Understanding Hodgkin Lymphoma (HL)



www.lymphoma.org.au





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Lymphoma Australia

PO BOX 676, Fortitude Valley, QLD 4006 Australia Telephone 1800 359 081 Email enquiries@lymphoma.org.au Website lymphoma.org.au

Contents

You are not alone	2
What is Lymphoma?	4
Why is the lymphatic system important?	6
About Hodgkin Lymphoma	9
Symptoms	
Diagnosis	14
Subtype and Staging	18
Subtype	
Staging	20
Treatment	22
Treating your HL	25
Treatment of Relapsed HL	26
Treating HL in older people	27
After treatment has finished	
Questions for your healthcare team	
Notes	
Glossary	
Lymphoma Australia	

You are not alone

Each year, more than 600 people find themselves in the same situation that you or your loved one are in right now - hearing the words 'you have 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 nearly 20 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 Hodgkin Lymphoma (HL). 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, HL is highly treatable and often 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 HL, and provides you with the information, clarity and confidence you need to manage your lymphoma.

- Al-

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 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



Why is the lymphatic system important?

The lymphatic system has three main jobs:

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





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 – B-cell 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 Hodgkin Lymphoma

Hodgkin lymphoma (HL) gets its name from the English doctor Thomas Hodgkin, who identified the first lymphoma in the 1830s. All lymphomas discovered after this were called "non-Hodgkin lymphoma' (NHL).



There are more than 80 different types of lymphoma, and HL is not as common as NHL. Out of every 10 people diagnosed with lymphoma, only 1 (10%) will have HL and 9 (90%) will have NHL.

We don't know how or why HL develops, so research into the cause of the disease is an important piece of the puzzle. It is thought that lymphoma cells grow after an abnormal immune response from a infection. One virus thought to increase your chances of developing HL is the Epstein Barr Virus, which causes glandular fever. Other people who develop HL may have a genetic tendency to abnormal immune responses. However this does not mean your family members are more likely to develop HL once you have it.

We do know HL is not contagious, so you cannot 'catch it' from someone, nor can you give it to anyone.

There is no evidence to suggest that lifestyle choices, such as what you eat or how much exercise you do, will cause HL (or prevent it). This is different to many other cancers, where lifestyle choices can be a factor in their development.

HL is a rare disease. About 1 in every 200 people diagnosed with any type of cancer, will have HL. Although undergoing treatment can be challenging, HL is one of the most curable cancers.

Fast Facts

- More than 600 people are diagnosed with HL each year in Australia.
- It is most likely to occur in people between the ages of 15 – 29 years, or those older than 66 years of age.
- In older adults, it is more common in males.

Symptoms

Lymphoma symptoms are similar to those seen in less serious illnesses, such as the flu or other viral infections. In less serious illnesses, the symptoms don't last long, but with lymphoma, they persist over time. If you develop any of the following symptoms, or your current symptoms get worse, **please contact your heamatologist or oncologist.**

The most common symptoms of lymphoma are:

• Swollen lymph nodes: HL often starts in the 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.

Swollen Lymph Nodes

 Immune system problems: in HL, 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.



B-Symptoms

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

Many tests are required to diagnose HL, and to see if the disease has spread to other parts of your body. These tests also determine the best way to treat your lymphoma. Tests may include:

• Biopsy: this is the only way to confirm the type of lymphoma you have . A biopsy is used to confirm the diagnosis of HL and your particular subtype.



 Bone Marrow Aspirate and Trephine: If your specialist suggests a bone marrow biopsy, it is to check if the HL has spread to your bone marrow. Your bone marrow is the middle part of your bones, where your blood cells are made.



- 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 to create detailed images.
- 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: a radioactive glucose injection is absorbed by cancer cells and a scanner, then highlights these areas. You will need to go to the hospital's Nuclear Medicine facility to have this test done.
- Laboratory tests: Blood tests and urine tests.



Allow up to three weeks for the tests to be done. It can be tempting to read your reports before seeing your doctor, but this can cause more 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 how this may affect your treatment options. They will also be able to answer any questions you have.

You may also have a number of other baseline tests prior to any treatment. These will be repeated during and after treatment to assess whether the treatment is working, or if it has affected how well your organs are working. Tests may include:

- Physical examination breathing and blood tests and scans of your heart and kidneys
- Vital observations (blood pressure, temperature, & 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**.



Subtype and Staging

Staging HL, and knowing your sub-type is necessary to determine the type of treatment you will need.

Subtype

Lymphoma is classified as HL if a specific cell, known as the Reed-Sternberg cell, is found in your biopsies.

There are different sub-types of HL. These subtypes describe the disease in more detail - what the affected lymph nodes look like, what other cells are present, and what characteristics the cells have. The five subtypes of HL are:

- Classical HL Nodular Sclerosing is the most common subtype of HL. It is more common in women than men and usually affects people under the age of 50. Nine out of every 10 people diagnosed with Nodular Sclerosing HL are cured.
- Classical HL Lymphocyte Rich: accounts for less than 5% of all cases. It is often diagnosed at an early stage in adults, and is more common in people aged 30-40 years. There is a low risk of relapse.
- Classical HL Mixed Cellularity: found more commonly in men than in women, and is more common in people aged over 65 years. It accounts for about 15-30% of all cases. More



advanced disease (stage 3 or 4) is usually present at diagnosis so the risk of relapse may be higher.

- Classical HL Lymphocyte Depleted: a rare subtype accounting for 1% of all lymphomas. It is usually diagnosed when lymphoma is widespread through your body.
- Nodular Lymphocyte Predominant HL: occurs in 4-5% of cases and more often in older adults. It is slower growing than classical HL subtypes and is treated differently. It is usually at an earlier stage than HL so you may not get B-symptoms.

Staging

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

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

There are four stages of lymphoma. Stage 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). ie 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 or lungs) as well as your lymph nodes (advanced stage).



Treatment

HL is treated by a haematologist or oncologist (specialist doctor treating people with blood disorders and/or cancer). If you are recommended to have radiation treatment, you will also see a specialist doctor called a radiation oncologist.

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

- Lymphoma stage and size of your lymph nodes
- Disease response
- Presence of B symptoms
- Age
- Medical history
- Current physical and mental health
- Blood test results
- Your preferences.

Your treatment is tailored specifically to you, so don't be concerned if people with the same HL stage are having different treatments to you. If you have any questions please ask your doctor. Some treatment types you may be offered include:

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 your own T-cells. The T-cells are altered in pathology in a process explained on our website. See the QR code below for more information.

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.



More information about treatments can be found at <u>www.lymphoma.org.au/about-</u> <u>lymphoma/treatments</u>

Treating your HL

You may have different types of anticancer treatment. These can include:

- A combination of chemotherapy
- A combination of chemotherapy and radiotherapy
- Radiotherapy alone to the affected lymph nodes
- Monoclonal antibody, depending on your subtype and stage.

Chemotherapy is given as a combination of different chemotherapy medicines (over 6-8 months). The chemotherapy combination, and how often you get it is called a "protocol". Your treating team may use a group of letters (each stands for a chemotherapy medicine) when they talk about your treatment. An example is a protocol called "ABVD":

- A = Adriamycin (also called doxorubicin)
- B = Bleomycin
- V = Vinblastine
- D = Dacarbazine

Your treating team will give you information about your protocol, and potential side effects to watch out for.

Treatment of Relapsed HL

Relapsed disease is when the cancer returns after a time of remission. Remission is when you have no detectable disease after finishing treatment. While this can be very upsetting, the good news is that it can still be treated.

The treatment you are offered this time, will depend on what treatments you have already had, and how long you have been in remission for. Your doctor may choose to use a combination of chemotherapy, or other anti-cancer medicines. In some cases, a treatment of high dose chemotherapy and a stem cell transplant might be offered to you.



More information about stem cell transplants can be found at <u>www.lymphoma.org.au/about-</u> <u>lymphoma/treatments/stem-</u> <u>cell-transplants</u>

Treating HL in older people

Approximately 20% of people diagnosed with HL are aged 60 years or older.

20% = 1 in 5

Older people often have other health problems at the time of diagnosis. This can make treatment more complex. Your doctor will need to consider your overall health, and other medicines you are taking when choosing the right treatment for your lymphoma. For example, if you have a heart condition, you may not be able to have some chemotherapies because of their effect on the heart. Your doctor might offer a different treatment to you.

Older age and other health problems (comorbidities) may also make tolerating treatment and its side effects more difficult. You may also take longer to recover from treatment. Notably, chemotherapy causes damage to the bone marrow, and an older person may take longer to build back healthy blood cells.

These are all factors your doctor will consider and manage. It does not mean you can't be treated. Your doctor will carefully assess your health status and response to treatment. Then, they will discuss the best options for you.

Some strategies your doctor might use to help you get the most out of treatment, and remain well include:

- extending the period between treatment doses
- reducing the dose of chemotherapy
- adding in some supportive medicines.

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.

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/aboutlymphoma/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.

С

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.

Ε

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.

Η

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

HSCT – Haematopoietic Stem Cell Transplant.

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.

Μ

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.

0

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'.

Reed–Sternberg cell – an abnormal cell that looks like 'owl eyes' under the microscope. These cells are usually found on the lymphoma cells people with HL, but not seen in people with non-Hodgkin lymphoma

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-peenee-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

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 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: <u>nurse@lymphoma.org.au</u>

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

Instagram www.instagram.com/lymphomaaustralia

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



www.lymphoma.org.au



