Understanding Chronic Lymphocytic Leukaemia (CLL) & Small Lymphocytic Lymphoma (SLL)

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Acknowledgements
Lymphoma Australia would like to acknowledge the traditional owners of the vast lands across Australia, and pay our respects to their Elders, past, present, and emerging. We would also like to acknowledge and pay our respects to all Aboriginal and Torres Strait Islander people living with or caring for those with CLL/SLL.

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Contents

You are not alone

Each year, around 1,000 people find themselves in the same situation that you or your loved one are in right now - hearing the words “you have Chronic Lymphocytic Leukaemia/Small Lymphocytic Lymphoma”.

It can be overwhelming. You might be in shock from being told you have cancer, trying to absorb what your doctor is telling you, and wondering what happens next.

For more than 18 years, Lymphoma Australia has provided essential information and support to people living with lymphoma. Our aim is not to make you an expert on all things Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL) but rather, we are here to listen to your needs and work with different healthcare professionals to meet those needs.

Information about lymphoma, its management, support for you and much more can be found at www.lymphoma.org.au

It may seem impossible to see the positives in life after receiving a CLL/SLL diagnosis; but the good news is, CLL/SLL is highly treatable and while it may not be curable many people diagnosed with this lymphoma can go on living for many, many years. New treatments are developed regularly, and treatment of lymphoma and CLL/SLL specifically, has improved a great deal over the last few years. So yes, there is good reason for you to have more hope than ever before.

You will need a variety of support when going through tough times though. We'll be here when you need us. But we also strongly encourage you to "gather your crew" – your friends and family who you can rely on. It will help if you can tell them what you need, and how they can best support you. You may need a conversation, a ride to the hospital, a meal cooked, help with shopping or just going out to take your mind off things. Share the load, and if people offer, let them help!

We hope this booklet helps answer many of your questions about CLL/SLL and provides you with the information, clarity, and confidence you need to manage your lymphoma. If you still find you have questions, I encourage you to visit our website or reach out to one of our dedicated Lymphoma Nurses on **1800 953 081** or **nurse@lymphoma.org.au**.

Sharon Winton
CEO, Lymphoma Australia

What is Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL)?

Lymphoma is not as familiar to many people as cancer, and learning about it can be like learning another language. We've added a glossary at the back of this book to help you learn this new language, and to refer to as you read this book.

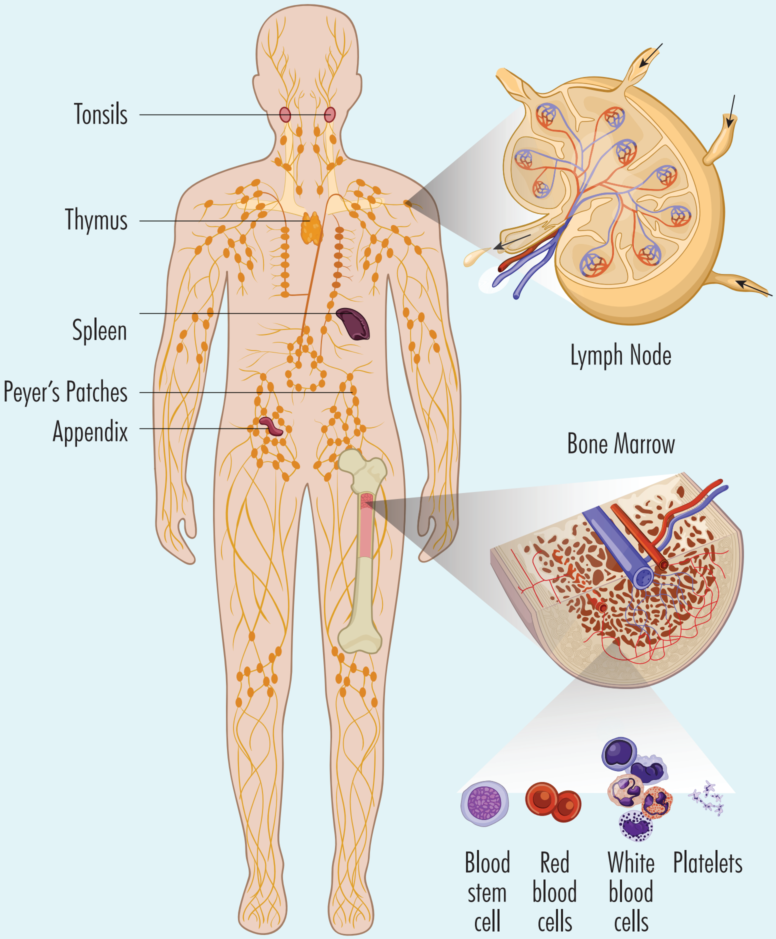
Lymphoma is a cancer of your B-cell lymphocytes (B-cells). B-cells are white blood cells that support your immune system by fighting infection and protecting you from disease. They live in your lymphatic system, but can also gather in the lining of your bowel, respiratory, genital and urinary tracts.

Your lymphatic system is the body's quiet achiever. It provides many life-saving functions - from controlling fluid in your body, to keeping your immune system healthy. It may not get the same attention as the cardiovascular or digestive systems, but it's just as important!

The lymphatic system is made up of:

- Lymph nodes: small, bean-shaped organs found throughout your body.
- Lymphatic vessels: circulate fluid in your body
- Lymphatic organs: where your lymphocytes mature, live and make antibodies

Lymphatic System



Lymphocytes are a type of blood cell, that live in your lymphatic system, and support your immune system. Lymphomas have been called cancer of the blood, cancer of the lymphatic system and cancer of the immune system. But rather than being three types of cancer, these terms provide the what, the where and the how.

What – your lymphocytes – a type of white blood cell

Where – living and usually starting in your lymphatic system

How – it affects your immune system, because your white cells fight infection and protect you from disease.

Chronic Lymphocytic Leukaemia (CLL) and Small Lymphocytic Lymphoma (SLL) are subtypes of lymphoma, which is the most common blood cancer as classified by the World Health Organisation. There are over 80 different subtypes of lymphoma that arise from a type of white blood cell called a ‘lymphocyte’.

About Chronic Lymphocytic Leukaemia (CLL) /Small Lymphocytic Lymphoma (SLL)

Chronic Lymphocytic Leukemia (CLL) and Small Lymphocytic Lymphoma (SLL) develop when certain blood cells in your body, B-cell lymphocytes (B-cells), become cancerous. They are classified as slow-growing (indolent) lymphomas.

CLL and SLL are basically the same disease. The difference between them is where the lymphoma cells are located. When lymphoma cells are mostly in the bloodstream and bone marrow, it is called CLL (that is why it is called leukaemia). When the lymphoma cells are mostly in the lymph nodes and lymphatic system, it is called SLL.

Because CLL and SLL are so similar the tests, management, and treatment for them are the same.

CLL is more common than SLL and is the second most common indolent B-cell cancer in people over 70 years of age. It is also more common in men than in women, and very rarely affects people under 40.

Most indolent lymphomas are not curable, which means once you are diagnosed with CLL/SLL, you will live with it for the rest of your life.

We understand that a cancer diagnosis is always overwhelming, no matter what. It can be particularly overwhelming hearing that your cancer is not curable. However, the good news is because CLL/SLL is a slow-growing blood cancer you may be able to live a full life without symptoms and not need medical treatment right away. In fact, some people with CLL/SLL may never need treatment. There may come a time when you experience symptoms and need treatment and if managed well, you can remain healthy and continue to do what you love.

Understanding CLL/SLL

To better understand CLL/SLL, it might be helpful to know more about your B-cell lymphocytes and the role they play.

B-cell lymphocytes are made in your bone marrow (the spongy part in the middle of your bones), but usually live in your spleen and lymph nodes. They are a type of white blood cell, and their main job is to fight infection and disease to keep you healthy. Your B-cells also serve to remember infections you have had in the past, so if you get the same infection again, your body's immune system can fight it more effectively. B-cells can travel around to any part of your body to fight an infection or disease.

When you are diagnosed with CLL/SLL it is because the B-cell lymphocytes have become abnormal and grow uncontrollably, resulting in too many B-cell lymphocytes. They do not die when they should to make way for new healthy cells. They also grow too quickly so they may not develop properly, therefore cannot do their job of fighting infection and disease.

Because they grow too quickly, they can take up too much space in your bone marrow, affecting other blood cells, such as red blood cells and platelets, that are then unable to grow properly.

Fast Facts

- Around 1,000 people are diagnosed with CLL/SLL each year in Australia.
- Around 30-50% of people diagnosed with CLL/SLL never need treatment.
- The risk of developing CLL/SLL increases with older age.
- Almost 80% of all new cases of CLL/SLL are diagnosed in people over the age of 60

Risk Factors

Factors that may increase your risk of CLL/SLL include:

- Your age – CLL/SLL most often occurs in older adults.
- Your race – Caucasian people are more likely to develop CLL/SLL.
- Your family history – if someone in your family has had a blood and bone marrow cancer, you may have a higher risk of developing CLL/SLL.
- If you have had exposure to certain chemicals - certain herbicides and insecticides, including Agent Orange used during the Vietnam War, have been linked to an increased risk of CLL
- A condition that causes excess lymphocytes – Monoclonal B-cell Lymphocytosis (MBL) causes an increased number of one type of lymphocyte (B-cell) in the blood. For a small number of people with MBL, the condition may develop into CLL. If you have MBL and have a family history of CLL, you may have a higher risk of developing the disease.

Symptoms

As CLL/SLL are slow-growing cancers, you may not have experienced any symptoms at the time you were diagnosed. In fact, many people are diagnosed when they have a routine blood test or a physical exam for something else. So it can be quite a shock to be diagnosed with a type of cancer especially if you are feeling healthy and well..

Many people with CLL/SLL live long healthy lives however, over time you may start to experience some symptoms. Symptoms you may experience are:

- Feeling unusually tired (fatigued) – this type of tiredness does not get better after a rest or sleep.
- Feeling out of breath.
- Bruising or bleeding more easily than usual. This can include when you go to the toilet, bleeding from you nose or gums, or even getting reddish/purplish spotty rash.
- Infections that don't go away (refractory) or keep coming back (recurrent.)
- Sweating at night more than usual.
- Losing weight without trying.

- A new lump in your neck, under your arms, in your groin, or other areas of your body.
- Low blood counts such as:
  - Anaemia – low haemoglobin (Hb). Hb is a protein on your red blood cells that carry oxygen around your body.
  - Thrombocytopenia – low platelets (also called thrombocytes). Platelets help your blood to clot, so you don't bleed and bruise easily.
  - Neutropenia – low white blood cells called neutrophils. Neutrophils fight infection and disease.
- B-symptoms *(see picture)*

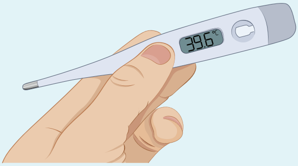
If any of these symptoms are new or worsening, please talk to your doctor or cancer care treatment team.

B-Symptoms

B-symptoms are a group of three distinct symptoms that some people with lymphoma/CLL can get. They often occur together and may indicate that your lymphoma or CLL is more advanced.

Drenching night sweats – where your clothes and bedding become saturated.

Losing weight without trying, and without other reason.



A high fever of 37.5° or more that keeps coming back or does not go away even when you don't have an infection. You may even get chills.

Diagnosis

Diagnosing CLL/SLL can be difficult or is sometimes delayed as symptoms are often like those you may have had with other more common illnesses, such as infections and allergies. You may not even experience any symptoms. But if you do go to the doctor with any of the above symptoms, they may want to do a blood test and physical examination. If they then think you may have a blood cancer like lymphoma or leukaemia, they will recommend more tests to get a more definitive diagnosis and if so, see if the disease has spread throughout your body.

To diagnose CLL/SLL you will need a biopsy of your swollen lymph nodes and/or your bone marrow. This is a procedure when a small part of tissue is removed and examined. There are three ways to get the best biopsy and your doctor will discuss with you the best type for your situation.

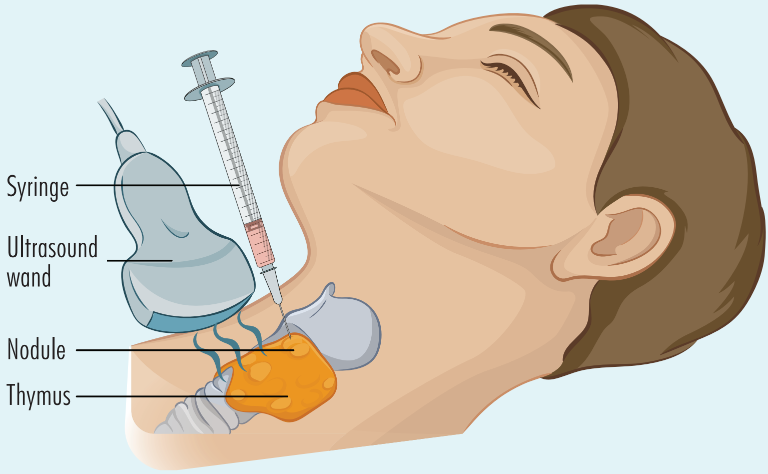
Some of the common biopsies include:

Excisional node biopsy - this type removes the whole lymph node.

Core or fine needle biopsy - this type only takes a sample from the affected lymph node.

Bone marrow biopsy - this biopsy takes a sample from your bone marrow.

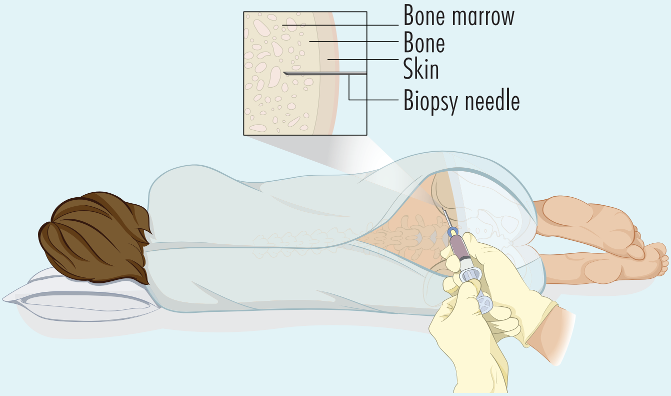
Biopsy



If you have a biopsy, you may have a local or general anaesthetic - this will depend on what part of your body the biopsy is taken from.

Your biopsy and your blood tests are then sent to the pathology to be examined. The pathologist will also run another test on your lymphocytes called a ‘flow cytometry’. This is a special test to look at any proteins or ‘cell surface makers’ on your lymphocytes that help to diagnose CLL/SLL, or

Bone Marrow Aspirate and Trephine



other subtypes of lymphoma. Knowing what these proteins and markers are, is important as they give your doctor information about what type of treatment may work best for you.

Waiting for Results

It can sometimes take quite a few weeks for your results to come back, and waiting for them can be a very anxious time. It may help to talk to family and friends or a counsellor while you wait. You can also contact us at Lymphoma Australia by reaching out to our Lymphoma Care Nurse via email at **nurse@lymphoma.org.au** or calling **1800 953 081.**

You might also find it helpful to chat to others who have been in a similar situation. You can connect with others through our online community on Facebook, Instagram or Twitter.

https://www.facebook.com/LymphomaAustralia

https://www.instagram.com/lymphomaaustralia/

https://twitter.com/lymphomaoz

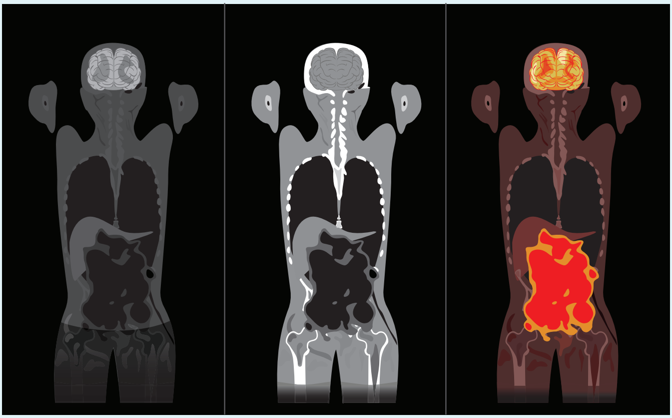
Staging and Grading

After your diagnosis is confirmed, your doctor will organise additional tests to check if the lymphoma has spread to other parts of your body, and how the lymphoma cells are growing. These tests are referred to as 'staging and grading' tests.

Staging tests tell your doctor how much CLL/SLL is in your body; how many areas of your body have the cancerous B-cells, and how your body is coping with the disease. These tests may include:

- **Position emission tomography (PET) scan** - an injection with a radioactive glucose (sugar) is given before you have a full body scan. Glucose is absorbed by the cancer cells and highlights these areas on the PET scan. This is done at the nuclear medicine facility in a hospital.
- **Computed tomography (CT) scan** - a series of X-rays provide detailed, 3D images of the inside of your body.
- **Lumbar puncture** - your doctor will use a needle to take a sample of fluid from near your spine. This is done to check if your lymphoma is in your brain or spinal cord. You may not need this test, but your doctor will let you know if you do.

PET Scan



One of the main differences in CLL/SLL (apart from their location) is in the way they are staged. There are two staging systems used for CLL/SLL – one specifically if you have been diagnosed with CLL and one if you have been diagnosed with SLL.

The RAI Staging System

Staging for CLL differs slightly from other subtypes of lymphoma including SLL, because CLL starts in your blood and bone marrow rather than your lymphatic system. However, even though it starts in your blood or bone marrow, it can still spread to other parts of your body including your lymphatic system, so staging will look at where else in your body it has spread to.

The RAI staging system will look at your CLL to see if you do, or do not have any of the following:

- High levels of lymphocytes in your blood or bone marrow – this is called lymphocytosis.
- Low levels of red blood cells in your blood – anaemia.
- Low levels of platelets in your blood – thrombocytopenia.
- Swollen lymph nodes – lymphadenopathy.
- An enlarged spleen – splenomegaly.
- Enlarged liver – hepatomegaly.

What each RAI stage means

RAI stage 0	Lymphocytosis and no enlargement of the lymph nodes, spleen, or liver, and with near normal red blood cell and platelet counts.
RAI stage 1	Lymphocytosis plus enlarged lymph nodes. The spleen and liver are not enlarged, and the red blood cell and platelet counts are normal or only slightly low.
RAI stage 2	Lymphocytosis plus an enlarged spleen (and possibly an enlarged liver), with or without enlarged lymph nodes. The red blood cell and platelet counts are normal or only slightly low.
RAI stage 3	Lymphocytosis plus anaemia (too few red blood cells), with or without enlarged lymph nodes, spleen, or liver. Platelet counts are near normal.
RAI stage 4	Lymphocytosis plus thrombocytopenia (too few platelets), with or without anaemia, enlarged lymph nodes, spleen, or liver.

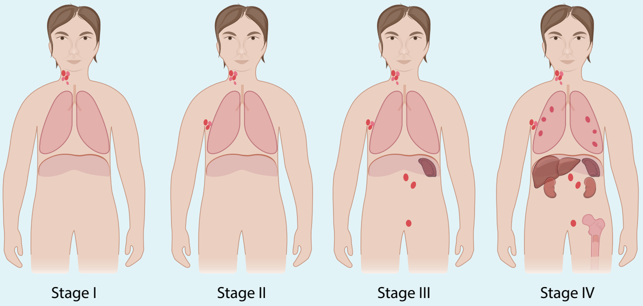
The Ann Arbour or Lugano Staging System

The Ann Arbour or Lugano staging system is used to determine what stage your SLL is. This will depend on:

- How many areas of your body have lymphoma.
- Where the lymphoma is, including if it is above or on both sides of your diaphragm (a large dome-shaped muscle under your rib cage that separates your chest from your abdomen).
- Whether the lymphoma has spread to your bone marrow or other organs such as your liver, lungs, skin, and bone.

Stages 1 and 2 are called 'early or limited' stage (involving a limited area of your body) where Stage 3 and 4 are called 'advanced stage' (more widespread).

Staging of lymphoma



Stage 1	One lymph node area is affected, either above or below the diaphragm.
Stage 2	Two or more lymph node areas are affected on the same side of the diaphragm.
Stage 3	At least one lymph node area above and at least one lymph node area below the diaphragm are affected.
Stage 4	Lymphoma is in multiple lymph nodes and has spread to other parts of the body (e.g. bones, lungs, liver).

Additionally, there may be a letter ‘E’ after your stage. The ‘E’ means that you have some SLL in an organ outside of your lymphatic system, such as your liver, lung, bones, or skin.

All this information gives your doctor a good picture to help decide the best type of treatment for you.

So, **staging** looks at **where** your CLL/SLL is growing and how it is affecting you.

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For more information about staging and grading, scan the QR code or **click here**

It can be tempting to read reports before seeing your doctor, but this can cause confusion or unnecessary concern, so we recommend holding off until you see your doctor. Each test is important, but remember they are only a small part of your whole picture. Your doctor will explain what the whole picture means, and what your best treatment options are. They will also answer any questions you may have.

Understanding your CLL/SLL Genetics

There are many genetic factors that may be involved in your CLL/SLL. Some may have contributed to the development of your disease, and others provide useful information about what the best type of treatment is for you. To find out what genetic factors are involved you will need to have cytogenetic tests done.

Cytogenetic tests are done on your blood and biopsies to look for changes in your chromosomes or genes. We usually have 23 pairs of chromosomes but if you have CLL/SLL your chromosomes may look a little different.

Genes tell the proteins and cells in your body how to look or act. If there is a change (variation or mutation) in these chromosomes or genes, your proteins and cells will not work properly, and you can develop different diseases. With CLL/SLL, these changes can change the way your B-cell lymphocytes develop and grow, causing them to become cancerous.

The three main changes that can happen with CLL/SLL are called a **deletion, translocation**, and a **mutation.**

Deletion

A deletion is when part of your chromosome is missing. If your deletion is a part of the 13th or 17th chromosome it is written as either “del(13q)” or “del(17p)”. The “q” and the “p” tell the doctor which part of the chromosome is missing, and it is the same for other deletions.

Translocation

If you have a translocation, it means a small part of two chromosomes - chromosome 11 and chromosome 14 for example, swap places with each other. When this happens, it is written as “t(11:14)”.

Mutation

If you have a mutation, it may mean you have an extra chromosome – this is called Trisomy 12 (an extra 12th chromosome). Or you may have other mutations called IgHV mutation or Tp53 mutation.

Genetic Testing Before You Start Treatment

It is important that you have genetic testing before you start any treatment for your CLL/SLL. Some of these tests you will only need to have once because the results do not change over time. Other tests however, you may need to have before every treatment, or at various times throughout your CLL/SLL journey - this is because over the course of time, new genetic mutations can occur as result of your treatment, your disease, or other factors.

The more common cytogenetic tests you should have include:

- **IgHV mutation status** - you should have this test before your first treatment. You only need this test done once as it does not change over time. This will be reported as either a mutated IgHV or an unmutated IgHV.
- **Fluorescent In Situ Hybridisation (FISH) test** - you should have this test before your first and every treatment as genetic changes to your FISH test can happen over time. This test can show if you have a deletion, a translocation or an additional chromosome and will be reported as del(13q), del(17p), t(11:14) or Trisomy 12.
- **TP53 mutation status** - you should have this test before your first and every treatment as TP53 can change over time.

It is important you understand these possible changes as we know that not all people with CLL/SLL have the same genetic variations. These variations provide information to your doctor about the type of treatment that may work or will likely not work for your particular CLL/SLL.

For example, we know that if you have a **TP53 mutation, an unmutated IgHV or del(17p)** you **should not receive chemotherapy** as you will not respond to treatment with it. However, this does not mean that there is no treatment. There are some targeted treatments available that can work well for people with these variations.

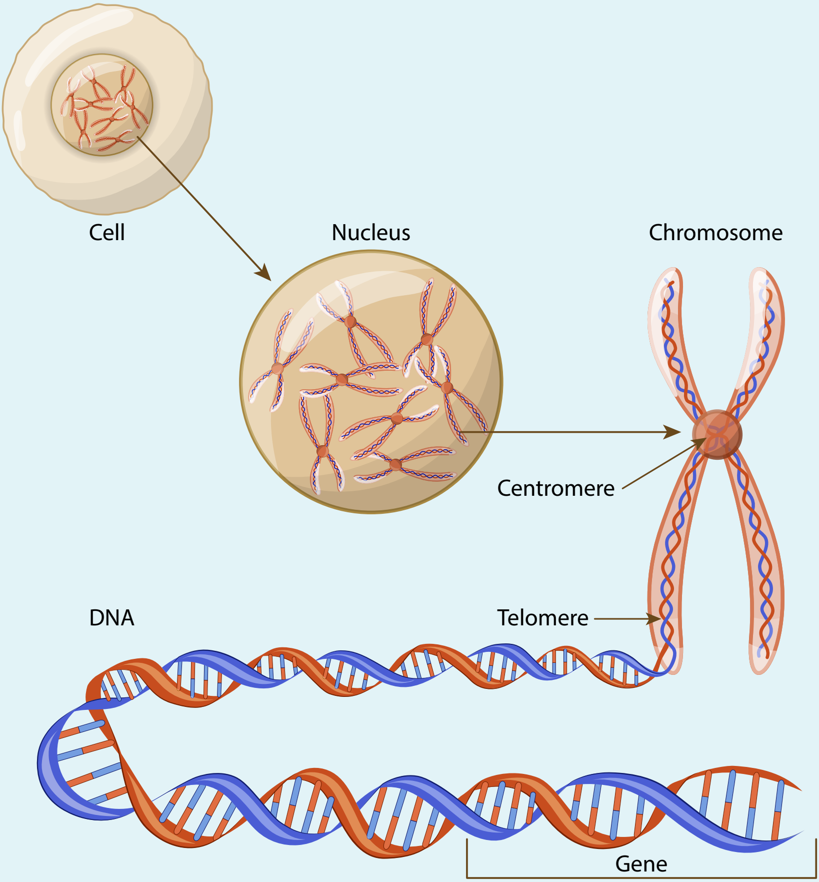
Talk to your doctor about your cytogenetic tests and what the results may mean for your treatment options.

Treating Your CLL/SLL

Once your doctor has all your results from your biopsy, cytogenetic testing and the staging scans, they will review them to determine the best possible treatment for you. Depending on where you are being treated, your doctor may meet with a team of specialists to discuss the best option. This is called a **multidisciplinary team (MDT)** meeting.

- The decisions about when and if you need to start treatment, and what that treatment is are based on many factors, including:

Cytogenetics



Treatment and Managing Care

- Your individual stage of lymphoma, genetic changes, and symptoms.
- Your age, past medical history, and general health*.
- Your current physical and mental wellbeing.
- Your personal preference once you have all the information and have had time to ask questions.

**Your doctor will also order more tests before you start treatment to make sure your heart, lungs and kidneys are able to cope with treatment prescribed.*

Active Monitoring (Watch and Wait)

Because CLL/SLL is a generally slow-growing cancer, you may have it for years without any signs or symptoms, and even when you are diagnosed you still may not need any treatment at all. In fact, around 1 in 10 people with CLL/SLL may never need treatment. Many people will only need to see their doctor for a regular check-up, including blood tests or scans to watch if the CLL/SLL starts growing more quickly. This is called 'active monitoring', or you may have heard it referred to as 'watch and wait'.

Sometimes, people feel a little uncomfortable if they are under 'active monitoring' because they are not doing anything to treat their cancer. If you find yourself in this stage of active monitoring, try to see it as a positive – it is a great way to start as it means your own immune system is doing a good job in keeping your CLL/SLL under control, and you do not need extra help to fight your cancer.

If through your regular check-ups things change at any point and you need to start treatment, there are many effective treatment options now available. More treatments are also being developed and tested in clinical trials, so your CLL/SLL can be controlled for many years.

For more information on active monitoring scan the QR code or **click here**

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Chemotherapy (chemo)

These medications might be taken as a tablet and/or be given as a drip (infusion) in a cancer clinic or hospital. There are several different chemo medications that may be combined with an immunotherapy medicine. Chemo kills fast-growing cells so not only can they affect cancer cells but affect some of your good cells that grow fast.

Monoclonal Antibody (MAB)

Monoclonal antibodies are given as an infusion at a cancer clinic or hospital. MABs attach to the lymphoma cell and attract other disease-fighting white blood cells and proteins to the cancer so your immune system can fight the CLL/SLL. Some MABs are a type of immunotherapy because they use your own immune system to fight the lymphoma.

Chemo-Immunotherapy

This is when a particular chemotherapy (e.g. fludarabine cyclophosphamide or FC) is combined with an immunotherapy (e.g. rituximab or obinutuzumab). The first letter of the immunotherapy drug is usually added to the abbreviation of the chemotherapy regimen, such as FC-R. Other chemo-immunotherapy combinations include bendamustine plus obinutuzumab or bendamustine plus rituximab.

Targeted Therapy

You may take a targeted therapy as a tablet either at home or in hospital. Targeted therapies attach to the lymphoma cell and block the signals it needs to grow and produce more cells. This stops the cancer from growing and causes the lymphoma cells to die. Some approved targeted therapies include ibrutinib, venetoclax and acalabrutinib.

Stem Cell Transplant

If you are young and have aggressive (fast-growing) CLL/SLL, a stem cell transplant (SCT) may be used, but this is rare. To learn more about SCTs click here.

https://www.lymphoma.org.au/lymphoma/treatments/stem-cell-transplants/

CAR T-cell Therapy

One treatment that is being used for other blood cancers and is currently being tested in clinical trials for CLL/SLL is chimeric antigen receptor (CAR) T-cell therapy. This is a new type of immunotherapy that uses a person's own T-cells (a different type of lymphocyte) to recognise and destroy cancer cells. In CAR T-cell therapy, T-cells are taken from your blood and sent to a lab. The cells are then modified by having a man-made CAR (chimeric antigen receptor) to them before they are sent back to your hospital and given back to you in a similar way you would have a blood transfusion. The CAR is able to better recognise and attach to the lymphoma cells which helps the T-cell find and attack your lymphoma more effectively.

CAR T-cell therapy for the treatment of CLL/SLL is not approved in Australia. To learn more about CAR T-cell therapy click here.

https://www.lymphoma.org.au/lymphoma/treatments/chimeric-antigen-receptor-car-t-cell-therapy/

First-line Treatment

- If you have stage 3 or 4 CLL/SLL, you may need to start treatment.

Remember, CLL and SLL have a different staging systemSo the decision to start treatment will depend on the relevant stage of your subtype (either CLL or SLL).

When you start treatment for the first time, it is called first-line treatment. You may have more than one medicine, and these may include chemotherapy, a monoclonal antibody or targeted therapy.

When you have these treatments, you will have them in a cycle. This means that you will have the treatment, then a break, then another round (cycle) of treatment.

You can find more information about first line treatments by clicking here.

https://www.lymphoma.org.au/types-of-lymphoma/chronic-lymphocytic-leukemia-cll/

Second-line and Ongoing Treatment

After treatment you will more than likely go into a period of 'remission'. This is a stage where you have no signs of CLL/SLL left in your body, or when the CLL/SLL is under control and does not need further treatment. Remission can last for many years but eventually CLL/SLL usually comes back. This is referred to as a 'relapse' and you will then need a different treatment.

Some of you may not achieve remission with your first-line treatment. If this happens, your CLL/SLL is called 'refractory'. If you have refractory CLL/SLL, your doctor will probably want to try a different medication.

The treatment you have if you relapse after a period of remission, or if you have refractory CLL/SLL is called second-line treatment. The goal of second-line treatment is to put you into remission again.

The choice for your second-line treatment will depend on various factors including:

- How long you were in remission for.
- Your general health and age.
- What CLL treatment/s you have received in the past.
- Your personal preferences.
- Mutation status.

If you have a further remission then relapse and have more treatment, these next treatments are called third-line treatment, fourth-line treatment and so on.

You may need several types of treatment for your CLL/SLL but please, don't despair. The good news is that researchers are discovering new and more effective treatments for CLL/SLL that are increasing the length of time you can be in remission, keeping your disease under control for longer periods.

Research and development in CLL/SLL have been some of the most dynamic in blood cancer clinical research, with significant advances made in diagnosing and predicting the course of the disease. It has also led to the approval of new targeted therapies that have potential to change the way in which CLL/SLL is managed, improving the overall outcomes for those living with the disease.

For more information about targeted therapies scan the QR code or **click here**

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Clinical Trials

It is always a good idea before you start a new treatment to ask your doctor about clinical trials you may be eligible to join. Clinical trials are important to find new treatments, or combinations of treatment to improve the management of CLL/SLL in the future.

Participating in clinical trials also gives you the chance to try a new medicine, a combination of medicines or other treatments that you would otherwise not be able to access outside of a clinical trial setting. If participating in a clinical trial is something you would like to consider, ask your doctor to see if there are any clinical trials you might be eligible for.

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For more information on clinical trials scan the QR code or **click here**

The main goals after treatment for your CLL/SLL are:

- **Be as active as possible in your work, family and other life roles.**
- **Lessen the side effects and symptoms of the cancer and its treatment.**
- **Identify and manage any late side effects.**
- **Help keep you as independent as possible.**
- **Improve your quality of life and maintain good mental health.**

Beginning Your Treatment Pathway

There is no preparing you for a cancer diagnosis, but when it comes to starting treatment, you can get ready for what lies ahead. Even taking small steps can improve your sense of wellbeing and help you feel more in control.

Below are some tips that can help you prepare for treatment.

- ✓ **Have a clear plan** - It's important to make sure you and your cancer care team agree to what your treatment involves. This includes what happens during treatment, how long it will take, what the potential side effects are and what the ultimate goal of treatment is. It is also a good idea to have a family member or friend with you when speaking with your doctor so they can take notes. It is also ok to ask for a second opinion. Your haematologist/oncologist or your local doctor (GP) can help you with a referral. Second opinions can help you feel more confident about your choice to start treatment.

✓ **Plan for what you can** - No matter what your treatment pathway may entail, it is more than likely you will not feel your best during treatment or during recovery, so think about what you might need and plan ahead. This might include travel to and from the hospital, caring responsibilities you may have for family or pets, work commitments and other personal commitments.

✓ **Tap into your network and gather your crew** - Have family and friends help you organise where they can support you before you start treatment. Now is not the time to hold back from asking your network to take on specific tasks – be it picking up children, walking the dog, cooking food, or keeping up with the housework. To help with this, look at https://www.gathermycrew.org.au/

- ✓ **Practice healthy habits** - Take note of your mental and physical health. In the lead up to starting treatment make sure to eat healthy foods, and exercise if you can. Consider ways of maintaining your mental health with things like meditation, mindfulness, yoga, or talking to a counsellor. How you feel going into treatment can affect how you feel as you go through it, so it is a good idea to try make sure you are feeling as good as you can – both physically and mentally – to help maintain a good quality of life. You might consider meeting with a dietitian or nutritionist, physical therapist or exercise physiologist who specialises in helping people with cancer. Your local doctor can help with this.

- ✓ **Expect changes in your appearance** - Some treatment side effects you may experience can affect your appearance. Chemotherapy for example, may cause hair loss, weight loss or skin rashes. It is a good idea to prepare yourself for these possibilities to lessen further anxiety or stress you may already be feeling. Ask your doctor or cancer nurse what to expect.

- ✓ **Talk to someone who's been through it** - Connecting with others who have lived experience of what you are going through can help ease uncertainty, anxiety or fear you may be naturally feeling. You can connect with someone by asking your doctor or through your hospital's social work department. You can also connect with others through our online community on Facebook, Instagram and Twitter.

A note about fertility and treatment

While CLL/SLL is more common in people over the age of 70, and very rarely affects those less than 40 years of age, it can happen.

If you are one of the rare few who has been diagnosed under 40 years of age and having children (or further children) is something you were considering up until this point, it is important to note that chemotherapy and radiotherapy can affect fertility. For many, fertility is the last thing they think about when they are first diagnosed with lymphoma. However, it is something you should openly discuss with your doctor and cancer care team before you start treatment, so you are aware of the options available to you, and understand the long-term effects from treatment.

Taking Care of Yourself During Treatment

There are many things you can do to take better care of yourself while living with and/or being treated for CLL/SLL. These lifestyle changes may help enhance your quality of life as well as your physical, mental, and emotional wellbeing. You'll see many of the things we have recommended you consider before you start treatment carry over as you undergo your treatment.

- ✓ **Exercise** - Add some type of exercise into your daily routine – even if simply just walking. As you go through treatment, it may be the last thing you feel like doing but regular exercise can improve your overall quality of life, boost energy, reduce stress, and keep your spirits up. It is important to talk to your cancer care team about the best forms of exercise for you. They can also refer you to an exercise physiologist who specialises in working with people living with cancer.
- ✓ **Rest and Prioritising Sleep** - Fatigue is the most common side effect you will experience living with cancer and as a result of various treatments. Get plenty of rest and avoid pushing yourself too hard, even if you feel good. Getting good sleep will help improve your mood and boost your

immune system. Try to get a good night's sleep each night and take the time to rest throughout the day. Be patient with yourself (and others) since it might take a little while before you feel your normal energy levels are restored.

- ✓ **Eat Well** - There is no specific CLL/SLL diet, but eating a healthy diet rich in fruits, vegetables, wholegrains, and lean protein may help you stay strong and energised throughout your treatment. If you need help with your diet and food choices, speak to your cancer care team about connecting you with a hospital dietitian or nutritionist.
- ✓ **Reach Out** - to your support crew as you are undergoing treatment. Call on them when you need to talk or need an extra pair of hands to work through daily life tasks. Support groups specific to people living with CLL/SLL can also help you to feel less isolated and allow you to talk about your feelings and experiences with those who understand exactly what you are going through. They are also a great support network for learning tips on how to cope with treatment side effects.
- ✓ **Relax** - Stress is ever-present and unfortunately, a cancer diagnosis and treatment can increase it. While you cannot change your diagnosis, focus

on how you can control stress. Find something that helps take the edge off and learn to incorporate into a daily practice. Simple things that may help include meditation or mindfulness, walking, listening to relaxing music or reading.

- ✓ **Understanding Impact of Sexuality and Intimacy** - When you receive a diagnosis of CLL/SLL and as you go through treatment, conversations about sexuality and intimacy are often not top of mind. We all deserve to live a healthy sexual life, but a CLL/SLL diagnosis and undergoing treatment can have negative impacts on your desire for sex and ability to have sex or be intimate. Remember, issues related to sexuality and intimacy are just as important as any other physical concerns you may have, so you should feel comfortable in bringing them up with your doctor or someone else in your cancer care team. They can also refer you to other health professionals to help you through any issues or concerns relating to sex and intimacy.

The Decision Not to Have Treatment

After you have been given all the information about treatment and have had your questions answered, you will need to decide whether you will have treatment of not. Your doctor and other members of your cancer care team can provide information on what they believe is the best option for you, but **the choice to start, or continue treatment, is always yours to make.**

If you decide to have treatment, you will need to sign a consent form, which is an official way of giving your doctor permission to give you the treatment. You will need to consent to each different type of treatment separately, such as chemotherapy, surgery, blood transfusions or radiation.

At any time, you can also withdraw consent and choose not to continue treatment if you feel it is the best choice for you. However, we recommend that you talk to your cancer care team about the risks of not starting, or stopping treatment, and what support is available to you if you decide not to have active treatment.

Living Well with CLL/SLL

For many people living with CLL/SLL it can be confusing and overwhelming. Due to the chronic nature of this type of blood cancer, living with it can include various approaches to treatment including active monitoring (watch and wait), active treatment or maintenance therapy.

Because CLL/SLL can include periods of remission and relapses, it can be hard to manage the range of emotions that can occur before, during and after your treatment. It is also not uncommon to experience physical changes and effects to your body, so it is important to take time to work through these and lean on your 'support crew' when you need to.

Remember that there is plenty of help available to support you. Open communication with your cancer care team including doctors and nurses, as well as your family and friends is helpful as you navigate your CLL/SLL journey, especially in the early stages. You might also find it helpful to speak with a counsellor during this time, especially if you find it a little challenging speaking to those most close to you. We are also here to help. Our Lymphoma Care Nurses can help you understand your diagnosis, answer questions you might have in relation to treatment or even connect you with other people living with CLL/SLL.

Many people find that after a cancer diagnosis, or treatment, that their goals and priorities in life change. Getting to know what your ‘new normal’ is can take time and be a little frustrating, but be patient, you will find a ‘new normal’ that works for you. Your new normal may include letting go of some things, while also trying new things.

We understand that being diagnosed with cancer brings with it a heightened sense of uncertainty and it may be challenging to plan for the future with confidence. You cannot change your diagnosis, but you can learn to adapt to it and manage any necessary and desired life changes to ensure you live life as fully as possible after your diagnosis.

Your ‘new normal’ might include making changes to the way you eat, the things you do, and where you turn to for support. It may mean fitting in cancer treatments into your work and holiday schedule, or making it a part of your everyday life, sometimes for the rest of your life.

Focussing on the things you can change and control, and not what you can’t, can help you feel more positive, empowered and able to deal with the uncertainty of a cancer that does not go away.

Below are some tips that have been shared by others that you may find helpful too.

- **Be informed.** Learn what you can do for your health and what services are available to you and those close to you.
- **Be aware** that you don't have control over all aspects of your cancer; focus on what you can control.
- **Be aware** of your fears and anxiety but practice letting go.
- **Express feelings of fear or uncertainty** with a trusted family member, friend, or counsellor.
- **Live for the present moment** rather than focussing on an uncertain future or challenging past.
- **Make time for what you really want** - it is ok to pursue these things.
- **Work towards having a positive attitude** but remember it is ok to have 'bad days'.

- **Use your energy to focus on what you can do now to stay healthy** as possible. Try to make healthy changes in what you eat and be as active as you can. Talk with your cancer care team about what is realistic for you when it comes to exercise.
- **Find ways to relax.** Enjoy some time both alone and with others.

Coping Practically with CLL/SLL

As well as coping with the emotional and mental aspects of your CLL/SLL diagnosis, you may find that you also need to manage some of the more practical things in life. This may include financial matters to sort out such as benefits, paid and unpaid personal (sick) leave, and grants. You may also have children or other dependents to consider.

Just try to remember that you do not have to sort everything out at once - try to deal with one issue at a time, take your time and ask for help if you need it. It is likely that your doctor or specialist nurse will know who you can contact for some help, and our Lymphoma Care Nurses can also provide guidance. You can reach our nurses by calling 1800 953 081 or via email at nurse@lymphoma.org.au.

It is important to:

- Do something for yourself.
- Know more about what to expect.
- Talk to someone who really knows about cancer, like your doctor or specialist nurse.
- Make lists of questions for your doctor, specialist nurse or GP before your appointment. You can also download our Questions to ask your Doctor here as a guide. https://www.lymphoma.org.au/wp-content/uploads/2022/04/2022_QTAYD_FactSheet_v02-1.pdf
- Take someone with you to your medical appointments to remind you what you need to ask and help you remember the answers and other important information.

Practical and Positive Things You Can Do

When you are having treatment, or recovering, you may not be able to do all the things you used to but as you begin to feel better it might help to:

- Have a go at simple tasks and try to do a little more each day - but remember, take one step at a time.
- Plan a healthy, well-balanced diet, incorporate some regular exercise, and learn relaxation techniques.
- Join a support group if you would like to meet others living with CLL/SLL.
- Try not to dwell too much on your cancer.
- Make the most of what you have – do the things you may have put off in the past, within reason of course and to your ability.
- Not make too many life changes at the one time, and understand that new habits and thought processes take practice.

Seeing a New Doctor

Following your diagnosis and treatment for your CLL/SLL you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you give any new doctor you see the details of your diagnosis and treatment. Gathering these details soon after your diagnosis and treatment may be easier than trying to at a later point in the future.

It will be handy if you have the following information available:

- A copy of your pathology report(s) from biopsies and blood tests.
- If you had surgery, a copy of your operation report(s).
- If you were in hospital, a copy of the discharge summary that you were sent home with.
- If you were treated with medicines (such as chemotherapy, monoclonal antibodies, or targeted therapies), a list of those medicines, the doses, when you took them and for how long.

The doctor may wish to have copies of this information for their records, but it is a good idea for you to also keep copies for yourself. And remember, you can always ask for a second opinion regarding your CLL/SLL management at any time.

Seeing Allied Health Professionals

Managing some of the effects of treatment can be helped by visiting certain allied health professionals. If you do need to visit an allied health professional, you may be eligible for a Medicare rebate under the "Chronic Disease Management Plan". The rules surrounding this can change so it is best to discuss with your GP first or you can access the patient information sheet here.
https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdisease-pdf-infosheet

Generally, you may be eligible for five subsidised visits per calendar year for allied health services combined (e.g. three visits to a podiatrist and two visits to a dietitian). Also, under the "Better Access Mental Health Care" initiative you may be eligible for rebates for up to 10 visits to a psychologist per calendar year. Your GP will be able to give you more information and let you know what you are eligible for.

When accessing allied health professionals you may need to pay a gap payment fee, which is at the discretion of each health professional. Allied health services may include:

- Aboriginal health workers

- Audiologists
- Chiropractors
- Diabetes educators
- Dietitians
- Exercise physiologists
- Mental health workers
- Occupational therapists
- Osteopaths
- Podiatrists
- Psychologists
- Physiotherapists
- Sexologist
- Speech pathologists

For more information on how to manage your overall health and wellbeing after a lymphoma diagnosis you can download a number of fact sheets from the Lymphoma Australia website here **https://www.lymphoma.org.au/support-for-you/living-with-lymphoma/health-and-wellbeing/.**

Questions for your Healthcare Team

It can be very difficult to know what questions to ask your doctor when you first learn you have CLL/SLL. It can be overwhelming, and there are many things you will need to learn about.

To make things easier, we have developed some questions you may like to consider asking. You might like to print this page out to take with you to your appointment and write in the answers you receive.

Questions to ask before you start treatment

- What tests have been done? What tests still need to be done before treatment?
- Do I have any genetic abnormalities in my blood or biopsies? If yes, can you explain these results to me and how it will affect my treatment and how I will respond to treatment?
- What is the stage and grade of my CLL/SLL?
- Why have you chosen this treatment for me? Are there better options available?
- What are the main, and most severe side effects I might get?
- Who do I contact (and what are their contact details) if I am unwell, get side effects or symptoms, need help, or have questions?

- Are there any other choices?
- Are there any clinical trials I can join? What would be the benefit of joining these?
- Will I need to have time off work during and after treatment? How much time?
- Is there a social worker, and other support services available to me to help me organise finances, meals, and housework during treatment?
- Is there anyone who can help me make a plan for my healthcare decisions in the future? How can I contact them?
- Will I be able to get pregnant, or get my partner pregnant during or after treatment?

Additional Questions if you live in rural or remote areas

- Can I have my appointment and treatment close to home?
- Is telehealth an option for me?
- How long will I need to be away from home for treatments?
- How often will I need to come to the city (or be away from home)?

- What support is available and who can I contact for financial, travel and accommodation support?

Additional questions if you have CLL/SLL and have young children?

- What organisations are available to help my children/dependents cope with my cancer diagnosis and while I undergo treatment?

Notes

Glossary

This glossary aims to explain some of the common words you will see in this booklet and words you may come across when you are with your doctor or specialist nurse. It is not a full list of words you will need to know while living with CLL/SLL, but it will help. For a full list, please see our definitions list on our website at www.lymphoma.org.au/about-lymphoma/definitions

SCAN ME

A

Advanced stage – widespread lymphoma – usually stage 3 (lymphoma on both sides of your diaphragm) or stage 4 (lymphoma that has spread to body organs outside your lymphatic system). The lymphatic system is all over the body, so it is common to have advanced lymphoma when first diagnosed.

Aggressive – a term used to describe a fast-growing lymphoma. Many aggressive lymphomas respond well to treatment and many people with aggressive lymphoma can be cured.

Active monitoring – also called ‘watch and wait’. A period where you have a slow-growing (indolent) lymphoma and do not need treatment, but your doctor will actively monitor you during this time.

Aggressive - a term used to describe a fast-growing lymphoma. Many aggressive lymphomas respond well to treatment and many people with aggressive lymphoma can be cured. This depends on the type of lymphoma you have.

Anaemia - low levels of haemoglobin (Hb) in your blood (contained on red blood cells). Haemoglobin carries oxygen around your body.

Antibody - a protein made by mature B-cells (called plasma cells) that recognise and stick to things that do not belong in your body, such as viruses, bacteria, or some cancer cells. It then alerts your other immune cells that they need to come and fight. Antibodies are also called immunoglobulins (Ig).

Aspirate - sample of cells taken by suction using a needle.

B

B-cells / B lymphocytes - a type of white blood cell (an immune cell) that fights infection by producing antibodies.

B symptoms - three significant symptoms of lymphoma – fevers, night sweats and unexplained weight loss – that can occur in people with lymphoma.

Biopsy - a sample of tissue or cells collected and checked under a microscope to see if abnormal cells are there. This can be done to confirm your diagnosis. For people with lymphoma, the most common biopsy is a lymph node biopsy (looking at the cells under the microscope to see what type of lymphoma it is).

Blood cells - the three main types of cells or cell fragments present in the blood are red cells, white cells, and platelets.

Blood count - a sample of blood is taken, and the numbers of different cells or proteins present in the blood sample are checked using a microscope and compared with the 'normal amount' of those cells or protein numbers found in healthy blood.

Bone marrow - the spongy tissue in the centre of some of the large bones of the body where blood cells are made.

C

Cancer cells - abnormal cells that grow and multiply quickly, and do not die when they should.

Cell - the microscopic building block of the body. All our organs are made up of cells and although they have the same basic structure, they are specially adapted to form each part of the body.

Central nervous system (CNS) - the brain and the spinal cord.

Chemotherapy ("KEE-moh-'ther-uh-pee") - a type of anti-cancer medication that damages and kills fast-growing cells. Sometimes it is shortened to "chemo".

Chemo-immunotherapy - chemotherapy (for example, CHOP) with immunotherapy (for example, rituximab). The initial of the immunotherapy drug is usually added to the abbreviation for the chemotherapy regimen, such as R-CHOP.

Chromosome - a small 'package' found in the centre (nucleus) of every cell in the body that contains a set of genes (DNA codes). They occur in pairs, one from your mother and one from your father. People normally have 46 chromosomes, arranged in 23 pairs.

Chronic - a condition, either mild or severe, that lasts for a long time.

Clinical trial - a research study testing new treatments to find out which one work best and for which people. For example, researchers might test effects of a new treatment or aspect of care against what is usually done, to see which one is most effective. Not all research studies involve treatment. Some might focus on improving tests or the quality of your life.

Combination chemotherapy - treatment with more than one chemotherapy drug.

Complete response - there is no evidence of lymphoma left after treatment.

CT scan - computed tomography. A scan performed in an X-ray department that provides a layered picture of the inside of the body; can be used to detect disease of a tissue or organ.

Cure - treating a disease or condition to the point where it has gone and will not come back in the future.

Cytogenetics - the study and testing of the chromosomes in cells that are involved in your disease. It helps to identify lymphoma sub-types and, reach an accurate diagnosis to help determine the best treatment for you.

D

Diagnosis - finding out what condition or disease you have.

Diaphragm ("DYE-a-fram") - a dome-shaped muscle that separates your tummy (abdomen) from your chest (thoracic) cavity. It also helps you breathe, by helping your lungs move in and out.

E

Early stage - lymphoma that is localised to one area or a few areas that are close together, usually stage 1 or 2.

Excision biopsy ("ex-SIH-zhun") - an operation to remove a lump completely; in people with lymphoma this often means the removal of a whole lymph node.

F

Fatigue - extreme tiredness and lack of energy, a common side effect of cancer and of cancer treatments.

Fine-needle aspiration - sometimes shortened to 'FNA'. It is a procedure where a small amount of fluid and cells are removed from a lump or lymph node using a thin needle. The cells are then examined under a microscope.

First-line treatment or therapy - refers to the first treatment you have after being diagnosed with lymphoma or CLL/SLL.

G

Gene - a stretch of DNA with enough genetic information in it to form a protein.

Genetic - caused by the genes.

H

Haematologist ("hee-ma-TOH-lo-jist) - a doctor specialising in diseases of blood and blood cells, including leukaemia and lymphoma.

I

Immune system - a system in the body including your white blood cells, spleen and lymph nodes that fight infections. It can also cause allergic reactions.

Immunoglobulins - sometimes shortened to 'Ig', the chemical name for antibodies.

Immunotherapy (“eem-you-no-ther-uh-pee”) - a treatment that helps your body’s own immune system to fight a cancer or lymphoma.

Indolent - lymphoma that is growing slowly.

Infection - bacteria, viruses, parasites, or fungi that don’t normally live in the body (germs) invade your body and can make you ill. If your immune system is not working well, infections can come from bacteria that normally live on or in your body, for example on your skin or in your bowel, but that has started to grow too much.

L

Lymph - a fluid that circulates in your lymph vessels. It is partly made up of fluid drained from the tissues, and it carries salts and lymphocytes.

Lymphatic system - a system of tubes (lymph vessels), glands (lymph nodes), the thymus and the spleen that help fight infection and, filter waste fluids and cells from the tissues.

Lymph nodes - small oval glands, usually up to 2cm in length. They are grouped together throughout your body in the lymphatic system – such as in the neck, armpit, and groin. They help the body fight infections and drain away waste fluids from the tissues. They are sometimes known as lymph glands.

Lymph vessels - tubes that carry lymph fluid and connect with the lymph nodes.

Lymphocytes ("LIM-foh-sites") - special white blood cells that are part of your immune system. There are three main types – B-cells, T-cells and natural killer (NK) cells. These cells provide you with an "immunological memory". This means they keep a record of all infections you have had before, so if you get the same infection again, they recognise it and fight it off quickly and effectively. These are also the cells affected by lymphoma and CLL.

Lymphoid tissue ("LIM-FOYD") - tissue involved in the production of lymph and lymphocytes and consists of:

- bone marrow
- thymus gland (the 'primary' lymphoid organs)
- the lymph nodes
- spleen
- tonsils
- tissue in the gut called Peyer's patches (the 'secondary' lymphoid organs)

Lymphoma (“lim-FOH-ma”) - cancer of lymphocytes. It affects both your lymphatic and immune system.

M

Monoclonal antibody - a type of medication that targets specific receptors on lymphoma cells (or other cancerous cells). They can work in several ways including:

- They can stop signals the lymphoma need for the cancer to grow and survive.
- They can strip the lymphoma cells of protective barriers they have used to hide from the immune system.
- They can stick to lymphoma cells and alert other immune cells of the lymphoma, which results in other immune cells coming to fight.

N

Needle aspiration biopsy – also sometimes known as ‘fine-needle aspiration biopsy’ or FNAB. A thin needle is inserted into a lump in your body (such as in the neck) to remove some cells. These cells are then examined under a microscope.

Neutropenia ("nyoo-tro-PEE-nee-ya") - low levels of neutrophils (a kind of white blood cell) in the blood. Neutrophils are the first cells to find and fight infections and diseases. If you have neutropenia, you are more likely to get infections, that can become serious quickly.

Neutrophils ("nyoo-tro-FILS") - a type of white blood cell that fights infection and disease. Neutrophils are the first immune cells that find and fight infection. If these are low, you are more likely to get infections. Some infections can become serious very quickly if you have neutropenia.

O

Oncologist ("on-COL-oh-jist") - a doctor who specialises in the diagnosis and treatment of people with cancer; may be either a medical oncologist who gives medicine to treat cancer or a radiation oncologist (also known as a radiotherapist) who treats cancer with radiotherapy.

P

Pathologist - a doctor who studies diseased tissues and cells under a microscope.

Peripheral blood stem cell transplant - a type of therapy that first uses high doses of chemotherapy and/or radiotherapy to destroy cancer cells, followed by transplantation of stem cells to replace the damaged bone marrow (this damage being a side effect of the high doses of chemotherapy).

PET – positron-emission tomography. A scan that uses a radioactive form of sugar to look at how active cells are. For some types of lymphoma, the cells are very active so show up clearly on a PET scan.

PET/CT scan - a scan in which PET and CT scans are combined.

Platelets ("PLATE-lets") - a type of blood cell that helps your blood to clot. Platelets are also called thrombocytes. So if you have been told you have thrombocytopenia, it means you have low levels of platelets. This means you may be more likely to bleed and bruise easily.

Prognosis - how your disease is likely to progress and how well you are likely to respond to treatment. Many factors affect prognosis including your type of tumour and your age and general health.

Protein - found in all living things, proteins have many roles, including helping to control how our cells work and fighting infections.

R

Radiotherapy ("ray-dee-oh-thr-ap-ee") - treatment in which powerful, carefully focused beams of radiation (like X-rays) are used to damage and kill lymphoma and other cancer cells. It is sometimes called 'external beam radiotherapy'.

Remission ("ree-MI-shon") - the time after your treatment when there is no evidence of the disease showing on your test results (complete remission). A partial remission is when the amount of lymphoma in your body has reduced by at least half but is not completely gone; and a 'good partial remission' is when three-quarters of the tumour has gone.

Response - when lymphoma shrinks or disappears after treatment.

S

Scan - a test that looks at the inside of the body, but is taken from outside of the body, such as a CT scan or ultrasound scan.

Spleen - an organ that is part your immune system. It is about the size of a clenched fist and lies just under your rib cage on the left-hand side of your body, behind your stomach. It is involved in fighting infection, and filters your blood, removing foreign particles and destroying old blood cells. The surgical removal of the spleen is called a splenectomy.

Stage - a guide to how many, and which areas of your body are affected by lymphoma. There are four stages used to describe most types of lymphoma, which are usually written with Roman numerals as stage I to stage IV.

Staging - the process of finding out what stage your lymphoma is. You will have scans and tests to find out what you stage have.

Stem cells - immature cells which can develop into the different types of mature cells normally found in healthy blood.

Stem cell harvest - also called stem cell collection, the process of collecting stem cells from the blood (for use in a stem cell transplant).

Stem cell transplant – the process of giving previously harvested stem cells to an individual. Stem cell transplants may be:

- Autologous stem cell transplant – where you harvest your own cells and then receive them back at a later time.
- Allogeneic stem cell transplant – where another person donates their stem cells to you.

Symptom - any change in your body or in how it functions; knowing your symptoms can help doctors to diagnose diseases.

Systemic - affecting your whole body (not just local or localised parts of the body).

T

T-cells / T-cell lymphocytes - cells of the immune system that help protect from viruses and cancers. T-cells develop in your thymus glands. They are a type of white blood cell and can become cancerous causing a T-cell lymphoma.

Thrombocytopenia ("throm-boh-SITE-oh-pee-nee-yah") - when you don't have enough platelets in your blood. Platelets help your blood to clot, so if you have thrombocytopenia, you are more likely to bleed and bruise easily.

Thymus - a small flat gland at the top of your chest, and behind your breast bone. It is where your T-cells develop.

Tumour - a swelling or lump that develops from a collection of cells; can be benign (not cancer) or malignant (cancer).

V

Virus – a tiny organism that causes disease. Unlike bacteria, viruses are not made up of cells.

W

Watch and wait – also called ‘active monitoring’. A period where you have a slow-growing (indolent) lymphoma and do not need treatment, but your doctor will actively monitor you during this time.

White blood cell - a cell found in the blood and in many other tissues that helps our bodies to fight infections. Our white cells include:

- Lymphocytes (T-cells, B-cells and NK cells) – these are the ones that can become cancerous in lymphoma.
- Granulocytes (neutrophils, eosinophils, basophils, and mast cells) - these fight disease and infection by releasing chemicals that are toxic to the cells so they can kill the diseased and infected cells. However the chemicals they release can also cause inflammation.

- Monocytes (macrophages and dendritic cells) – these cells fight the infection or diseased cells by swallowing them and then letting your lymphocytes know there is an infection. In this way they "activate" your lymphocytes so they can fight infection and disease better.

Lymphoma Australia

Lymphoma Australia is the only Australian charity dedicated to Lymphoma patients and their loved ones. We provide awareness, advocacy, education and support to help lymphoma patients, their carers, family, friends and healthcare professionals.

We are a small team with bold ambitions, encouraged by our achievements to date and

building on the passion and dedication of lymphoma patients and our Founding President, Shirley Winton OAM.

We provide practical support in many forms including Lymphoma Care Nurses. Their free support is available to you regardless of where you live in Australia. Our nurses help patients and their families from the time of diagnosis to after treatment. They also educate and support cancer nurses to best support you.

Lymphoma Nurse Support Line 1800 953 081 or email: nurse@lymphoma.org.au

We have a comprehensive range of educational materials available, as well as resources to help you manage lymphoma including a Patient Diary for keeping track of your condition. We also have newsletters, education days and videos.

Internationally, we are a member of the Lymphoma Coalition, a global network of 50 patient groups working together to provide support to millions of people around the world living with lymphoma.

We'd love to hear from you, so why not join us on any of our social channels:

Facebook www.facebook.com/LymphomaAustralia

Twitter www.twitter.com/lymphomaoz

YouTube www.youtube.com/LymphomaAustralia

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