.

Resistant or refractory disease

This means that the disease is not responding to treatment.

Remission (or complete remission)

When there is no evidence of disease detectable in the body. Note: this is not always equivalent to a cure as relapse may still occur.

Spleen

An organ that accumulates lymphocytes, acts as a reservoir for red cells for emergencies, and destroys blood cells at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It cannot normally be felt on examination unless it is enlarged. It is often enlarged in diseases of the blood – this is known as splenomegaly.

Splenomegaly

Another term used to describe an enlarged spleen.

Standard therapy

The most effective and safest therapy currently being used.

Stem cells

Stem cells are primitive blood cells that can give rise to more than one cell type. There are many different types of stem cell in the body. Bone marrow stem cells have the ability to grow and produce all the different blood cells including red cells, white cells and platelets.

Stem cell transplant (peripheral blood stem cell or bone marrow transplant)

These treatments are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment

of a wide range of blood cancers including leukaemias, lymphomas, myeloma, certain solid tumours, and other serious diseases.

T-cell

A type of white cell (lymphocyte) involved in controlling immune reactions.

Thrombocytopenia

A reduced platelet (thrombocyte) count.

Tumour

An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

Ultrasound

Pictures of the body's internal organs built up from the interpretation of reflected sound waves.

White blood cells (white cells)

Specialised cells of the immune system that protect the body against infection. There are five main types of white blood cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

X-ray

A form of radiation used in diagnosis and treatment.



MAKING A DONATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life. It exists only because of the generous and ongoing support of the Australian community.

How can I give?



ONLINE leukaemia.org.au



PHONE 1800 620 420



POST (complete this form or enclose cheque/money order and return)
The Leukaemia Foundation, Reply Paid 9954 in your capital city

Name

Address

Postcode

Phone

Mobile

Email

I enclose my gift of (please tick box)

\$30 \$50 \$75 \$100 \$250 Other \$

My cheque/money order made payable to the Leukaemia Foundation is enclosed.

I wish to pay with my credit card and my details are included below:

Visa MasterCard Diners Amex

Card Number

Expiry Date

MM

YY

Cardholder's Name

Signature

Your privacy is important to us. That is why we treat your personal information with confidence. To learn more about how and why we collect and use any personal or sensitive information about you, please view our Notification Statement at www.leukaemia.org.au/privacy



PLEASE SEND ME A COPY OF THE FOLLOWING BOOKLETS:

- Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders
- Acute Lymphoblastic Leukaemia in Adults (ALL)
- Acute Lymphoblastic Leukaemia in Children (ALL)
- Acute Myeloid Leukaemia (AML)
- Amyloidosis
- Chronic Lymphocytic Leukaemia (CLL)
- Chronic Myeloid Leukaemia (CML)
- Hodgkin Lymphoma
- Non-Hodgkin Lymphoma (NHL)
- Myelodysplastic Syndrome (MDS)
- Myeloma
- Myeloproliferative Neoplasms (MPN)
- Eating Well
- Living with Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders
- Allogeneic Stem Cell Transplants (also called Bone Marrow Transplants)

- Autologous Stem Cell Transplants
- Young Adults with a Blood Cancer
- My Haematology Diary

Books for children:

- Tom has Lymphoma
- Joe has Leukaemia
- Ben's Stem Cell Transplant
- Jess' Stem Cell Donation

Or information about:

- The Leukaemia Foundation's Support Services
- Giving at work
- Monthly giving program
- National fundraising campaigns
- Volunteering
- Receiving our newsletters
- Leaving a gift in my will

Name

Address

Postcode

Phone Mobile

Email

POST TO The Leukaemia Foundation, Reply Paid 9954 in your capital city

PHONE 1800 620 420 **EMAIL** info@leukaemia.org.au

FURTHER INFORMATION ONLINE www.leukaemia.org.au

This information booklet is produced by the Leukaemia Foundation and is one in a series on leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders.

Copies of this booklet can be obtained from the Leukaemia Foundation by contacting us.

The Leukaemia Foundation is a not-for-profit organisation that depends on donations and support from the community. Please support the Leukaemia Foundation today.

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CONTACT US



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Leukaemia
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VISION TO CURE
MISSION TO CARE