CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL)

A guide for patients, families & whānau

leukaemia & blood cancer NEW ZEALAND

Vision to Cure. Mission to Care.

INTRODUCTION

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

If you or someone you know has 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 treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your health care team.

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

Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed, either in person or through a telephone interpreter service. NZ Sign Language interpreters are also available.

Informed consent

If you are supporting a family/whānau member who needs language support at appointments, your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain medical information clearly.

HOW TO USE THIS BOOKLET

Detailed information

Key points

Important information

More information available online

There are many resources available at **leukaemia.org.nz** such as fact sheets, booklets and more. Most resources available on the Leukaemia & Blood Cancer New Zealand (LBC) website can be obtained in a printed version. Ask your LBC Support Services Coordinator if you would like information posted to you.

Space for your questions

There is space at the end of this booklet to write questions that you can ask next time you see a doctor, nurse or LBC Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

Glossary

On page 46 there is a glossary (word list).

In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases. A Dictionary of Terms booklet is also available from LBC.

CONTENTS

WHAT IS LEUKAEMIA?

Leukaemia is a type of blood cancer. Blood is made up of red blood cells, white blood cells and platelets. These are made in the bone marrow, which is the spongy tissue found in the centre of some bones in the body.

Leukaemia is a cancer of the white blood cells. White blood cells are an important part of the immune system and help fight infection. Normally baby (immature) white blood cells divide and then mature (go from immature cells to adult cells) in a controlled way. It is the mature white blood cells which fight infection.

When someone has leukaemia, the immature white blood cells divide too quickly in the bone marrow, and do not mature. This means the bone marrow is overcrowded with immature white cells that are not able to fight infection.

Types of leukaemia

Leukaemias can be acute or chronic. Acute leukaemias typically develop very quickly and treatment must start right away. Chronic leukaemias usually develop slowly and may not need treatment right away, if at all. In medical terms, the word 'chronic' means persisting for a long time – it does not mean 'severe'.

The names of the main types of leukaemias are:

Acute

Acute Myeloid Leukaemia (AML)

Acute Lymphoblastic Leukaemia (ALL)

Chronic

Chronic Myeloid Leukaemia (CML)

Chronic Lymphocytic Leukaemia (CLL)

Both adults and children can develop leukaemias, but certain types are more common in different age groups. Each year in New Zealand around 680 adults and 50 children are diagnosed with leukaemias.

Key points

- Leukaemia is a type of blood cancer of the white blood cells.
- Leukaemia can be acute (develops fast) or chronic (develops slowly).

WHAT IS CHRONIC LYMPHOCYTIC LEUKAEMIA?

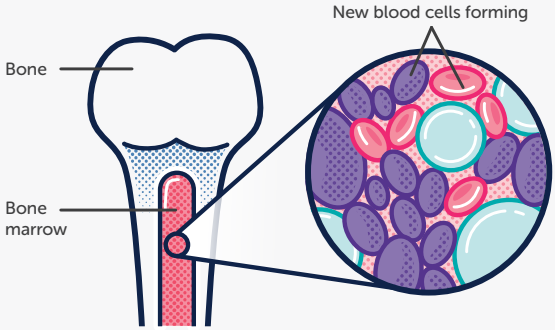
Chronic lymphocytic leukaemia (CLL) is a type of slow-growing (chronic) leukaemia that occurs when your body makes too many abnormal white blood cells.

To fully understand CLL it is helpful to learn about the cells in your body and bone marrow.

BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).

Figure 01
Bone marrow



In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

The two main functions of blood stem cells are to:

- Make exact copies of themselves.
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

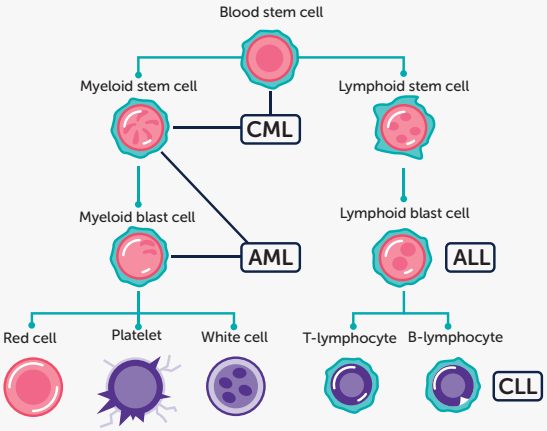
Myeloid and lymphoid stem cells create the blood cells for your body including white blood cells, red blood cells and platelets.

In Figure 02 (on next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

Leukaemia can start in either the myeloid cell line or the lymphoid cell line. This determines what type of leukaemia it is (either CLL or CML). As you can see in Figure 02, CLL affects B-lymphocytes (lim-fo-sites), which will be explained further on page 6.

Figure 02

The cells created from blood stem cells



This indicates the different cells where abnormalities occur, causing the different leukaemias.

Detailed information

- The medical term for blood stem cells is haematopoietic (he-ma-to-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-to-po-ee-sis). In adults, haematopoiesis occurs in the bone marrow of large bones such as the breastbone (sternum), thigh bone (femur) and the hip bone (iliac crest).

Key points

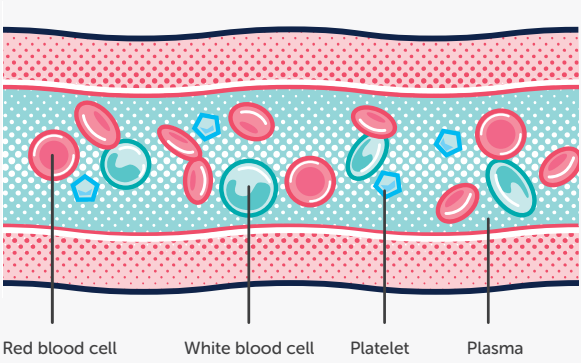
- Blood stem cells in your bone marrow make exact copies of themselves, as well as divide to create myeloid and lymphoid stem cells. These cells create all the blood cells for your body, e.g. red blood cells, white blood cells and platelets.
- Leukaemias can develop from either myeloid cells or lymphoid cells.

YOUR BLOOD

The red blood cells, platelets and white blood cells, created in your bone marrow, are released into your bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. Figure 03 shows the three main types of blood cells in the plasma. The role of plasma and each type of blood cell is discussed in the next section.

Figure 03
Blood vessel and cells in your blood



Red blood cells

Red blood cells transport oxygen from the lungs to all cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

White blood cells

White blood cells, also called leukocytes (loo-kar-sites), fight infection. For example, if bacteria entered your bloodstream through a cut, the white blood cells would attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Neutrophils (nutra-fils) are the most common type of white blood cell. A low amount of neutrophils in your body is called neutropenia (nutra-pee-nee-a).

Platelets

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding. A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a).

Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body.

Detailed information

There are many different types of white blood cells, all with specific jobs to do.

Below is a list with the names of different types of white blood cells and what they do.

- **Neutrophils (nutra-fils)**
  Kill bacteria and fungi.
- **Eosinophils (ee-o-sin-o-phils)**
  Kill parasites.
- **Basophils (bay so-phils)**
  Work with neutrophils to fight infection.
- **T-lymphocytes (T-lim-fo-sites) (T-cells)**
  Kill viruses, parasites and cancer cells.
- **B-lymphocytes (B-cells)**
  Make antibodies which can target harmful microorganisms (germs).
- **Monocytes (mono-sites)**
  Work with neutrophils and lymphocytes to fight infection. They also help act as scavengers (cleaners) to remove dead tissue.
- **Macrophages (mac-row-fages)**
  Monocytes are known as macrophages when they move to body tissue to help fight infection there.

Key points

- There are three main types of blood cells (red blood cells, white blood cells and platelets), each with an important role.
- Blood cells travel around your bloodstream in a light-yellow coloured liquid called plasma.

CHRONIC LYMPHOCYTIC LEUKAEMIA

Chronic lymphocytic leukaemia (CLL) is the most common type of leukaemia in New Zealand with approximately 288 people diagnosed every year. CLL is more common with age. The majority of people are over 50 years old when they are diagnosed.

CLL is a type of leukaemia that affects B-lymphocytes (often called B-cells). B-lymphocytes are a type of white blood cell that produce antibodies (immunoglobulins), which help protect our bodies against infection and disease. B-lymphocytes are present in the bone marrow, the blood, the glands of the lymphatic system (lymph nodes and spleen), and to a lesser extent in other organs.

In people with CLL, some of the B-lymphocytes have undergone a malignant (cancerous) change and become leukaemic cells that grow uncontrollably. Over time these leukaemic cells can crowd out the bone marrow, interfering with the production of normal blood cells, and can accumulate in the lymph nodes and spleen, causing enlargement of these organs.

CLL usually develops slowly, over many years. Most people have no symptoms of their disease when they are first diagnosed. Some people may not need treatment for a long time (if at all). Others may need to be treated soon after they are diagnosed. People known to have CLL usually have monitoring by a doctor, to check whether treatment is needed.

Detailed information

- **Small lymphocytic lymphoma (SLL)**
  SLL is considered the same condition as CLL, and the diagnostic term 'CLL/SLL' is sometimes used to reflect this. The only difference is that in SLL, the level of malignant cells is below a specific level in the blood, and the malignant B-cells are in the lymph glands, spleen and/or bone marrow. SLL may require a lymph node biopsy for diagnosis, but is otherwise monitored and treated the same way as CLL.
- **Monoclonal B-lymphocytosis or MBL**
  Modern laboratories can detect very small numbers of CLL-like cells in the blood, which are below the level needed to diagnose CLL. This is called monoclonal B-lymphocytosis, or MBL. MBL is very common, and can be found in up to 20% of healthy adults over 60 years of age. MBL is not considered a malignancy, but approximately 1% of people with MBL will go on to develop CLL each year. For some people with MBL, annual blood test monitoring may be recommended.

What causes CLL?

Like most other types of leukaemia, CLL is thought to develop after DNA is damaged causing genetic mutations (errors). In day-to-day life, we are all exposed to low levels of radiation and chemicals that can damage the DNA in our bodies. Usually this DNA damage is corrected by the cell, or the cell dies, and no harm is done. However, in some people, a particular mutation occurs that helps a cell to divide more (proliferate), and this cell can eventually become malignant and cause a leukaemia.

Large studies show that there is a slightly higher rate of CLL and related conditions among first-degree relatives (parents, siblings and children) of people with CLL. However, this risk is small, and CLL is not thought to benefit from early detection or treatment. For this reason, screening of family members for CLL is not usually recommended.

CLL is not contagious; you cannot 'catch' CLL by being in contact with someone who has it.

Key points

- CLL is a type of leukaemia that affects developing B-lymphocytes, which are a type of white blood cell.
- CLL usually develops slowly, over months and years, and may not have any noticeable symptoms when diagnosed.
- The cause of CLL is not entirely clear, but risk factors include older age, ethnicity, a family history of CLL, and exposure to certain chemicals.

WHAT ARE THE SIGNS AND SYMPTOMS OF CLL?

The symptoms of CLL vary from person to person. Many people with CLL have no symptoms when they are first diagnosed and it is discovered incidentally, when they have a blood test for a different reason. Some people will have symptoms, which are explained in this section.

As mentioned earlier in this booklet, the normal blood cells in the bone marrow, blood and lymph glands can be 'crowded out' by large numbers of leukaemic cells. This can result in symptoms such as anaemia, bleeding or bruising and infections.

Anaemia

Having a low haemoglobin level (because of a low number of red blood cells) can cause anaemia.

The symptoms of anaemia include:

- Lack of energy (lethargy)
- Feeling very tired all the time (fatigue)
- Shortness of breath, especially when exercising
- Dizziness
- Pale skin (pallor).

Bleeding and bruising

Having a low platelet count (thrombocytopenia) can mean it's harder for your blood to form clots to stop bleeding.

The symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or injuries that take a long time to stop bleeding
- Frequent or severe nosebleeds or bleeding gums
- Unusually heavy periods in women
- Red or purple pinhead-sized spots on your skin called petechiae (pe-tee-kee-i).

Infections

People with CLL are at increased risk of infection, even before receiving any treatment. This is because the CLL cells can interfere with normal immune responses and antibody production.

Common signs and symptoms of infection include:

- Fever (high temperature of 38°C or above)
- Shivering or rigours
- Coughing up yellow or green phlegm
- Fatigue or extreme tiredness.

Common types of infection in people with CLL include:

- Chest infections (including pneumonia)
- Urinary tract infections (UTI or bladder infection)
- Cellulitis (a skin infection causing redness, swelling and tenderness that can spread)
- Viral colds and influenza (head cold or flu)
- Shingles (a rash with tiny blisters, usually localised to one side and area of the body).

Your doctor may recommend vaccinations to help protect you against certain types of pneumonia. Some people with CLL who experience frequent infections may benefit from regular antibiotics or transfusions of antibodies (immunoglobulin infusions).

Other

Other symptoms of CLL can include:

- Swollen lymph nodes in the neck, armpits or groin
- Swollen tummy or feeling very full after meals (early satiety) caused by enlarged spleen (splenomegaly)
- Recurrent drenching sweats at night
- Unexplained weight loss.

Important information

- All people with CLL should see their GP or emergency doctor if they develop symptoms of an infection. It is important to have a low threshold for seeing a doctor, earlier is a lot better than waiting to see if the infection gets worse. Infections can be more severe and can develop more rapidly in people with CLL than those without it.
- If you are currently receiving chemotherapy for CLL, or if you are neutropenic due to your CLL or its treatment, you must seek urgent medical care if you develop a fever or other symptoms of infection. Your health care team should advise you how to seek help, as this varies from hospital to hospital.

Key points

- Many people with CLL have no symptoms when they are diagnosed.
- CLL can cause shortness of breath or tiredness as a result of low red blood cells.
- CLL can cause increased bruising and bleeding as a result of low platelets.
- People with CLL are at increased risk of infection.
- CLL can cause enlargement of the lymph glands and spleen.

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

People with CLL who do not need treatment may be monitored by a GP.

Because CLL is usually detected incidentally on a blood test done for another purpose, most people with a new diagnosis of CLL do not need CLL-directed treatment immediately, and many will never need treatment.

In New Zealand, people with early-stage CLL are often monitored by their GP. Monitoring of early-stage CLL typically involves a blood test and examination for enlarged lymph glands or spleen every 6–12 months. If the GP finds features that suggest the CLL may need treatment, they can refer you to a hospital specialist. Regular monitoring without treatment is called 'active monitoring'. See page 20 for more information about active monitoring.

People with CLL needing treatment may meet a range of health professionals who are part of the health care team.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you and your family/whānau the best available treatment and support so that you can live as well as possible with CLL.

Some of the health professionals you will meet are, in alphabetical order:

- Charge nurse – A senior nurse in charge of an outpatient department, day unit or hospital ward.
- Clinical nurse specialist (CNS) – A nurse with advanced skills in a specific area of clinical care. This person works closely with you and members of your health care team to coordinate treatment, and help you manage the symptoms of CLL and the side effects of treatment.
- Dietitian – A dietitian may advise you on what to eat and drink to minimise symptoms or side effects from CLL or your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- General practitioner (GP) – A family and community doctor. You may be monitored by your GP if you have no symptoms and do not need treatment. They will work together with other health professionals to support you at home, in the community and after treatment. They can also refer you to a specialist if needed.
- Haematologist – A senior doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist usually oversees any treatment for CLL.
- Occupational therapist – Helps you manage everyday activities and achieve activities you want or need to do.
- Outpatient clinic nurse – A nurse who gives you treatment as an outpatient or who works alongside a doctor in clinic.

- **Pathologist** – A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.
- **Pharmacist** – Prepares and checks your drugs/medications. Pharmacists can advise you on how to take your medicine, possible side effects and interactions with other medications.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.
- **Psychologist** – Specialises in helping you manage the emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is in training. You may see a registrar in clinics, day units and wards. Registrars works closely with senior specialists (haematologists).
- **Social worker** – Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- **Ward nurse** – A nurse who looks after you during a stay in hospital.

Other people you might hear about or meet are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of CLL, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-governmental organisation (NGO)** – Gives emotional and practical support for those affected by cancer, e.g. Leukaemia & Blood Cancer New Zealand (LBC).
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your health care team.

TESTS AND INVESTIGATIONS

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

If CLL is suspected then the doctor will ask you questions about your general health and any symptoms you might have, and will examine you for enlarged lymph glands and spleen. The first step in diagnosing CLL is a blood test. You may also be asked to have other tests, which are explained in this section.

Blood test

The main blood test used to diagnose CLL is called a full blood count (FBC) or complete blood count (CBC). Blood is taken from a vein in your arm and sent to a lab (laboratory) where it is looked at under a microscope. Other specialised blood tests are also required to confirm a diagnosis of CLL.

Full blood count (FBC)

A FBC measures the number and appearance of red blood cells, white blood cells and platelets, as these can all be abnormal in CLL.

If you have CLL, the FBC may show the following:

- A high number of leukocytes (white blood cells), particularly lymphocytes
- A lower number of platelets than normal
- A lower number of red blood cells than normal
- Large numbers of small lymphocytes, which are often broken (smeared) when examined under a microscope.

Normal blood test results for adults are shown on page 14.

Immunophenotyping (im-u-no-feen-o-tie-ping)

Immunophenotyping is one of the most important laboratory techniques used to confirm a diagnosis of CLL. It involves using a machine called a flow cytometer.

Flow cytometry uses lasers to detect the abnormal cells typical of CLL in blood or bone marrow samples. A specific combination of surface markers (e.g. CD19, CD20, CD5, CD23, CD200) are found on the outside of leukaemic cells. The presence of these markers can confirm a diagnosis of CLL, and flow cytometry is helpful to rule out related conditions that might be treated differently. See glossary on page 46 for definition of markers.

Cytogenetic (cy-toe-gen-et-ic) and molecular tests

Cytogenetic and molecular tests typically use blood or bone marrow samples to see if the leukaemia cells have acquired changes in their genes compared to normal cells.

One common cytogenetic test used for CLL is fluorescent in situ hybridisation (FISH). FISH uses fluorescent dyes that attach to certain parts of chromosomes. Analysing chromosomes in this way can detect large genetic changes that can affect how CLL responds to treatment. Molecular tests look at the DNA sequence itself, and can detect smaller changes, called mutations.

A gene called TP53 is involved in the way CLL cells respond to chemotherapies. When CLL cells have a deleted or mutated TP53 gene, conventional 'cytotoxic' chemotherapies can be less effective. The TP53 gene can be investigated by FISH looking for deletion of the portion of chromosome 17 where TP53 resides (deletion 17p or del17p), and by a molecular test to look for TP53 mutation. At the time of first needing treatment, around one in 10 people with CLL have TP53 gene disruption, and clinicians may use this result to inform treatment. Prognosis is explained further on page 18.

Cytogenetic and molecular tests are usually reserved for people whose CLL needs treatment soon, as the results do not affect the monitoring of early CLL.

MRD testing

MRD stands for minimal residual disease, which represents the smallest quantity of leukaemia cells that current technology can detect. It aims to be able to detect one leukaemia cell, if present, among 10,000 or fewer normal cells, whereas the standard microscope methods of examination of your bone marrow can only reliably detect leukaemia cells down to a level of one in 100.

MRD testing is a method of testing your blood and/or bone marrow to detect a low level of leukaemia cells. For CLL, flow cytometry is most commonly used for this purpose, although molecular techniques can also be used.

The term 'MRD negative' indicates that the number of leukaemia cells left in the body is so low that the technology cannot detect them. The term 'MRD positive' indicates that there are still some leukaemia cells detected, and suggests a greater potential for relapse compared with someone who is MRD negative.

MRD testing is not universally recommended as part of CLL treatment, but is often used in clinical trials to determine how well a treatment has worked.

Other tests

Other tests include:

- **Bone marrow biopsy** – A bone marrow biopsy is not usually needed to diagnose or treat CLL, but may be requested by your haematologist to investigate low blood counts, or to confirm remission of CLL after treatment. See our website for more information on bone marrow biopsy.
- **Imaging tests** – CT (computed tomography) scans are not routinely needed to diagnose or treat CLL, but can help confirm remission after a treatment, and can be useful to rule out other causes of enlarged lymph glands. PET (positron emission tomography) scans are rarely used for people with CLL. A PET scan may be requested if there is a clinical concern that the CLL might have changed into a more aggressive lymphoma.
- **Lymph node biopsy** – Lymph node biopsies are not routinely needed to diagnose or treat CLL, but are used to diagnose SLL, or if there is a clinical concern that the CLL might have changed to a more aggressive condition. A lymph node biopsy is a procedure where a small sample is taken from a lymph node and examined under a microscope.

More information available online

Preparing for tests

Before you go for a test, ask your health care team how long the test will take, what the test involves and how you will feel afterwards.

Things that you can do to help prepare for going to the test are:

- Plan your journey so that you arrive on time and do not have to rush.
- Find out about parking. Your LBC Support Services Coordinator can help.
- Ask a support person to come with you.
- Ask for an interpreter if needed. Your health care team can help facilitate this.
- Take your favourite music on a device with headphones.
- Take something to read.

Normal blood test results

Table 01 gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range.

Please note that there may be small variations compared with the data used at your hospital or clinic.

Table 01: Normal range for adults (local laboratory ranges may differ slightly)

	Adult men	Adult women
Haemoglobin (Hb)	130–175 (g/L)	115–155 (g/L)
Neutrophils	2.0–7.5 ($x10^9$/L)	2.0–7.5 ($x10^9$/L)
Platelets	150–400 ($x10^9$/L)	150–400 ($x10^9$/L)

Key points

- The main tests for diagnosing CLL are blood tests where your blood is analysed under a microscope to see any abnormal changes.
- Immunophenotyping is a specific test that is necessary for diagnosing CLL, and can usually be done using a blood sample.

Staging

In other cancers, the 'stage' is used to describe the location or spread of a cancer. However, because CLL is a disease of the blood, it is always widespread. Therefore, CLL staging is different to that for solid cancers. CLL staging describes the extent to which the CLL is affecting normal blood cell production and causing lymph node or spleen enlargement.

The two staging systems used in CLL are the Binet system and modified Rai system. These grading systems are summarised in table 02.

People with Binet stage A (modified Rai stage low) CLL do not usually require treatment. People with Binet stage C (modified Rai stage high) CLL usually require treatment. People with Binet stage B (modified Rai stage intermediate) CLL may or may not need treatment. In addition to this staging, a haematologist will use specific criteria (by the international working group for CLL, iwCLL) to help determine if treatment is needed, as well as considering your own situation.

Table 02

Stages	Findings
Binet stage A **Modified Rai stage low**	• Increased lymphocyte count • Normal platelet and red blood cell count • Fewer than three areas of lymph node enlargement (swollen lymph nodes)
Binet stage B **Modified Rai stage intermediate**	• Increased lymphocyte count • Normal platelet and red blood cell count • Three or more areas of lymph node enlargement
Binet stage C **Modified Rai stage high**	• Increased lymphocyte count • Low red blood cell count (anaemia) and/or low platelet count (thrombocytopenia) • Unlimited number of areas of lymph node enlargement

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your health care team.

Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you.

If you have any doubts or questions or need more information about a procedure or treatment, it is important you speak to your doctor or nurse again. You may need to sign a consent form (written consent) or you may just say you agree to a treatment or procedure (verbal consent).

If someone is not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney (EPOA) can give consent on behalf of the patient.

Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 19.

Key points

- Informed consent means that you understand the information around treatment or a procedure.
- Speak to your health care team if you have any doubts or need more information about treatment or a procedure.

MAKING TREATMENT DECISIONS

The main aim of CLL treatment is to destroy the leukaemia cells in the body and allow the bone marrow and blood to function normally again.

No two people are the same. To help you make the best treatment decision, your doctor will consider all the information available. Some people with CLL may never need treatment while others may need several different types of treatment over a number of years.

Many people feel overwhelmed when they are diagnosed with CLL. Waiting for test results and discussing treatment options can be very stressful. It can also be very stressful not immediately starting treatment but having regular follow-up appointments and blood tests. This is called active monitoring or 'watch and wait', which is discussed in more detail on page 20.

Your doctor will spend time with you and your family/whānau discussing what they feel is the best option for you. Ask as many questions as you need to, at any stage. You should feel that you have enough information to make the important decisions you are facing.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current haematologist, about getting a second opinion.

Questions to ask your health care team

Before going to see your GP or haematologist, or another member of your health care team, make a list of the questions you would like to ask.

In Appendix A on page 51 there are some examples of questions you could ask your GP or haematologist. You could write your questions and answers at the back of this booklet or in the LBC Haematology Patient Diary available from your LBC Support Services Coordinator. On page 11 of the Haematology Patient Diary there is also a list of questions that you might like to ask your doctor.

Bring a support person

We recommend that you bring a support person along to your appointments. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information.

Prognosis

Prognosis means an estimate of the likely course of a disease. It provides a guide of how long your CLL might be controlled or the likelihood that it will progress and get worse. Among people with a new diagnosis of early-stage (Binet A, modified Rai low) CLL, over half will have no need to start CLL treatment over the following decade.

For people commencing CLL treatment, the prognosis will depend on several factors including characteristics of the leukaemia itself, and any other medical conditions. Your doctor is the best person to indicate prognosis, and advise how well your leukaemia is likely to respond to treatment.

When doctors and other members of the health care team talk about prognosis, they might use the terms: complete remission, partial remission, stable disease or relapse.

Here is what these terms mean:

- **Complete remission** – The treatment has successfully killed the CLL cells so they can no longer be detected in the blood or bone marrow, and there are no remaining enlarged lymph glands.
- **Partial remission** – The number of CLL cells has reduced, but there are still some CLL cells present in the blood, lymph nodes or bone marrow.
- **Stable disease** – The CLL has not improved or worsened with treatment.
- **Relapse** – The CLL has come back again. Some people's CLL may never relapse while others may have a higher chance of relapse.
- **Refractory disease** – The leukaemia is not responding to treatment (it is 'resistant' to treatment).

Being in a clinical trial

Your doctor might ask you to take part in a clinical trial. Clinical trials are also called research studies. Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available. Participation in a clinical trial can provide an opportunity to access these latest treatments, or to use existing treatments for CLL in a new way.

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected. You do not have to give a reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or health care team.

Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist and other members of the health care team before signing the consent form.

More information available online

Key points

- Your doctor will recommend a course of treatment to you, and will give you the opportunity to discuss your treatment and ask questions.
- Some people with CLL may never need treatment, while others will.
- You will be given information so that you can understand the risks and benefits of treatments and procedures. You will be asked to give your written or verbal consent for treatments and procedures.
- We recommend you bring a support person to your appointments if possible.
- Clinical trials (research studies) help find new treatments or aim to improve current treatments. Clinical trials are voluntary.

MANAGING MY CLL

CLL can be well controlled with ongoing monitoring and treatment.

It is common for people with CLL to be monitored by their doctor and only start treatment when they start experiencing certain symptoms. This could be many years after being diagnosed, or it may never need treatment. In contrast, some people might have to start treatment sooner.

Active monitoring

Active monitoring means that your disease does not need any treatment at this point in time. It does not mean that your disease is too advanced to treat, or that you are too old for treatment.

Ongoing monitoring and regular check-ups will likely include routine blood tests and physical examinations. The timing of doctor visits and tests might vary from person to person.

While being monitored, you can still be active and maintain healthy habits. These include:

- Regular exercise
- Eating a healthy diet
- Reducing stress levels
- Stopping smoking and stopping or limiting alcohol intake
- Using a high-factor sunscreen and wear a hat while outdoors, to protect against skin cancers
- Receiving the influenza vaccine each year.

There is more information on keeping in good health with a CLL diagnosis on page 44.

More information available online

Important information

It is important that you remain aware of any changes in your body and report any new symptoms to your doctor. If you develop any symptoms of an infection, seek medical advice as you may need antibiotics. Common signs of infections are explained on page 8.

Which doctor will be managing my CLL?

Which doctor you see will vary depending on how stable your CLL is. CLL that is not causing problems (early-stage CLL) will often be monitored by a GP (general practitioner). If your CLL is getting worse or you need treatment, you will see a haematologist (blood specialist).

It may feel unsettling to be told that you have a type of leukaemia but that you do not need treatment or referral to a specialist right away. GPs in New Zealand follow written pathways that have been developed with haematologists. These pathways provide specific guidance to GPs about monitoring CLL, and when referral to a specialist might be needed. There are particular combinations of symptoms that mean your GP will need to refer you to see a specialist.

Haematologists are doctors who specialise in blood cancers like CLL. Once a referral is made for you to see a haematologist, you will likely see them in a hospital clinic. If you do need to start treatment for CLL then your haematologist will explain the options to you and make a plan with you. Haematologists work with other health care professionals that you will also meet. These are explained in more detail on page 10.

More information available online

Key points

- CLL that is not causing problems (early-stage CLL) will often be monitored by a GP. If your CLL is getting worse or you need treatment, you will see a haematologist.
- People with CLL should have regular check-ups with their GP or haematologist and blood tests to monitor any changes.
- Active monitoring (watch and wait) means that the CLL does not need treatment at this point in time but will be monitored by their GP or haematologist.

TREATMENT FOR CLL

The aim of starting treatment is to improve your symptoms and/or improve blood cell counts and prolong survival with a good quality of life. CLL is very treatable and it is usually possible to control the disease with treatment.

Types of treatment

The treatment of CLL has changed dramatically over the last 20 years and is likely to continue to improve as more research is done. Often a combination of different drugs are used to increase effectiveness and response.

Currently the main treatment options for CLL are:

- Chemoimmunotherapy
- Targeted therapies
- Allogeneic stem cell transplantation.

Each of these treatments will be discussed on the following pages.

Chemoimmunotherapy

Chemoimmunotherapy has been one of the main types of treatment for CLL since the late 2000s.

Chemoimmunotherapy is a treatment plan that uses both chemotherapy and immunotherapy drugs. By combining chemotherapy with immunotherapy, the effectiveness of each drug is improved. Various combinations of chemotherapy and immunotherapy are in use.

The term chemotherapy (chemo) is used to refer to 'cytotoxic' drugs, which work by damaging the DNA in leukaemia cells. The term immunotherapy is used to refer to artificial (synthetic) antibodies, which latch onto the leukaemia cells and label them for destruction by your own immune system.

Chemotherapy and immunotherapy drugs travel around the body in the bloodstream, which means they can reach cancer cells anywhere in the body. Chemotherapy drugs can damage healthy cells, causing side effects, and immunotherapy drugs can cause side effects by activating the immune system in undesirable ways. Side effects are discussed later in this section.

One immunotherapy technique uses monoclonal antibodies to attack and destroy CLL cells. Monoclonal antibodies are targeted therapy drugs that attach to particular proteins on the surface of cancer cells and destroy them.

Common monoclonal antibody drugs used in CLL are:

- Rituximab
- Obinutuzumab.

Common types of chemotherapy used to treat CLL include:

- Fludarabine
- Cyclophosphamide
- Bendamustine
- Chlorambucil.

Common chemoimmunotherapy combinations for treatment for CLL are:

- Fludarabine, cyclophosphamide and rituximab
- Bendamustine and rituximab
- Chlorambucil and obinutuzumab.

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

Chemotherapy drugs come in many different forms and are administered (given) in different ways. For CLL, these include:

- Into a vein (intravenously or IV)
- In a tablet (orally).

Immunotherapy drugs are given intravenously, or occasionally subcutaneously (beneath the skin).

IV chemotherapy or immunotherapy is given directly into your bloodstream through a cannula, usually in your arm or hand. IV chemotherapy or immunotherapy needs to be given in hospital (either day clinic or ward). How long your stay in hospital will be depends on what treatment you are having, and whether you experience particular side effects. Some IV infusions are over a couple of hours, some are longer or shorter. Your doctor will let you know if you have to stay the night in hospital, otherwise you will just go in for part of the day. The dose (amount) of chemotherapy will vary from person to person. Your doctor will consider things like your general health, weight and specific CLL characteristics.

Side effects of chemotherapy

Healthy cells that multiply quickly in your body can also be killed or damaged during chemotherapy. Examples of these cells are those in your mouth, gut (stomach), bowel and bone marrow. This cell damage can also cause side effects.

The side effects for each chemotherapy drug are different. Most people will have some side effects, but some people do not. Most side effects of chemotherapy begin to go away when your treatment is finished.

Chemotherapies are usually given in cycles, with one or more days of treatment, followed by breaks during the treatment so that your body, the bone marrow in particular, has time to recover before the next cycle.

Side effects of treatment may be short or long term. Short-term side effects usually resolve a few weeks after treatment finishes. Long-term side effects can last for months or years after treatment, sometimes called 'late effects'.

Here is a list of the most common side effects of chemotherapy – in alphabetical order:

- Anaemia (from a low number of red blood cells)
- Bruising and bleeding (from a low number of platelets)
- Constipation
- Diarrhoea
- Difficulty concentrating or remembering (chemo brain)
- Early menopause
- Fatigue (extreme tiredness)
- Fertility issues
- Hair loss (not usually seen with chemotherapies for CLL)
- Increased risk of infection (from a low number of white blood cells)
- Low mood, anxiety, depression or difficulty coping
- Nausea and vomiting
- Organ damage
- Pain
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis).

Some of the more common side effects, and what you can do if you have these side effects, are discussed in the section called 'Living with CLL' on page 30.

Detailed information

Chemotherapy that is given through an IV drip can cause pain and swelling at the injection site.

Bendamustine can cause inflammation of the vein, called 'phlebitis'. It may cause pain, stinging, swelling or redness at or near the site. Tell your doctor or nurse immediately if you get any of these symptoms during or after treatment.

Side effects of monoclonal antibody therapies

The most common side effect of monoclonal antibody therapies is having a reaction against the drug while it is being administered for the first time.

The side effects of an infusion reaction might include:

- Fever (high temperature)
- Chills or rigour
- Nausea
- Headache
- Rash
- Itch
- Weakness.

If you experience any of these symptoms, let your nurse know immediately. The symptoms usually get better as soon as the infusion is stopped and are not as severe the next time you have the infusion. Paracetamol and antihistamine drugs can be given prior to the infusion to reduce symptoms.

Detailed information

Rituximab
Rituximab is commonly used in the treatment for CLL as it kills a protein (called CD20) that is found on most CLL cells.

Rituximab is administered (given) as an IV infusion usually in a day clinic at the hospital. Because rituximab only targets cells that have the CD20 protein, it doesn't kill all the other normal cells like some chemotherapy drugs.

Obinutuzumab
Obinutuzumab is another anti-CD20 drug sometimes used in treating CLL. It is also given as an IV infusion. There is also the risk of having an infusion reaction.

Key points

- Chemoimmunotherapy is a common treatment for CLL. There are several different combinations of chemotherapy and immunotherapy used to treat CLL. The immunotherapy (antibody treatment) is typically given via a drip (IV), while the chemotherapy can be in tablet form or IV.
- Chemoimmunotherapy can be started in hospital, as an outpatient (in a day unit), while chemotherapy tablets alone can be taken at home.
- Chemotherapy works by killing leukaemia cells but it can also damage normal cells, which can lead to side effects.
- Immunotherapy works by latching onto the leukaemia cells and labelling them for destruction by your own body.

Targeted therapies

Treatments for CLL are constantly improving. Targeted therapies are a group of drugs that target signalling pathways within the leukaemia cells, with minimal damage to healthy cells.

Targeted therapies used for CLL include:

- BTK inhibitors, such as ibrutinib, zanubrutinib and acalabrutinib
- BCL2 inhibitors, such as venetoclax.

BTK inhibitors

BTK inhibitors are a type of drug called tyrosine kinase inhibitor (TKI). Kinases are proteins in the body that control how the cells grow and survive. BTK inhibitors, such as ibrutinib, block the proteins (kinases) from sending signals to the leukaemia cells to grow and survive, eventually reducing the number of leukaemia cells.

BTK inhibitors are given as capsules or tablets that you usually take every day for as long as it keeps the CLL under control. It is important to keep taking the right dose every day as the doctor has prescribed. If doses are missed, it won't be as effective in killing the CLL cells.

Side effects of BTK inhibitors

Common side effects include:

- Increased risk of infection
- Anaemia (from a low number of red blood cells)
- Bruising and bleeding
- Diarrhoea
- Constipation
- Nausea and/or vomiting
- Muscle or joint pain
- Headaches
- Skin changes
- Irregular heart rhythm (atrial fibrillation)
- High blood pressure (hypertension).

These side effects, and what you can do if you have them, are discussed in the section called 'Living with CLL' on page 30.

BCL2 inhibitors

Another type of targeted therapy is BCL2 inhibitors, such as venetoclax. BCL2 is a protein that promotes the survival of some cancer cells, including CLL cells. Venetoclax blocks the BCL2 protein, leading to death of the CLL cells.

Venetoclax is given as tablets that you take once a day. Typically, the dose of venetoclax starts very low, and builds up each week over five weeks. It is very important that you take venetoclax exactly how the doctor, specialist nurse or pharmacist has explained.

Side effects of venetoclax

Common side effects include:

- Tumour lysis syndrome (TLS)
- Increased risk of infection
- Neutropenia (from a low number of white blood cells)
- Anaemia (from a low number of red blood cells)
- Diarrhoea
- Constipation
- Nausea and/or vomiting.

Detailed information

Tumour lysis syndrome (TLS) is a complication when lots of leukaemic cells break down very quickly. When these cells break down, they can release salts such as uric acid, potassium and phosphate into the bloodstream, overwhelming your kidneys.

TLS can cause swelling and pain in the joints (gout), kidney problems, abnormal heartbeat, and can be life-threatening.

TLS is only usually a risk when you first start venetoclax. To avoid TLS, you will start with a very low venetoclax dose, and the dose will be increased gradually.

You may be asked to take a medicine to reduce your uric acid level when you first start venetoclax, and to maintain water intake. You may also be asked to have close blood test monitoring, which can detect high amounts of potassium and phosphate in your bloodstream. If you have any symptoms of TLS, contact your health care team or hospital immediately.

Key points

- Targeted therapy drugs are used to treat CLL. They work by targeting the cancer cells while causing less damage to normal healthy cells.
- Targeted therapy drugs still have side effects.
- Certain drugs, including some antibiotics, can interfere with the way targeted therapy drugs are processed by your body. Let your pharmacist or doctor know that you are taking a targeted therapy for CLL if they offer you a new medicine (including an antibiotic), so they can check for harmful interactions.

Stem cell transplant

A stem cell transplant is a transplant of stem cells that is given after high doses of chemotherapy. The aims of a stem cell transplant are to allow much higher doses of chemotherapy to be given and/or to replace your blood and immune system with that from a healthy donor, in the hope this new immune system eradicates the leukaemia.

High doses of chemotherapy and/or radiotherapy destroy many of the bone marrow and immune cells, and you are then given healthy bone marrow stem cells (your own or from a donor) through an IV drip (infusion). These new stem cells find their way to your bone marrow, and replace your blood and immune system.

A stem cell transplant may also be called a bone marrow transplant, a haematopoietic (he-ma-to-po-ee-tick) stem cell transplant or a peripheral (per-if-er-ral) blood stem cell transplant.

There are two main types of stem cell transplants:

- Allogeneic (al-o-jen-ay-ick)
- Autologous (or-tol-o-gus).

Stem cell transplants are usually only given if other treatments for CLL do not work, and because of severe side effects, are not suitable for everyone. Your haematologist will discuss with you if they think you will benefit from having a stem cell transplant.

See the LBC website for specific booklets about stem cell transplants.

More information available online

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays, usually x-rays, to destroy malignant cells. It is not a common part of CLL treatment, but is occasionally used to treat individual large or painful lymph glands, if other treatments are not suitable.

Radiotherapy is given in the radiology department in larger hospitals. It is administered using a large machine positioned over the body and targets the exact area the doctor wants treated. Radiotherapy needs to be planned very carefully so there are usually some appointments with the doctor before receiving treatment. It is important that the exact target area of the body is measured through imaging scans like x-ray, CT or MRI.

The radiation specialist then calculates the right dose, which is individual for each person. Depending on what area of the body is being treated, you may need to have a mould or mask made. These are used to keep you still throughout the radiotherapy session.

It might feel similar to getting an x-ray. The radiation beam is invisible and is a painless procedure. There may be some side effects from radiotherapy, which are listed below. There may be noise and movement from the machines that are used.

Side effects of radiotherapy

Unfortunately, there can be side effects to radiotherapy, but this will vary from person to person.

Common side effects include:

- Pain and sensitive skin (might feel similar to sunburn)
- Tiredness and fatigue
- Nausea and/or vomiting
- Diarrhoea (if the abdomen or pelvic area is treated)
- Loss of hair in the treated area.

Supportive care

Supportive care is important to help people cope with their diagnosis of CLL, symptoms of CLL and the impact of treatment. Supportive care ensures that you have the best quality of life.

Examples of supportive care include:

- Being given blood products via a drip (transfusion) to help with symptoms of low numbers of red blood cells and/or platelets.
- Being prescribed medicines to help manage side effects or symptoms, e.g. pain relief or antiemetics (drugs to stop you feeling sick).
- Being given vaccines, antibiotics or immunoglobulin to help prevent or manage infections.
- Support from a dietitian, psychologist or chaplain.
- Practical support at home.
- Support for families/whānau that have to relocate for treatment.

Supportive care is used in two situations:

1. To manage symptoms or effects of CLL, even if not receiving treatment.
2. To manage symptoms of CLL treatment (such as chemotherapy or targeted therapy).

Supportive care may start at diagnosis, during treatment, after treatment and at end of life.

Palliative care

The palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of diseases, including CLL. They aim to improve quality of life through support and services as you face a life-limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end-of-life care. Palliative care does include end-of-life care, but the palliative care team also supports people with symptoms and side effects of their disease or treatment.

Complementary therapies

Many people find complementary therapies, or a combination of these, help them to feel better physically and emotionally.

Examples of complementary therapies are:

- Relaxation
- Yoga
- Mindfulness techniques
- Massage
- Reiki
- Acupuncture
- Aromatherapy
- Homeopathy
- Reflexology
- Meditation
- Art therapy
- Music therapy
- Visualisation
- Tai chi.

If you are not sure what some of these therapies are, ask a member of your health care team. If you plan to use complementary therapies, including any supplements, make sure they are a safe option for you by asking your haematology health care team first. Some supplements or natural therapies can interfere with some drugs, which is why it is important to let your doctor know if you are taking anything else.

Key points

- Supportive care helps people cope with their diagnosis of CLL, the impact of symptoms and the side effects of treatment.
- Supportive care ensures you have the best quality of life.
- Palliative and end-of-life care provide people with support and services as they face a life-limiting disease.
- The palliative care team can support all people with CLL regardless of whether or not they are receiving treatment.

LIVING WITH CLL

There are a number of symptoms of CLL or side effects of treatment, some are more common than others.

Each person's experience will be different. Some people feel very unwell, while others have milder or no symptoms. If you are having chemotherapy, your side effects may be more severe.

This section helps you manage the more common symptoms of CLL and the side effects of treatment, and are listed below in alphabetical order.

Remember to report any side effects to your doctor or nurse. Your LBC Support Services Coordinator can give you support and more information.

Anaemia

A low red blood cell count is called anaemia. Anaemia is described in more detail on page 8.

If you have a low red blood cell count, you may be given red blood cells via a drip (IV), which is called a blood transfusion.

Bruising and bleeding

If you have a low platelet count (thrombocytopenia), or as a side effect of some drugs (such as BTK inhibitors), you may bruise easily or bleed more than usual from minor cuts. Symptoms of thrombocytopenia are described on page 8.

Things you can do to help or prevent bruising and bleeding include:

- Use a soft toothbrush.
- Don't floss your teeth.
- Don't shave with a razor blade (men and women).
- Move about carefully so you don't bump into things or trip.
- Don't play contact sports such as rugby or hockey.
- Wear protective gloves when doing work around the home or garden.
- Don't eat food with sharp edges, e.g. potato chips.
- Let your doctor or nurse know if you are constipated.

If you have a very low platelet count, you might be given a transfusion of platelets via a drip (IV) to help stop bruising and bleeding.

Important information

Call the hospital straight away if you have:

- Nosebleeds
- Bleeding gums
- Tiny red or purple spots on the skin that look like a rash.

Constipation

Constipation means that you cannot pass a bowel motion easily, usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of your bowel and cause bleeding or infection.

Things you can do to help:

- Drink plenty of water.
- Eat more fibre such as cereals, raw fruit and vegetables. See page 34 for recommendations on food safety.
- Do some gentle exercise.
- Tell your doctor or nurse, as they can give you something to soften your bowel motions.
- Talk to a dietitian.

Diarrhoea

Sometimes treatment (e.g. chemotherapy) damages the lining of your bowel wall. This might cause diarrhoea (die-a-rea) (loose bowel movements) and other symptoms such as:

- Cramping (pains in the lower abdomen or gut)
- Abdominal swelling (swollen tummy/ lower gut).

If you have diarrhoea, the health care team will do a test to see if you have an infection.

Things you can do to help:

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or flushable wipes.
- Apply a barrier cream around your bottom to protect and soothe the skin.
- Drink plenty of fluids.
- If you are unable to drink fluids, tell your doctor or nurse as you may need to have a drip (IV).
- Eat less fibre, such as cereals, raw fruits and vegetables.

Important information

Call the hospital if you have more than four episodes of diarrhoea in a day.

Difficulty concentrating or remembering (chemo brain)

Chemo brain is another symptom or side effect of CLL and treatments such as chemotherapy.

Chemo brain is also called mild cognitive impairment (MCI). It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

The symptoms of chemo brain are:

- Difficulty concentrating
- Difficulty remembering things, including finding the right word
- Feeling very tired.

Chemo brain can be frustrating and it can make everyday life difficult. Things you can do to help:

- Keep a diary of your symptoms.
- Make lists, take notes, and use sticky pads or your phone for reminders.

- Keep a calendar or diary.
- Do mental exercises such as crosswords and puzzles.
- Try to keep calm.
- Do some regular exercise.
- Get plenty of rest and sleep.
- Read short articles rather than books and watch episodes of programmes rather than films.

More information available online

Fatigue (extreme tiredness)

Fatigue is very common for people with CLL or if you are having CLL treatment. Extreme tiredness can be caused by:

- CLL itself
- Chemotherapy and targeted therapies
- Emotional stress
- Poor sleep
- Low blood counts (especially anaemia caused by low red blood cells)
- Muscle loss
- Loss of appetite or dehydration.

Extreme tiredness can have a huge impact on your life. If you have chemotherapy, it can sometimes be several months before you feel your energy levels are back to normal. Some people feel tired for a year or more afterwards.

Things you can do to help:

- Have a regular night sleep routine.
- Have regular rest periods throughout the day.
- Don't try to do too many things in a day, just do the important things.
- Note the times in the day when you have the most energy and set goals to do your main activities at these times.
- Do some light exercise each day. This will help your body condition and make you feel good.
- Keep a diary so you can look back and see your improvements in energy levels over time.

In hospital your sleep can be very interrupted. Speak with your health care team if you are finding this is making you very tired during the day. Also speak with the team about emotional support if you are having trouble coping due to fatigue.

More information available online

Feelings of isolation

A diagnosis of CLL can also make you feel isolated or alone for a number of reasons, including:

- Being unable to continue working, studying or doing the things you usually can.
- Symptoms and side effects, such as fatigue or risk of infection, can make it hard to be with other people or attend social events.
- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties can make it hard to maintain social activities or visit family/whānau and friends.

Feeling isolated can have an impact on your physical and mental well-being. It is important to speak to your doctor, nurse, social worker or LBC Support Services Coordinator if you feel isolated or alone.

Increased risk of infection

CLL itself, and treatments for CLL, including chemotherapy, immunotherapy and targeted therapies, can increase the risk of infection.

If you are receiving chemotherapy, you may be at risk of a very low white blood cell count (neutropenia). If this is the case, your health care team should tell you what to do if you develop a fever or other symptoms of infection. Infections during chemotherapy can be very serious and even fatal if you do not seek medical advice quickly for an assessment and antibiotics.

Even if you are not receiving chemotherapy, and do not have a low white blood cell count, you should consider yourself at increased risk of infection due to CLL. The most common infections in people with CLL are chest infections (including pneumonia), skin infections (including cellulitis and shingles) and bladder infections (urinary tract infections or UTIs). You should promptly see a doctor if you develop fevers or other symptoms of an infection, as you are more likely to need antibiotic or antiviral treatment

Important information

- Make sure you have a thermometer at home and you know how to check your temperature correctly.
- All people with CLL are at increased risk of infection. You should promptly see your GP or an emergency doctor if you develop a fever or other symptoms of infection. Infections can rapidly get worse if left untreated.
- If you are currently receiving chemotherapy or if you have been told you are at risk of, or have, neutropenia, you should contact your hospital immediately if you have a temperature over 38°C. Do not wait to see if your temperature goes away as you could deteriorate very quickly. Your health care team should provide you with instructions and/or emergency telephone numbers if you are in this risk group.
- If you use paracetamol to lower your temperature, record your temperature beforehand and report this to your doctor.
- Be cautious about using aspirin or ibuprofen in any form. These drugs can increase your risk of bleeding if your platelet count is low. Always check with a doctor or nurse first.
- Ask a member of your health care team for the phone numbers of the hospital and write them here:

  Monday to Friday (during office hours) ph.....

  Evenings/nights/weekends ph.....

than someone who does not have CLL. You should ask your doctor about vaccinations against pneumonia and influenza.

See page 8 for common signs of infection and different types of infections.

There are a number of things you can do to reduce your chance of getting an infection. These are as follows:

Food

You need to be careful when preparing and cooking food. Be sure to:

- Always wash your hands before preparing or eating food.
- Tell your family/whānau to wash their hands before preparing food.
- Prepare food in a clean place.
- Prepare raw chicken on a separate chopping board from other foods.
- Wash fresh fruit and vegetables well.
- Cook food well and makes sure it is very hot.
- Make sure reheated food is very hot.
- Eat food before its best before/use-by date.
- Do not reheat food more than once.

Avoiding viral infections

People with CLL may be at increased risk of viral infections. If possible, and particularly if you are currently receiving, or have recently received, chemoimmunotherapy, you should:

- Try to avoid people, including children, who are unwell with colds, flu or other infections.
- Try to avoid people who had, or have been near others who have had chicken pox or measles.

The annual influenza vaccine is recommended for most people with CLL, but might be less effective if you are currently receiving, or have recently received, CLL treatment. Check with your doctor if you are unsure whether to have the influenza vaccine or not.

Important information

People with CLL should avoid live vaccines, including the MMR vaccine and Zostavax brand of shingles vaccine. If you are unsure, check with your doctor. If you have been in contact with someone with chicken pox or shingles, contact your doctor immediately, as you may need a medicine to help protect you.

It is important that you maintain your usual social activities when you are able. Touching, hugging and kissing your close family/whānau and friends is important. It is fine if they are well.

Pets

You need to:

- Wash your hands after touching pets.
- Avoid letting a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Wash your hands carefully if you come into contact with a litter tray or animal poo.

Gardening

Garden soil can cause infections in people with a low white blood cell count.

If you have a low white blood count (neutropenia), you need to:

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Wash any cuts from gardening very thoroughly.
- Check cuts for signs of infection.
- Wear a mask when working with manure or soil to avoid breathing in particles.

Talk to your health care team if you would like more information about preventing or treating infection.

Low mood, anxiety, depression or difficulty coping

After finding out you have CLL or during treatment, it can be common to have a low mood, feel anxious or depressed, or find it difficult to cope. There can be a lot of things that cause these feelings.

Things you can do to help:

- Talk about how you're feeling with someone you feel comfortable with, e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger long-term goals.
- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to maintain your social circle by keeping in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditation, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Cry if you need to.
- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 29.

It is important to tell a member of your health care team if you continue to have feelings of low mood, anxiety, depression or difficulty coping. They can make sure you get the support you need.

Nausea, vomiting and dehydration

Some chemotherapy can make you feel sick (nausea) or be sick (vomiting). Feeling anxious can also cause nausea and vomiting.

There are drugs called antiemetics which can help treat nausea and vomiting. Different antiemetic drugs work in different ways and you may have one or more types to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch.

Tell your doctor or nurse if you still feel sick because they might be able to try a different antiemetic or give it to you in a different way.

Controlling your nausea and vomiting is important so you can keep up your food

and drink intake. If you have bad nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with your doctor or nurse to ensure you don't become dehydrated.

Things you can do to help:

- Eat smaller meals or snacks, more frequently throughout the day.
- Don't eat foods with a strong smell or taste.
- Don't eat hot or fatty foods.
- Try fizzy drinks.
- Try ginger tea or ginger ale.

Complementary therapies such as relaxation, aromatherapy or massage might help some people.

Pain

Some people may experience pain as a result of CLL or its treatment, e.g. with mucositis (sore mouth) or heartburn.

It is important to tell your health care team if you have pain. Your health care team will ask you about the pain, for example:

- What is the pain like, e.g. dull, sharp, burning?
- How bad is the pain on a scale of 0–10? (0 being no pain, 10 being the worst pain you've ever felt)
- What makes the pain worse and what makes it better?

Pain can be caused, or made worse by, your emotions or how you are coping with your diagnosis and treatment. This is called 'total pain'. Total pain can be psychological, social and/or spiritual. Examples of things that might cause total pain are anxiety, worries about your family/whānau or a crisis of faith. It is important total pain is managed as well as physical pain. Ask your health care team for the support you need.

Poor appetite and taste changes

You may not feel like eating and have changes in tasting food. This may be because of the chemotherapy, other drugs, the worry of having CLL, or doing less physical activity.

Poor appetite

Having a poor appetite can be disappointing for people who usually enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of fluids, especially if you are not eating very much.

It can be common for people to really feel like eating certain foods but then by the time it has been made, they cannot eat it. Choose meals that can be made quickly and are easy to eat.

If you are finding it difficult to eat, or are worried about your weight, ask to speak with a dietitian who will be able to advise you.

Things you can do to help:

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts and dried fruit.
- Add extra energy and protein to your diet by using full-fat products or prescribed supplements.
- Eat what you feel like, you can return to your normal diet when your appetite returns.

Taste changes

You may find that your sense of taste changes or that the texture of food seems different. This may mean that you no longer enjoy food, that all food tastes the same, or food has a metallic taste. Your sense of smell can also be affected.

Things you can do to help:

- Eat food cold as it often tastes better and smells less.
- Suck boiled sweets or drink fruit juice as they leave a pleasant taste in the mouth.
- Try different seasonings such as herbs and spices on your food.

If you are in hospital and don't feel like eating the hospital food, ask your charge nurse about suitable foods that family/whānau or friends can bring in for you.

LBC has an 'Eating well' fact sheet available on the LBC website or from an LBC Support Services Coordinator.

More information available online

Sex and fertility issues

Fertility means a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Some chemotherapy may cause infertility.

It is important that you discuss any questions or concerns you might have about your fertility with your doctor and nurse as soon as possible. There may be some things you can do before you start treatment that mean you might be able to have a baby, or father a child, in the future.

For some people, the possibility of losing their fertility can be very upsetting. There is practical and emotional support available. Talk to a member of your health care team. They will help you get the support you need.

LBC has a 'Fertility' fact sheet for both men and women available on the LBC website or from an LBC Support Services Coordinator.

More information available online

Even though chemotherapy can cause infertility, it does not make all people infertile. Chemotherapy can affect a developing foetus, so use a condom when you have sex in the months before, during and after chemotherapy to avoid a pregnancy.

More information on contraception, sex and relationships can be found on page 42.

Skin changes

Chemotherapy can affect your skin and nails. Your skin may become dry or oily. Your skin can also become red, sore, itchy and more sensitive.

Nails may become brittle and flaky. Ridges or lines may appear on your nails and they can also become painful or swollen.

Things that you can do to help:

- Don't use soap and perfumed products or products that contain alcohol.
- Moisturise dry skin once a day, or more if needed.

- Use lip balm regularly.
- Don't scratch.
- Don't shave with razor blades.
- Use oil-free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

Sun protection

After chemotherapy, you might find that the sun burns your skin much quicker than it used to.

Things you can do to help:

- Wear sunscreen with a high SPF and reapply regularly.
- Don't go outdoors in the hottest part of the day.
- Cover exposed skin with clothing.

You should do this for the rest of your life. If you are having problems with your skin or nails and none of the above suggestions are helping, get support and advice from a member of your health care team or your LBC Support Services Coordinator.

Sore mouth (mucositis)

A sore mouth is an uncomfortable side effect of some chemotherapy. It is not a common symptom from CLL treatment but if you are experiencing a sore mouth, there is more information about mucositis on the LBC website.

Contacting the hospital after-hours

If you are receiving treatment for CLL, ask your health care team for the hospital after-hours phone number.

If you are on chemotherapy and are feeling unwell, ring the hospital number (found on page 55) and ask for advice, no matter what

Important information

When to contact your doctor or the hospital for help.

Contact your doctor or the hospital straight away (night or day) if you are feeling unwell or have any of these symptoms:

- A temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in your urine, bowel motion or sputum (spit), bleeding gums or a nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or severe constipation.
- Coughing or shortness of breath.
- A new rash, reddening of the skin or itching.
- A headache that won't go away, confusion or blurry vision.
- A new pain or soreness anywhere.
- A serious cut or an injury.
- Pain, swelling, redness or pus anywhere on your body.

time it is. Your health care team would rather that you rang to discuss how you feel than not ring and feel worse. If in doubt, make the call. There will always be an open emergency department at a hospital in your region.

It can also be useful to keep a letter from your doctor that has important information about your diagnosis and treatment and take it with you to the ED or hospital. This is especially useful if you are going on holiday and have to go to a different hospital.

Coping with isolation while in hospital

There may be periods of time that you have to stay in hospital. This may be for treatment, a complication or monitoring. If you are on treatment and have a low white blood cell count, you may be in a single room, which may be referred to as 'protective isolation'.

Isolation means that you are in a hospital room by yourself and your main visitors may be limited. This is to protect you from serious infections while your white blood cell count is very low. Being separated from family/whānau can be a challenging time for everyone, especially children.

Each hospital has a policy around protective isolation, and they will tell you if you are allowed to leave your room and what precautions visitors should take, e.g. hand hygiene and wearing a mask.

Things you can do to help:

- Set yourself daily goals. Your physio, occupational therapist or nurse could help you with this.
- Have special photos in your room.
- Maintain regular contact with family/whānau via phone and video conferencing.
- Shower and get dressed in day clothes each day.
- Do light exercise and relaxation.
- Write in a diary about your thoughts and feelings.
- Do things you enjoy such as watching favourite TV shows, listening to music, playing games or doing puzzles, contacting friends, and keeping up with world news and events.
- Ask your visitors to come at different times throughout the day.

Contact your LBC Support Services Coordinator if you need support while you are in isolation.

Moving to a main centre hospital for treatment

If your local hospital cannot provide the treatment you require, you may need to move to another hospital in a main centre.

A social worker can help you with information and practical support such as advice on how to get accommodation, transport and financial assistance.

Moving to another hospital for treatment can be stressful for you and your family/whānau.

Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main centre hospital.

RELATIONSHIPS

A diagnosis of CLL can have both positive and negative impacts on relationships with family/whānau and friends.

Relationships with your partner, family/whānau and friends

Relationship with your partner

A diagnosis and the treatment of CLL can put a lot of strain on a relationship but some couples grow closer as they go through this experience together. Good communication is essential to supporting your relationship, including sharing how you feel with your partner.

Other things you can do to help:

- Planning activities together such as meals out. If you are in hospital and feel well enough, you and your partner could eat together and you could ask your nurse if it would be possible to have some time when no one comes into your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information or a referral.

There are other practical things you might want to discuss with your partner, such as setting up your partner, or another trustworthy person, to be your 'power of attorney'. A power of attorney is where you give a person the authority to act on your behalf if you are not well enough to do so yourself.

You could complete an Advanced Care Plan (ACP) and discuss this with your partner. An ACP gives you the opportunity to say what is important for you. Your doctor, nurse or LBC Support Services Coordinator can explain what an ACP is and how to get a copy of the booklet.

Talking to your children

Helping children to understand CLL and how this will affect them can help them to cope with the changes and challenges.

You can encourage younger children in your treatment journey to use an LBC sticker journal. Your children can record your treatments and write and share journal entries with you. Ask your LBC Support Services Coordinator for more information about the LBC sticker journal.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For pre-school or school-age children, it is a good idea to speak with their teachers to let them know about your diagnosis and how this is affecting family/whānau routines and relationships.

LBC has a 'Supporting a child through a loved one's cancer diagnosis' fact sheet available on the LBC website or from an LBC Support Services Coordinator.

More information available online

Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your CLL diagnosis, and they may also find it difficult to discuss with you. Sometimes people, without realising it, make comments that can be hurtful or make suggestions that are unhelpful.

Most people are very keen to offer support but just don't know how. Here are some suggestions to help you build your own support team:

- Let people know what you need such as a regular phone call, text or visit.
- Share how you are feeling and any worries you have with a good listener.
- Encourage people to read this booklet or speak to your LBC Support Services Coordinator to learn more about CLL.
- Either you or a friend could make a list of practical tasks others can do to help you. You might like to include things like cooking meals, picking a child up from school or cleaning the house.

You may not always feel well enough to take individual phone calls or respond to texts. Some people find it helpful to have one person who updates friends and colleagues on how you are doing. That person can set up an email or social media group to share information.

Because CLL is a chronic type of leukaemia, it can be difficult for some friends and family to understand that you don't suddenly 'get better' or 'are cured'. Your journey with CLL may look different to other types of cancer and other people with leukaemia. You also may have periods of time that you are quite unwell or that your condition is well managed and you can continue to work and socialise as you normally would have before your diagnosis.

Some people find that after a year or so of having CLL others don't ask how they are doing or understand that they might still be having ongoing treatment and appointments for their CLL. Try and find a 'support network' that help you feel validated and cared for. This might be a variety of people like close friends, family/whānau, colleague, counsellor/ psychologist and/or LBC support Services Coordinator.

Financial worries

A diagnosis of CLL can cause money worries, perhaps through a drop in income or extra expenses. If you are working, keep in touch with your boss to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your Support Services Coordinator.

Ask your social worker for advice and support about money worries.

More information available online

Sexual relationships

You cannot give cancer to another person when you have sex with them.

People who receive a diagnosis of CLL and have treatment can experience changes in their sex life. The reasons for this include:

- Extreme tiredness
- The side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety
- Changes to body image, e.g. due to hair loss, weight change
- Changes to libido
- Vaginal dryness or difficulty getting an erection.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

Contraception

Women are advised not to become pregnant while on some treatments for CLL. This is because CLL drugs may harm a developing baby. It is important to use contraception during treatment and for several months afterwards.

If you are having, or recently finished, treatment, always use a condom when having sex.

Even if you are beyond childbearing age or no longer need birth control, it is still important to use condoms until after your treatment has finished, for two main reasons:

1. To protect yourself from getting an infection. Your low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, bowel motions and sperm and vaginal secretions. The small amounts of chemotherapy that come out this way can cause irritation (a rash or itching) to your partner's skin.

Talk to your health care team if you have any questions about contraception or getting pregnant.

Sex when you have a low platelet count

Speak with your doctor or nurse about sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea for women to use a lubricating jelly (lube) such as KY Jelly.

New relationships

Some people feel worried about starting a new relationship following a diagnosis of CLL. It can be difficult to know what to say. Being open and honest about your experience will make it easier for you. Talk to your friends, family/whānau or your health care team if you have concerns about what to say.

Information for people supporting someone with CLL

As the partner, parent or carer of someone with CLL, it is quite common to experience feelings of stress, anger, fear, anxiety or depression. Speak with the health care team or LBC Support Services Coordinator if you are feeling this way. There is a lot of support available to you.

Other things you can do:

- Look after yourself by eating well, getting enough sleep, doing regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group and/or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Use these tips to assist you now. Some ideas might include talking to friends or writing a diary.

A diagnosis and the treatment of CLL can put a lot of strain on a relationship. However, some people find that they feel closer as a result of what they go through together.

Remember the health care team or LBC Support Services Coordinator are there to support you at any time throughout your diagnosis, treatment and beyond.

KEEPING IN GOOD HEALTH AFTER YOUR CLL DIAGNOSIS

After a diagnosis of CLL, it is important to look after your health. When you feel well enough, doing regular exercise and eating healthy food are very important.

The following health changes should be made immediately to reduce complications from your treatment or any long-term side effects:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol or cut down.

Your health care team can advise you on how to keep well.

The physiotherapist can advise you about the exercise that is right for you.

The dietitian can advise you about eating well, especially if your treatment is making you feel sick or you have taste changes.

Ask your doctor or nurse about support to help you stop smoking and reduce or stop drinking alcohol.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.

THE FUTURE

A diagnosis of CLL can affect many areas of your life such as work, your emotions, relationships and finances.

For some people, a diagnosis of CLL can mark a turning point in their lives. For others, a diagnosis means they feel their life has been put 'on hold'. The length of time it may take to recover emotionally and physically from a CLL diagnosis or treatment is different for everyone. Getting back to your previous routine of work or childcare, for example, may be a goal, or it may not be what you want any more. You may need to make a few adjustments to your life.

Your health care team and LBC Support Services Coordinator can help you manage:

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with family/whānau, friends and colleagues.
- Emotional effects of CLL and treatment including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and those around you cope.

Some people find it helpful to speak to someone else who has been diagnosed with CLL, or their support person. Your nurse, specialist or LBC Support Services Coordinator may be able to put you in contact with someone you can talk to.

Travelling overseas

If you are thinking of travelling overseas, speak to your doctor before making any bookings to check if they have any concerns about you travelling.

It can sometimes be difficult to get travel insurance when you have been diagnosed with cancer. Speak with your LBC Support Services Coordinator, who will be able to help you.

After treatment

Once your treatment has finished, you will have regular check-ups with your haematologist and health care team. You will also be encouraged to go back to see your GP. Your health care team will send regular letters to your GP to tell them about your progress and what needs to be followed up, e.g. blood tests and vaccinations. If your GP has any questions, they are able to contact your haematologist for advice.

GLOSSARY

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.

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

Antiemetic – A drug which prevents or reduces feelings of sickness (anti-sickness).

Antigens – An antigen can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see immune system.

Anxiety – An ongoing worry or concern about something that doesn't go away. Feelings of worry that a person does not seem to be able to control or seem greater than they should be for a situation.

Blood count – Also called a full blood count (FBC) or complete blood count (CBC). A routine blood test that measures the number and types of cells circulating in the blood.

B-lymphocyte – A type of white blood cell normally involved in the production of antibodies to combat infection. Also called B-cells.

Bone marrow – The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

Bowel – Also known as intestines or guts. After your stomach has finished with the food you eat it goes into your small bowel, which absorbs nutrients that the body needs. What is left after this moves into your large bowel and eventually moves out of your body as waste, known as a bowel motion or, as it is commonly known, poo.

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 that is inserted into a vein (intravenously or IV) to allow fluid to enter the bloodstream.

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 unwanted side effects. Most of the side effects of chemotherapy are usually temporary and reversible.

Chromosomes – Your body is made up of cells. Inside most cells are chromosomes which, under a microscope, look like threads. These threads contain hundreds to thousands of genes. Genes determine things like what colour your hair and eyes are and how your body develops. You have 23 pairs of chromosomes and you get half from your mother and the other half from your father.

Chronic – An illness or disease that persists for a long time or is constantly recurring.

Cold sores – Red sores filled with fluid that mainly form around the mouth. Caused by a herpes virus, which is contagious and can take two weeks or longer to go away.

Complementary therapies – Therapies used alongside your medical treatment that help you feel better or help you cope with your diagnosis and treatment, e.g. massage, yoga.

Complete remission – Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology.

Cure – This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytogenetic tests – Cytogenetic tests are commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

Digestive system – The system in your body that deals with food. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

Disease progression – This means that the disease is getting worse despite treatment.

DNA (deoxyribonucleic acid) – The cell's hereditary material which contains instructions for development, growth and reproduction. DNA is located in nearly every cell of the human body. DNA is found in chromosomes.

Foetus – An unborn child.

Genes – Genes are made up of DNA. Each chromosome contains many genes. Every person has two copies of each gene, one inherited from each parent.

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

Haemopoiesis (or haematopoiesis) – The processes involved in blood cell formation.

Immature – Not fully developed, e.g. a cell that is immature is still at a baby stage. It will mature (or develop) over time to an adult stage.

Immune suppression – The use of drugs to reduce the function of the immune system.

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

Immunocompromised – When the function of the immune system is reduced.

Immunoglobulin – See Antibodies.

Immunophenotyping – Specialised laboratory test used to detect markers on the surface of cells. These markers identify the origin of the cell.

Incurable – A disease or illness that is unable to be completely removed or treated to the point it doesn't exist in a person's body. Unable to be cured.

Leukaemia – Cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

Leukaemic cells – Abnormal 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.

Lymph nodes or glands – Structures found throughout the body, e.g. in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are hundreds of lymph nodes throughout the body.

Lymphatic system – An extensive network of vessels that carries a fluid called lymph through almost all tissues in the body. Lymph circulates through the body in a similar way to blood. The lymphatic system is part of the immune system.

Lymphocytes – Specialised white cells involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-cells.

Lymphoid – Term used to describe a pathway of maturation of blood cells in the bone marrow. White blood cells (B-lymphocytes and T-lymphocytes) are derived from the lymphoid stem cell line.

Malignancy – See cancer.

Markers – A gene or DNA sequence with a known physical location, and where it has come from. In genetics, markers act as chromosomal landmarks. They are used to trace or identify a specific region of a gene or chromosome.

Menopause – The time in a woman's life when her period stops and she is no longer able to have children. Hormones produced by the ovaries decrease after menopause. Also see Ovaries.

Minimal residual disease (MRD) – A very small number of cancer cells that remain in the body during or after treatment. MRD can be found only by highly sensitive laboratory tests that are able to find one cancer cell among one million normal cells. This is called MRD testing.

Mucositis – An inflammation of the lining of the mouth, throat or gut.

Myeloid – A term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, white blood cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

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.

Neutrophils – Neutrophils are the most common type of white blood cell. They are needed to mount an effective fight against infection.

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

Osteoporosis – A condition where bones become brittle and fragile and can break more easily.

Ovaries – Small organs that produce and then release eggs into a women's reproductive system, and produce female hormones.

Partial remission – The tumour shrinks to less than half its original size after treatment. In people with leukaemia, this means that the proportion of blast cells in the bone marrow has been reduced following treatment, but not necessarily below 5%. There are still some leukaemic cells present.

Petechiae – Tiny purple or red spots on the skin caused by bleeding into the skin. They commonly appear in clusters and may look like a rash. They are usually flat to the touch and don't lose their colour when you press on them.

Power of attorney – One person gives another person permission to act on their behalf, such as making decisions about their health or operating their bank account. You usually go to see a lawyer to arrange this.

Prognosis – An estimate of the likely course of a disease.

Psychological – Concerning your mental and emotional well-being.

Radiotherapy (radiation therapy) – The use of high-energy x-rays to kill cancer cells and shrink tumours.

Relapse – The return of the original disease.

Resistant or refractory disease – This means that the disease is not responding to treatment.

Rigours – A chill (feeling cold), usually with shivering, at the onset of having a high fever (temperature).

Spleen – An organ that accumulates lymphocytes, acts as a reservoir for red blood cells for emergencies, and destroys red blood cells, white blood cells and platelets at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It is often enlarged in diseases of the blood or bone marrow.

Splenomegaly – Enlargement of the spleen.

Stable disease – When a disease is stable, it is not getting any worse or any better with treatment.

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 cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the different blood cells including red cells, white cells and platelets.

Stem cell transplant (haemopoietic or blood stem cell transplant) – The general name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma, myeloma and other diseases.

Supplements – Tablets or liquids you take as well as the food you eat. Supplements include vitamins, minerals, herbs or other plants.

T-lymphocyte – A type of white blood cell involved in controlling immune reactions. Also called T-cells.

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.

Urinary tract infection – A urinary tract infection (UTI) is an infection in any of the parts of your body which make or store urine or take urine out of your body, e.g. bladder or kidneys.

White blood 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.

APPENDIX A

The following are sample questions to ask your doctor when you are diagnosed with CLL, referred to a haematologist or considering treatment.

Place a tick alongside the questions you would like to ask. You could add your own questions in the space provided. Record the answers to your chosen questions in your Haematology Patient Diary or on the 'Questions and notes' page that follows.

- ☐ What doctor will be managing my CLL?.
- ☐ How often do I need to have a blood test? Will my GP or haematologist review my blood tests and who will contact me with the results?
- ☐ How do I arrange an appointment if I develop new symptoms?
- ☐ What should I do if I develop an infection during the night or at the weekend?
- ☐ Is there anything I can do to help my general health?
- ☐ What exactly does the treatment involve? How long will the entire treatment take? What are the alternatives to this treatment?
- ☐ How ill might I feel before, during and after treatment?
- ☐ What are the potential side effects, how long might they last and how serious are they? Why are you recommending this treatment for me?
- ☐ What is the expected outcome of this treatment for me? For example, complete remission, prolong remission, symptom management.
- ☐ If the CLL comes back (relapse), what are the options for me?
- ☐ How can I prepare myself for starting treatment?

QUESTIONS AND NOTES

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ACKNOWLEDGEMENTS

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Leukaemia & Blood Cancer New Zealand

LBC is the leading organisation in New Zealand dedicated to supporting patients and their families/whānau living with leukaemia, lymphoma, myeloma and related blood conditions.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants. We do not receive government funding.

LBC is committed to improving the quality of life for patients and their families/whānau living with these blood cancers and conditions by providing patient support services, investing in and supporting research, providing information, raising awareness and advocating on behalf of patients and their families/whānau.

HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna	09 486 8900
Auckland City Hospital	Park Road, Grafton	09 367 0000
Starship Hospital	Park Road, Grafton	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	03 364 0640
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949

Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, and our Support Services Coordinators are here to help.

Freephone 0800 15 10 15
Telephone 09 638 3556
Facsimile 09 638 3557
Email info@leukaemia.org.nz

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leukaemia.org.nz

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Charities Commission no. CC24498

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