Understanding Non-Hodgkin Lymphoma (NHL)

www.lymphoma.org.au

Lymphoma Australia

SCAN ME

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 lymphoma.

Lymphoma Australia would like to give a very special thank you to sponsors, hospitals, doctors, nurses, patients, families and friends that make our educational resources possible.

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Lymphoma Australia

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Contents

You are not alone

Each year, more than 6,000 people find themselves in the same situation that you or your loved one are in right now - hearing the words "you have non-Hodgkin Lymphoma".

It can be overwhelming. You might be in shock from being told you have a blood 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 non-Hodgkin Lymphoma (NHL). Instead, we will listen to your needs and work with different healthcare professionals to meet those needs.

It may seem impossible to look for the silver lining after receiving a lymphoma diagnosis; but the good news is, NHL is highly treatable and can be curable.

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

New treatments are developed regularly, and treatment of lymphoma has improved a lot in the last few years. There is good reason for you to have more hope than ever before.

You will need a variety of support when going through difficult times though. We'll be here when you need us. But we also strongly encourage you to "gather your crew" of friends and family. 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 going out and having fun. Share the load and let people help!

We hope this booklet helps answer many of your questions about NHL, 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 Lymphoma Nurses on 1800 953 081 or nurse@lymphoma.org.au

Sharon Winton
CEO, Lymphoma Australia

What is Lymphoma?

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.

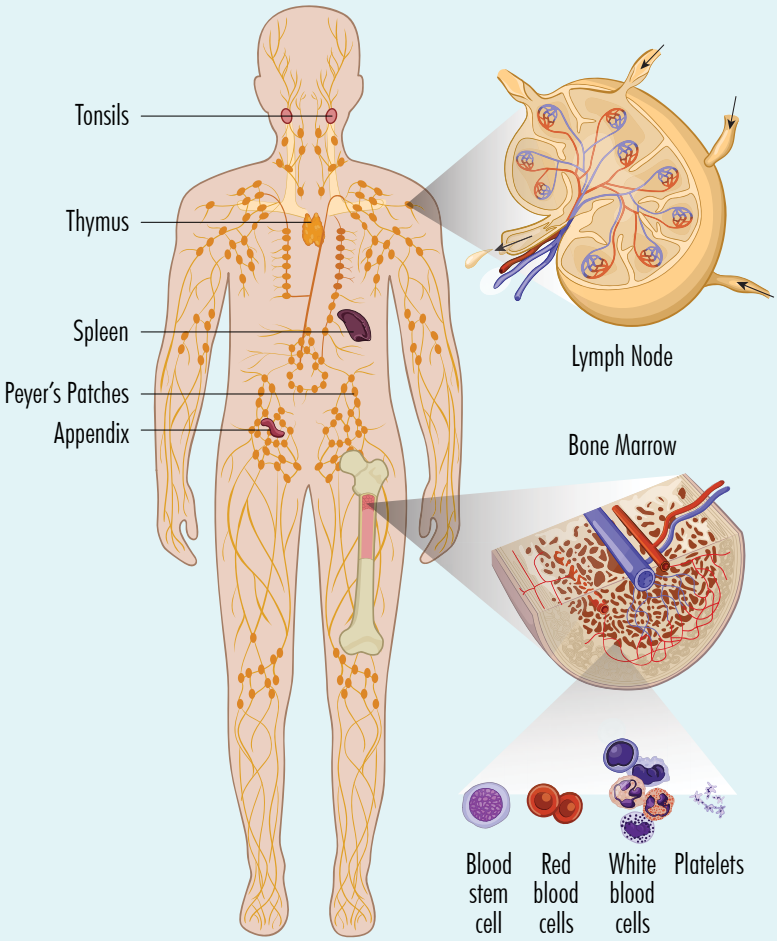
Lymphoma is a cancer of your lymphocytes, including B-cells, T-cells and Natural Killer T-cells. Lymphocytes are white blood cells that support your immune system by fighting infection and disease. They live in your lymphatic system, but also gather in the lining of your bowel, respiratory, genital and 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: move fluid through your body.
- Lymphatic organs: where your lymphocytes mature, live and make antibodies

Lymphatic System

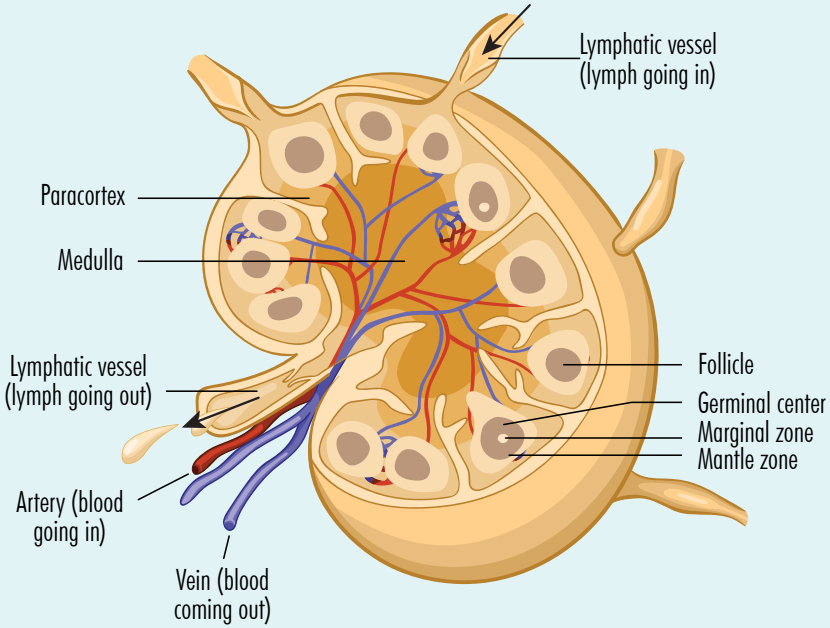


Why is the lymphatic system important?

The lymphatic system has three main jobs:

1. **To circulate and regulate fluid levels in your body.** Sometimes, extra fluid in your blood can leak out of your blood vessels. Your lymphatic system catches this extra fluid and returns it to where it should be. This helps to stop you from swelling (oedema) and keeps your fluid levels within normal limits.
2. **To absorb fats from your digestive system.** Lacteals are special lymph vessels located in the lining of your digestive system. They absorb fat and fat-soluble vitamins from food. They then transport the fats to your bloodstream so they can be used by your body for energy.
3. **To defend your body against infection.** The vessels of your lymphatic system move lymphatic fluid and lymphocytes around your body. As they go, they pass through your lymph nodes. Lymph nodes are important cleaners that protect you from infection. They do this by mopping up and removing or killing bacteria, viruses, and other harmful substances.

Lymph Node


Lymphatic vessel
(lymph going in)
Paracortex
Medulla
Lymphatic vessel
(lymph going out)
Artery (blood
going in)
Vein (blood
coming out)
Follicle
Germinal center
Marginal zone
Mantle zone

Because 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 3 types of cancer, these terms provide the what, the where and the how.

The what – your lymphocytes – a type of white blood cell

The where – living and usually starting in your lymphatic system

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

About non-Hodgkin lymphoma

Non-Hodgkin lymphoma (NHL) is a group of blood cancers that includes all types of lymphoma; except for Hodgkin lymphomas. All NHLs are classified into two groups - B-cell lymphomas or T-cell lymphomas. Lymphomas arise when developing B or T lymphocytes undergo a cancerous change, and multiply in an uncontrolled way. These abnormal lymphocytes, called lymphoma cells, form collections of cancer cells called tumours, in lymph nodes and other parts of the body.

B-cell NHL is much more common, with 17 out of every 20 (85%) people with NHL having a B-cell cancer. T-cell NHL occurs in about 3 out of every 20 people (15%).

There are over 70 different subtypes of NHL. Different subtypes are identified by how they grow – if they are indolent (slow-growing) or aggressive (fast-growing), how they look, and what proteins they have on them. All these things can provide information on the best type of treatment for you.

Fast Facts

- Lymphoma is the sixth most common cancer diagnosed in adults
- More than 6,400 people are diagnosed with NHL each year in Australia

- NHL can affect people of all ethnicities and ages, including children and the aged
- Risk of developing NHL increases with age, especially over the age of 55 years
- NHL is slightly more common in men.

Risk Factors

People with the following risk factors may have an increased chance of developing NHL:

- Previous infections with certain viruses such as
  - Epstein-Barr virus (EBV)
  - Human immunodeficiency virus (HIV)
  - Human T-lymphotropic virus type 1 (HTLV-1)
  - Hepatitis C (Hep C)
- Chemical exposure including pesticides, fertilisers, or solvents
- Autoimmune diseases including rheumatoid arthritis, scleroderma, and Sjögren's syndrome
- Previous organ transplant
- Infections with certain bacteria including helicobacter pylori (H. pylori - causes stomach ulcers)
- Possibly a family history of NHL.

It's not clear yet if NHL is inherited through families. But, with new developments and understanding of the genetics of NHL, we may find out more. It is also important to note that having risk factors does not mean you will get NHL. Likewise, many people who do develop NHL, have absolutely no known risk factors.

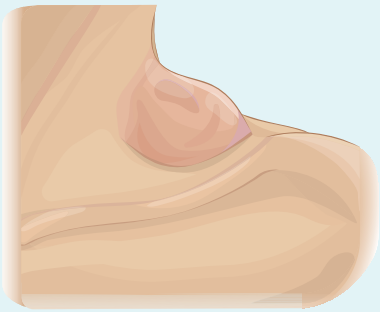
Symptoms

Lymphoma symptoms are similar to those seen in less serious illnesses, such as the flu (influenza) or other viral infections. In less serious illnesses, the symptoms would not last very long, but with lymphoma, they persist over time and cannot be explained by an infection or another disease.

The most common symptoms of lymphoma are:

- *Swollen lymph nodes: those caused by lymphoma are found in your neck, groin or armpit area but can occur in other parts of your body. You may not notice any swelling of the lymph nodes until they cause other symptoms. For example, a lump in your neck or throat area may cause a cough or changes to your voice.*

Swollen Lymph Nodes



- *Immune system problems:* with lymphoma, cancer cells are produced instead of normal lymphocytes. This will leave your body with less healthy cells to protect you from infection. If you get an infection, you may have trouble getting over it, even if it's just a common cold. You may also get lots of different types of infection, just as you get over one, another happens.

If any of these symptoms are new or worsening, please report this to your Haematologist/Oncologist and 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.

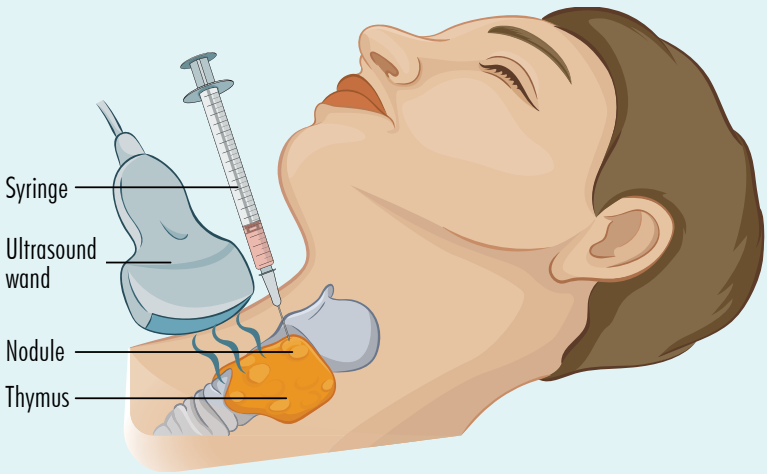
Losing weight without trying, and without other reason.

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.

You will need many tests to diagnose NHL, and to see if the disease has spread throughout your body. The tests help your doctor find the best way to treat your lymphoma and may include:

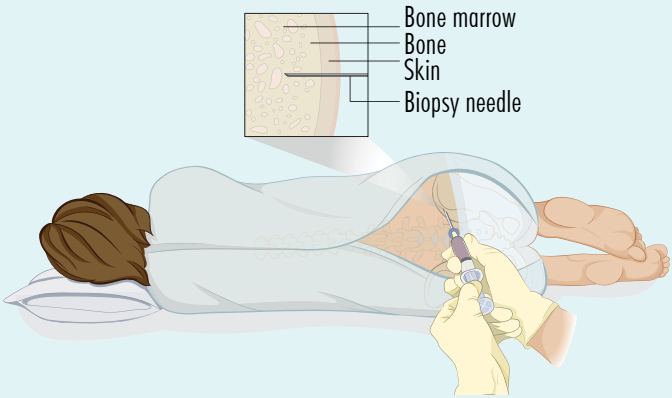
- Biopsy: A biopsy is used to confirm the diagnosis of NHL and your particular subtype.

Biopsy



- Bone marrow aspirate and trephine: this is done to check if the NHL has spread to your bone marrow. Your bone marrow is the middle part of your bones, where your blood cells are made.

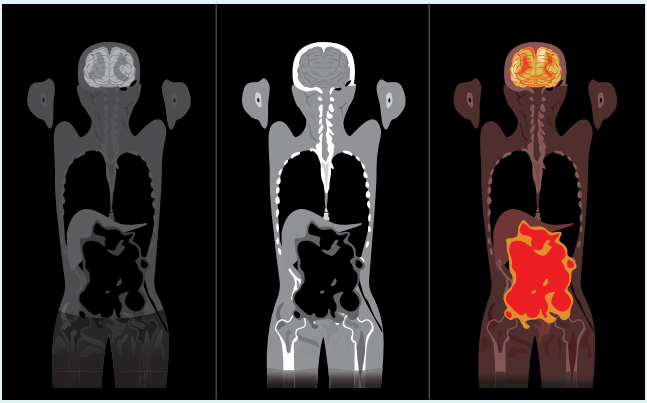
Bone Marrow Aspirate and Trephine



- X-ray: low dose radiation beams provide images of the inside of your body for diagnostic purposes.
- Ultrasound: sound waves create images of your lymph nodes and other structures in your body.
- CT (computed tomography) scan: a series of X-rays provide detailed, 3D images of the inside of your body.

- MRI (magnetic resonance imaging) scan: similar to a CT scan but using magnets instead of x-rays.
- Gallium scan: a radioactive gallium injection is given before an X-ray to make your tumour(s) visible. This is conducted in the Nuclear Medicine facility at a hospital.
- PET (positron emission tomography) scan: an injection with a radioactive glucose (sugar) is given before you have a full body scan. Glucose is then absorbed by cancer cells highlights these areas. This is done at the Nuclear Medicine facility.

PET Scan



- Pathology tests: blood tests and urine tests.

Allow up to three weeks for tests to be done. It can be tempting to read reports before seeing your doctor, but this can cause confusion or unnecessary concern. Each test is important, but 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.

You may have other baseline tests before starting treatment. These will be repeated during and after treatment to check if treatment is working, and how well your organs are coping. (Remove comma after working). Tests may include:

- Heart & kidney scans, breathing & blood tests
- Vital observations (blood pressure, temperature, and pulse rate)

This can be a tough time with a lot uncertainty. If you need support, we are here for you. Contact our Lymphoma Nurse Team **1800 953 081.**

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Staging and Subtype

Staging describes how far the lymphoma has spread within your body and is determined by:

- The number and location of lymph nodes affected.
- If affected lymph nodes are above, below or both sides of your diaphragm.
- If lymphoma has spread to your bone marrow or other organs such as your liver, lungs, bones or brain.

There are four stages of lymphoma. Stages 1 & 2 are "early" stages and stages 3 & 4 are "advanced" stage. Unlike other cancers, **advanced stage lymphoma may be curable.**

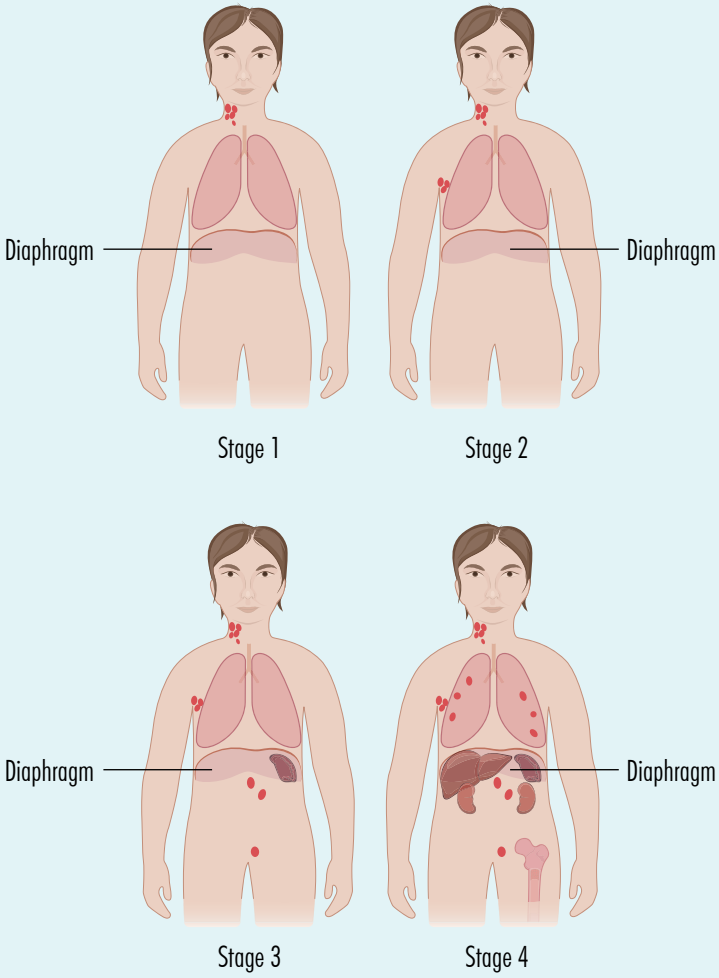
Stage 1: Found in only one group of lymph nodes (early stage).

Stage 2: Found in two groups of lymph nodes on the same side of your diaphragm (early stage) i.e., all above or all below the diaphragm.

Stage 3: Found on both sides of your diaphragm (advanced stage).

Stage 4: Found in at least one organ (e.g., bone marrow, liver, lungs, bone or brain) as well as your lymph nodes (advanced stage).

Staging


Diaphragm
Diaphragm
Stage 1
Stage 2
Diaphragm
Diaphragm
Stage 3
Stage 4

Non-Hodgkin lymphoma subtypes

There are over 70 subtypes of NHL, and they are classified into two groups called B-cell lymphomas or T-cell lymphomas. Below is a list of some of the main subtypes of NHLs.

B-cell lymphomas

- Diffuse large B-cell lymphoma (DLBCL)
- Follicular lymphoma (FL)
- Mantle cell lymphoma (MCL)
- Burkitt lymphoma (BL)
- Chronic lymphocytic leukaemia (CLL) / Small lymphocytic lymphoma (SLL)
- Marginal zone lymphoma (MZL)
- Waldenstrom's macroglobulinaemia (WM)
- B-cell acute leukaemia/lymphoma (B-ALL)

T-cell lymphomas

- Adult T-cell lymphoma/leukaemia (ATCL)
- Peripheral T-cell lymphoma (PTCL)
- Cutaneous T-cell lymphoma (CTCL)
- Anaplastic large cell lymphoma (ALCL)
- T-cell acute leukaemia/lymphoma (T-ALL)

Overview of B-cell lymphomas

Below is an overview of the main B-cell lymphomas. For more information on each subtype, scan the QR code or click on the link.

Diffuse large B-cell lymphoma (DLBCL)

DLBCL is an aggressive (fast-growing) B-cell lymphoma. It is the most common subtype of NHL accounting for around 30% of all cases. The average age of diagnosis for DLBCL is over 60 years, however it can also affect younger adults, teenagers, and children.

The most common first sign of DLBCL is a lump that rapidly grows in your neck, armpit or groin. The lump is caused by too many cancerous lymphocytes gathering in your lymph node. This causes the lymph node to swell. Sometimes this can cause pain if it presses on your nerves or other organs. Other symptoms may include:

- drenching night sweats
- fever
- unexplained weight loss
- fatigue – extreme tiredness that doesn't get better with rest

- loss of appetite – not wanting to eat
- shortness of breath.

In most cases the cause of lymphoma is not known. However, on rare occasions there are some risk factors connected with DLBCL, including conditions affecting your immune system. These risk factors may include autoimmune conditions, HIV, and organ transplantation.

DLBCL is usually treated with the intention to cure. DLBCL responds well to immunochemotherapy (chemotherapy and antibody therapy), and many patients achieve complete remission, with around 7 out of 10 people achieving remission with standard first-line treatment. Complete remission means that there is no visible lymphoma left in your body.

Remember Indolent means slow growing Aggressive means fast growing

Follicular lymphoma (FL)

Follicular lymphoma (FL) is the most common subtype of indolent NHL. About one in every four people with NHL has FL. FL affects men and women, but it is slightly more common in men, and in people over the age of 50 years.

Symptoms usually develop slowly over time, and sometimes there are no symptoms. A diagnosis of FL is often made by chance after having tests done for other reasons. The most common sign is a painless lump that is slowly growing in the neck, armpit or groin, which is caused by the swelling of the lymph nodes due to the presence of lymphoma.

Many people diagnosed with FL will not need treatment straight away. When treatment does start, it is to keep the lymphoma under control, rather than to cure it.

For more information on Diffuse large B-cell lymphoma (DLBCL), scan the QR code or **click this link**

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Mantle cell lymphoma (MCL)

Mantle cell lymphoma (MCL) is a rare subtype of NHL. It is usually an aggressive lymphoma, but may be indolent in some people. MCL affects men more than women over the age of 50 years. MCL can grow aggressively and may spread to other organs in your body. It has usually spread to different parts of your body by the time you get diagnosed.

It is called 'mantle cell lymphoma' because the lymphoma cells grow from the 'mantle zone' (the outer edge) of the lymph node. About 85% of people with MCL have a genetic change called a translocation in their B-cells. This is when two chromosomes, 11 and 14, break apart to then join . This change causes the cells to produce too much of a protein called cyclin D1. In normal amounts, cyclin D1 helps to promote normal cell growth, but too much results in uncontrolled growth of mantle zone cells, which can lead to MCL.

MCL can start anywhere in your body resulting in many symptoms. Most symptoms can also be symptoms of many other illnesses, which can make MCL hard to diagnose. Like some other types of lymphoma, the first sign of MCL is usually a swelling in the neck, armpit and/or the groin. Multiple lymph nodes may be affected, as well as other sites of your

body including your spleen, bone marrow, blood, tonsils, lungs, liver, brain/spinal cord and gut. MCL in the gut can cause diarrhea, blood in your poo (stool) or iron deficiency. Other symptoms may include:

- abdominal bloating
- nausea
- tiredness
- loss of appetite (not wanting to eat)
- fevers
- unexplained weight loss
- drenching night sweats.

For more information on Mantle cell lymphoma (MCL), scan the QR code or **click this link**

Burkitt lymphoma (BL)

Burkitt lymphoma (BL) is a rare but very aggressive form of lymphoma. It can affect children and adults and affects males three time more often than females. It accounts for approximately 1-2% of adult lymphomas and up to 30% of childhood lymphomas.

Symptoms often develop quickly, over just a few days or weeks. It can cause many lymph nodes to enlarge in many different parts of your body, and often involves your abdomen and bowel. Other organs including your spleen, liver and bone marrow. It can also spread to your central nervous system (brain and spinal cord).

BL is named after British surgeon Denis Burkitt, who first identified this unusual disease in 1956 among children in Africa.

BL often responds well to treatment, and in many cases can be cured.

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For more information on Burkitt lymphoma (BL), scan the QR code or **click this link**

Chronic lymphocytic leukaemia (CLL)/Small lymphocytic lymphoma (SLL)

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are both indolent non-Hodgkin lymphomas that affect men and women equally. CLL is the second most common lymphoma accounting for around 15% of all cases and SLL accounts for around 5% of all cases.

Although CLL has the word 'leukaemia' in its name, it is essentially the same type of B-cell lymphocyte, blood cancer as SLL. The diseases are so similar that in 2016 the World Health Organisation (WHO) regrouped CLL and SLL together with the only difference between the two is where the cancer is located. In CLL, most of the lymphoma cells are in the bloodstream (this is why it is called 'leukaemia'). In SLL, most of the lymphoma cells are in the lymph nodes.

Most patients with CLL/SLL do not appear to have any obvious symptoms when they are diagnosed. It is often found with a blood test and/or a physical examination as part of a routine check-up or to check something else.

Some patients have symptoms that may include:

- feeling very tired most of the time
- shortness of breath
- anaemia (low red blood cells and iron)
- bruising or bleeding easily
- infections that are hard to get rid of, or keep coming back
- night sweats
- unintentional weight loss.

In most cases, CLL/SLL it is not curable but is considered a long term (chronic) condition. The aim of treatment is to keep the CLL/SLL under control for as long as possible. Many people with CLL/SLL live well with a normal life span.

For more information on Chronic lymphocytic leukaemia (CLL)/ small lymphocytic lymphoma (SLL), scan the QR code or **click this link**

Marginal zone lymphoma (MZL)

Marginal zone lymphoma (MZL) is a type of indolent lymphoma that affects about one in every 12 people diagnosed with NHL. The average age of diagnosis is 65 years and is slightly more common in women than men.

It is called 'marginal zone lymphoma' because it mainly affects lymphocytes at the edges of lymphoid tissue or nodes, in what is called the marginal zone. This can be seen when biopsy samples are analysed under a microscope.

There are three main subtypes of MZL that are categorised based on the parts of the body that are affected.

- **Mucosa-associated lymphoid tissue (MALT)** lymphoma – also known as 'extra nodal MZL', is the most common form of MZL. It occurs outside of the lymph nodes, in places like your stomach, small intestine, salivary gland, thyroid, eyes and lungs. MALT lymphoma is divided into two categories: gastric, which develops in the stomach, and non-gastric, which develops outside of the stomach. In many cases of MALT lymphoma, there is a previous medical history of inflammation or autoimmune disorders.

- **Nodal MZL** – sometimes called monocytoid B-cell lymphoma, occurs within the lymph nodes.
- **Splenic MZL** – occurs most often in the spleen and blood. It has been associated with hepatitis C.

Many people with MZL do not have symptoms and are diagnosed when they go to the doctor for something else. If you do get symptoms, they may include:

- enlarged lymph nodes
- fatigue (feeling very tired for no reason)
- unexplained weight loss
- skin rash / itchy skin
- pains in the chest, abdomen or bones
- fever
- drenching night sweats.

For more information on Marginal zone lymphoma (MZL), scan the QR code or **click this link**

Waldenstrom's macroglobulinaemia (WM)

Waldenstrom's macroglobulinaemia (WM) is a rare form of lymphoma making up only 1-2% of all NHL cases, and typically affects older adults. WM normally develops slowly over a long period of time. Symptoms are not obvious, and the disease is often found by chance when getting a routine blood test or an examination for some other reason.

Swollen glands are less common with WM than other types of lymphoma. Some symptoms can include:

- abnormal bleeding especially from the nose, gums and lining of the gastrointestinal tract due to thrombocytopenia (shortage of platelets)
- fatigue
- shortness of breath
- headache
- recurrent infections
- muscle cramps.

WM causes overproduction of a protein called "immunoglobulin M" referred to as IgM. This can result in a thickening of your blood known as hyper-viscosity. Because the blood becomes thick it may not flow easily through your body.

WM cannot be cured, but is very treatable. However, if you have no symptoms you will likely not need treatment, but will be monitored closely by your specialist doctor. This is called watch and wait. Treatment is only started once the IgM protein is too high and symptoms are present.

For more information on Waldenstrom's macroglobulinaemia (WM), scan the QR code or **click this link**

B-cell acute lymphoblastic leukaemia/ lymphoma (B-ALL)

B-cell acute lymphoblastic leukaemia/lymphoma (B-ALL) is an aggressive lymphoma that occurs mainly in children, teenagers and people aged over 40 years. It is more common in males, with two males diagnosed for every one female.

Lymphoblastic leukemia occurs when there are immature lymphocytes in your blood and bone marrow. Lymphoblastic lymphoma occurs when

the same cells are found in your lymph nodes and lymphatic system.

Common symptoms include:

- swollen lymph nodes
- pale skin
- fatigue
- bleeding
- fever
- recurrent infections
- enlarged liver or spleen
- dizziness, weakness, confusion or seizures
- enlargement of testicles in men
- skin rash.

You will need a bone marrow biopsy to diagnose B-ALL.

For more information on B-cell acute lymphoblastic leukaemia/ lymphoma (B-ALL), scan the QR code or **click this link**

Overview of T-cell lymphomas

Below is an overview of the main T-cell lymphomas. For more information on each subtype, scan the QR code or click on the link.

Adult T-cell leukaemia lymphoma (ATLL)

Adult T-cell lymphoma/leukaemia (ATLL) is a rare and very aggressive type of lymphoma. Cancerous T-cells are found in your blood stream, lymph nodes, skin, and other areas of your body.

ATLL is linked to the viral infection HTLV-1 (human T-cell lymphotropic virus 1) and only affects people who have this virus. HTLV-1 is common in Japan, China, the Caribbean, central and South America, Iran, Romania, and parts of Africa.

The average age of onset is 55 years of age, however can occur from young adulthood through to old age.

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For more information on Adult T-cell lymphoma/leukaemia (ATLL), scan the QR code or **click this link**

Peripheral T-cell lymphoma (PTCL)

Peripheral T-cell lymphoma (PTCL) is the name given to a group of aggressive T-cell lymphomas, affecting a small number of people with NHL.

PTCL develops from mature-stage T-cells and natural killer (NK) cells. 'Peripheral' refers to a cancer that arises in the lymphoid tissue, but outside of the bone marrow lymph nodes, spleen, gastrointestinal tract, or skin.

There are four main groups of PTCL that include cutaneous, extra nodal, nodal and leukemic. Within those four groups, there are more than 29 different subtypes - each very rare and mostly aggressive in behaviour. There are some exceptions that are indolent, and these usually include some forms of cutaneous T-cell lymphomas.

- Cutaneous refers to the skin
- Extra-nodal refers to areas outside of lymph nodes
- Nodal refers to lymph nodes
- Leukemic refers to blood

The most common PTCL subtypes are:

- PTCL not otherwise specified (not belonging to any other PTCL subtype)
- Angioimmunoblastic T-cell lymphoma (AITL)
- Anaplastic large cell lymphoma (ALCL)
- Cutaneous T-cell lymphoma (CTCL)
- Sezary syndrome
- Enteropathy-type T-cell lymphoma
- Nasal NK/T-cell lymphoma (NKTCL)
- Hepatosplenic gamma delta T-cell lymphoma

PTCL affects both men and women and can also affect children and young adolescents.

For more information on Peripheral T-cell lymphoma (PTCL), scan the QR code or **click this link**

Cutaneous T-cell lymphoma (CTCL)

CTCL is a subtype of Peripheral T-cell lymphoma. Can this section be moved to after Peripheral T-cell lymphoma and before Anaplastic large cell lymphoma.

Cutaneous T-cell lymphomas are rare subtypes of NHL affecting your skin. It is caused by T-cells becoming cancerous, then travelling, and gathering in the layers of your skin. This causes a rash, lesions or tumours to appear. It often starts as an itchy rash that can change shape, grow or spread as the lymphoma progresses. Over time, the itchy rash can form hardened areas of skin called plaques, or tumours.

CTCL is more common in older people, but can also affect children. The average age of diagnosis is around 55 years of age. You may have a higher risk of getting CTCL if a family member has it.

Types of CTCL include:

- **Mycosis fungoides –** the most common subtype of CTCL, accounting for about half of all cases of CTCL. This subtype can sometimes run in families, but this is very rare.
- **Primary cutaneous anaplastic large-cell lymphoma –** a usually indolent lymphoma,

this subtype can affect people of all ages, including children but is more common in 45-60-age group.

- **T-cell skin lymphoma –** more common in people who have had a transplant, or who have HIV (human immunodeficiency virus).
- **Lymphomatoid papulosis –** a non-cancerous condition of the immune system, this is a precursor (pre-cancerous) for CTCL. This condition can occur at any age from childhood to middle age.

CTCL can often be brought under good control with current therapies available today. Most of the time, CTCL cannot be cured, but can be managed as a chronic (long-term) condition. Many people with CTCL can live a normal life, without much affect from the disease.

For more information on Cutaneous T-cell lymphoma (CTCL), scan the QR code or **click this link**

Anaplastic large cell lymphoma (ALCL)

Anaplastic large cell lymphoma (ALCL) is a rare, aggressive subtype of peripheral T-cell lymphoma. Anaplastic refers to the appearance of the lymphoma cells, which look quite different from normal lymphocytes. The lymphoma cells have a protein called CD30 on their surface, which is a hallmark of the disease.

The causes of ALCL are mostly unknown. People of all ages are affected, but certain subtypes are more common in particular age groups.

There are three main types of ALCL that can be divided into systemic (affecting the lymphatic system such as the lymph nodes or tissue) or cutaneous (affecting the skin).

- **Systemic ALCL** – ALK positive - is the most common subtype of ALCL and is aggressive. In ALK-positive ALCL, the cancerous T-cells have a genetic change (mutation) that causes them to make a protein called "anaplastic lymphoma kinase" - or ALK. These lymphomas are called ALK positive because of the presence of ALK. It usually affects children and young adults less than 40 years of age. Males are affected three times more often than females.

- **Systemic ALCL –** ALK negative - is an aggressive subtype that accounts for around 3% of all ALCL cases. This subtype mainly affects older adults, mostly around 40-65 years of age, and is more common in men than in women. Unlike ALK positive subtypes, you will not have the ALK protein on your lymphoma cells.
- **Breast implant associated ALCL –** Is a very rare, indolent subtype that only occurs in people who have breast implants. It is more common if you have textured implants. While more needs to be learned, it is thought that it happens due to an inflammatory reaction to the implants. Although it occurs in the breast, it is not a type of breast cancer.

For more information on Anaplastic large cell lymphoma (ALCL), scan the QR code or **click this link**

T-cell acute lymphoblastic leukaemia/ lymphoma (T-ALL)

T-cell acute lymphoblastic leukaemia/lymphoma (T-ALL) is an aggressive lymphoma that occurs mainly in children and teenagers or, people over the age of 40 years. It is more common in males than females. Lymphoblastic leukemia occurs when there are immature lymphocytes in your blood and bone marrow. Lymphoblastic lymphoma occurs when the same cells are found in your lymph nodes and lymphatic system.

Common symptoms relate to the location of your lymphoma. Examples include:

- lymphoma in or near your lungs and airways can make it hard to breathe
- lymphoma in your brain or spinal cord can cause headache, weakness, dizziness, confusion or seizures

For more information on T-cell acute lymphoblastic leukaemia/ lymphoma (T-ALL), scan the QR code or **click this link**

If your subtype has not been covered in this information resource, please visit the Lymphoma Australia website 'Types of Lymphoma' section: **www.lymphoma.org.au/lymphoma-types/** or contact the Lymphoma Nurse Support Line on **1800 953 081** or via email at **nurse@lymphoma.org.au**

Treatment

NHL is treated by a haematologist (specialist doctor managing conditions that affect the blood) or oncologist (cancer specialist). If you are recommended to have radiation treatment, you will also see a specialist doctor called a radiation oncologist.

Your doctor and medical team will consider several factors when deciding on the best treatment for you, including your:

- Subtype and stage of lymphoma
- Symptoms
- Presence of B symptoms
- Age
- Medical history
- Current physical and mental health
- Blood test results including results from any genetic tests
- Personal preferences

These factors mean your treatment is tailored specifically to you. So don't be concerned if people with the same type of NHL or at the same stage as you, are having different treatments to you. If you're curious about this, or have any questions about your treatment, don't hesitate to ask your doctor.

More information?

We have a lot of treatment information available at Lymphoma Australia, so if you'd like more, you can:

- Visit the extensive Treatments section of our website: www.lymphoma.org.au/about-lymphoma/treatments

Review a range of fact sheets which are also available on our website here: **www.lymphoma.org.au/support-for-you/fact-sheets**

Understanding lymphoma treatments

Lymphoma often responds very well to treatments. This does not mean that all types of lymphoma are always curable. However, treatment can often provide long cancer-free periods (remissions), reduced symptoms and improved quality of life for many people.

There are many different types of treatment approaches for lymphoma including:

- Watch and wait (active monitoring)
- Chemotherapy
- Radiotherapy
- Targeted therapy
- Immunotherapy
- Stem cell transplant
- Chimeric Antigen Receptor (CAR) T-cell therapy
- Clinical trials

Types of Lymphoma Treatments

Lymphoma is often treated with, chemotherapy and/or radiotherapy. Other treatments, such as hormone or targeted therapy, can also be used with or instead of chemotherapy.

Watch and wait (active monitoring) - this treatment approach is most often used if you have indolent NHL, and no symptoms or risk factors that need urgent treatment. You will be closely monitored with regular visits with your doctor, blood tests and imaging (such as PET or CT scans). During this time, you will not have treatment. If your disease progresses, or you start getting symptoms, your doctor will talk to you about starting treatment.

Please visit our website for more detailed information. You can find more information by clicking your lymphoma subtype under 'types of lymphoma.

Chemotherapy - a common medication used to kill cancer cells or prevent their growth. Most (but not all) people with lymphoma will have chemotherapy at some point during their treatment. It works by attacking fast growing cells.

Radiotherapy – a localised therapy meaning that it only treats the area of the body where the cancer is located. Radiotherapy is often combined with chemotherapy, but can be used alone as the main treatment in some cases.

Targeted therapy - targeted therapies are treatments that target proteins or receptors on your lymphoma cells to interrupt it's ability to grow and make more cancer cells. Some targeted therapies can also engage the immune system for a stronger anti-cancer affect. Monoclonal antibodies, cell signal blockers and antibody-drug conjugates are examples of targeted therapy.

Immunotherapy - immunotherapies work by targeting your immune system to improve the way it works. Immunomodulators and immune checkpoint inhibitors are examples of immunotherapy

Stem cell transplant – (also known as a bone marrow transplant). Replaces blood-forming cells in your bone marrow (including cancer cells) that have

been destroyed by chemotherapy or radiotherapy with healthy stem cells. These cells then develop into new bone marrow and produce healthy blood cells.

Chimeric antigen receptor (CAR) T-cell therapy - CAR- T-cell therapy, is a new form of immunotherapy that uses specifically altered T-cells to target cancer cells directly and precisely. After a small portion of your own T-cells have been collected, they are re-engineered in a special laboratory. They the carry special structures called chimeric antigen receptors (CARs) on their surface. When these CAR T-cells are re-injected, they multiply rapidly, and may help the T-cells to identify, and attack cancer cells throughout your body.

Clinical trials – a major part of developing new treatments involves clinical trials. Clinical trials are carefully planned research conducted on patients, to test new medications or new treatment approaches. The new treatment is usually compared with an existing treatment to assess if the outcome is more beneficial for patients.

After treatment has finished

Whatever treatment you have, when it is completed, you will continue to have follow-up appointments with your specialist doctor. Usually these are quite regular (monthly) to start with. If remission continues and you are well, you may only need to go every 3 or 6 months. If you continue in remission, they may be decreased again to only once-a-year.

Follow-up appointments can be difficult due to the worry of the disease relapsing (coming back). But these appointments are an important part of your care. They allow your doctor to assess your progress and pick up any signs of relapse early. It also gives you the opportunity to talk about any concerns you might have following treatment.

It is also important to have regular contact with your general practitioner (GP). Your GP can offer support and advice on a more regular basis, and monitor your general health.

Questions for your healthcare team

It can be very difficult to know what questions to ask your doctor when you first learn you have lymphoma. It can be overwhelming, and there are many things you will need to learn about. But if you don't already know about them, how can you know what to ask?

To make things easier for you, we've developed some questions you may like you consider asking. Please feel free to print this page out to take with you to your appointment and write in the answers you get.

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 including how it will affect my treatment and how I will respond to treatment
- What is my subtype of lymphoma called?
- Will I be cured after treatment? If not why not, and what happens when treatment ends?
- Why have you chosen this treatment for me? Are there any better ones 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?
- Will I be able to get pregnant, or get my partner pregnant during or after my treatment?
- 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 to help me make a plan for my health care decisions for the future? How can I contact them?

Additional Questions if you live in the rural and/or remote Australia

- 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 lymphoma or CLL and have young children, or if you are the parent of child or teenager with lymphoma

- What organisations are available to help my children cope with my cancer diagnosis?
- Is there support available for my child, and their brothers and sisters while they go through treatment?
- How much time, and how often will my child need time off school?
- What tutoring services are available for my child with lymphoma, and my other children?
- Will my child be able to have children when they grow up? Is there anything that can be done to improve their chances?

Notes

Glossary

This glossary aims to explain some of the common words you will see in this booklet. It is not a full list of words you will need to know while living with and beyond lymphoma. For a full list, please see our definitions list on our website at www.lymphoma.org.au/about-lymphoma/definitions/

A

Acute – an illness or symptom that develops quickly and lasts a short time.

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 to have advanced lymphoma when first diagnosed. Many people with advanced lymphoma can be cured.

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.

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 don't 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).

Antibody–drug conjugate – a treatment using a monoclonal antibody joined to a chemotherapy that can deliver the chemotherapy directly to the target lymphoma cell.

Antigen – the part of a 'foreign' substance that is recognised by the immune system. This then triggers your immune system to produce antibodies to fight the foreign substances (such as a virus, bacteria, or other disease).

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).

Blast cell – an immature blood cell, in your bone marrow. Not normally found in your blood.

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 proteins 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.

CAR T-cell therapy – treatment that uses your own, genetically modified T-cells to recognise and kill lymphoma cells.

CD – Cluster of differentiation (may be CD20, CD30 CD15 or various other numbers). See cell surface markers.

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.

Cell signal blockers – cells receive signals that keep them alive and make them divide. These signals are sent along one or more pathways. Cell signal blockers are newer medications that block either the signal or a key part of the pathway. This can make cells die or stop them from growing.

Cell surface markers – proteins found on the surface of cells that can be used to identify particular cell types. They are labelled using letters and numbers (for example CD4, CD20, in which the 'CD' stands for 'cluster of differentiation')

Central nervous system (CNS) – the brain and 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.

Classification – the grouping of similar types of cancer together, based on how they look under the microscope and after doing specialised tests.

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 involves 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 you chest (thoracic) cavity. It also helps you breath, 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.

Epstein–Barr virus (EBV) – a common virus that causes glandular fever (mono), that may increase your chance of developing lymphoma – most often Burkitt lymphoma.

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.

Extra-nodal disease – lymphoma that starts outside the lymphatic system.

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 therapy – refers to the first treatment you have after being diagnosed with lymphoma or CLL .

G

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

Genetic – caused by the genes.

H

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

Helicobacter pylori – a bacterium that causes inflammation (swelling) and ulcers in your stomach and is associated with a subtype of lymphoma that starts in your stomach (gastric MALT lymphoma).

HIV – human immunodeficiency virus. A virus that attacks the immune system and can cause acquired immune deficiency syndrome (AIDS).

Hormone – a chemical messenger produced by a gland and carried by the bloodstream to another part of the body to affect how that part works.

HSCT – Haematopoietic Stem Cell Transplant.

Hyper viscosity – when your blood is thicker than usual. This can happen when you have high levels of abnormal antibodies in your blood. It is common in people who have Waldenström's macroglobulinaemia.

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 you 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 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 helps fight infection and, filters 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; 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") – a 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.

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-ther-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. See also 'complete response' and 'partial response'.

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 you 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 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.

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

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 gland. 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).

Tumour markers – a protein or other marker in your blood or urine that is usually only present if a cancer or other disease is developing.

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 of time where you have a slow growing (indolent) lymphoma and do not require treatment, but your doctor will actively monitor during this time. For more details on watch and wait please see our page here.

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. But 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 fight infection and disease better.

Lymphoma Australia

Lymphoma Australia is the only Australian charity dedicated to people living with lymphoma and their loved ones. We provide awareness, advocacy, education, and support to help you and your 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 those living with lymphoma, 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 in Australia you live, or what stage of "life with lymphoma" you are at. 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, webinars, in-person and virtual forums, 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

Instagram www.instagram.com/lymphomaaustralia

If you would like to support Lymphoma Australia, please call 1800 359 081 or visit **www.lymphoma.org.au/donate/make-a-new-donation**

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