What is lymphoma

Lymphoma Australia Nurse hotline: 1800 953 081 nurse@lymphoma.org.au

Learning about your lymphoma can be like learning a new language. It takes time and practice. Please keep this document handy so you can refer back to it as often as you need to. It will become easier to understand the more you read it.

Overview

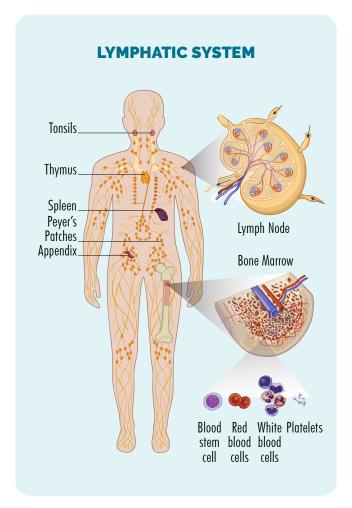
Lymphoma is a cancer that affects your blood cells called lymphocytes. Lymphocytes are a type of white blood cell and are responsible for fighting infection and disease. We have two main types of lymphocytes:

- B-cell lymphocytes
- T-cell lymphocytes (these include Natural killer (NK cells)

Lymphocytes mostly live in our lymphatic system which is responsible for cleaning our blood of toxins and waste products. It includes our lymph nodes, spleen, thymus, tonsils, appendix and a fluid called lymph. Our lymphatic system is part of our immune system, and is where our disease fighting antibodies are made by our B-cell lymphocytes.

Lymphocytes also have a special function called "immunological memory". They remember infections we had in the past and create "Memory cells" that are able to fight infections if we ever get the same infection again.

Even though our lymphocytes are a type of blood cell, lymphoma often does not show up in blood tests – because they live mostly in our lymphatic system.





Only very small amounts of lymphocytes are found in our blood. However, lymphocytes can travel to any part of our bodies to fight infection disease. This means that lymphoma can also be found in any part of your body.

Blood, lymphatic or immune cancer?

Lymphoma has been called a blood cancer, a cancer of the lymphatic system and an immune system cancer. But rather that being three different types of cancer, we refer to it as the "The What", "The Where" and "The How" of lymphoma.

The what – lymphoma is cancer of your white blood cells – called lymphocytes.

The where – lymphocytes live in your lymphatic system and lymphoma usually starts in your lymphatic system.

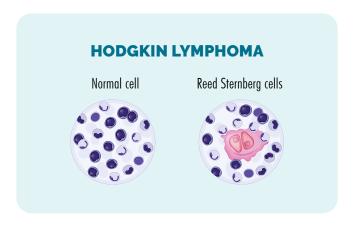
The how – your lymphocytes are part of your immune system. When you have lymphoma, your immune system cannot work as effectively to fight infection and disease.

Types of lymphoma

There are more than 80 different subtypes of lymphoma and it can affect either your

B-cell lymphocytes or T-cell lymphocytes. They are broadly grouped into:

- Hodgkin Lymphoma There are five different types of Hodgkin Lymphoma and they are all lymphomas of B-cell lymphocytes. Hodgkin Lymphoma is different to Non-Hodgkin Lymphoma because the B-cell lymphocytes look very different. When they undergo cancerous changes they become "Reed Sternberg" cells. The Reed Sternberg cells usually also have a protein on them called CD15 or CD30. Some treatments target these proteins to fight Hodgkin lymphoma.
- Non-Hodgkin Lymphoma (NHL) –
 the other 75+ subtypes of lymphoma
 are a subtype of NHL, and can
 include lymphomas of B-cell or T-cell
 lymphocytes. Chronic Lymphocytic
 Leukemia (CLL) is also considered a
 subtype of NHL, as it is essentially the
 same disease as a subtype of NHL
 called Small Lymphocytic Lymphoma.





Lymphoma is further grouped into indolent or aggressive.

Indolent - Indolent means that the lymphoma is very slow growing - or even sleeping. Many people with indolent lymphoma will not need treatment straight away. This is because the lymphoma is not able to do any harm when it is not growing, or when it is growing very slowly. Also, current treatments are designed to work on actively growing cancer cells, so your indolent lymphoma is unlikely to respond to treatments while it is sleeping, or growing too slowly. Your doctor will actively monitor you to make sure that the lymphoma stays indolent. Sometimes, indolent lymphomas "wake up" and begin to grow faster, or grow in an area that starts to cause you symptoms. If this happens, your doctor will be able to pick it up early and start you on treatment if needed.

Most indolent lymphomas cannot be cured, but many people can live a long and healthy life with indolent lymphoma. You may need treatment at some point for indolent lymphoma if it "wakes up". The purpose of treatment is to put it back to sleep in a remission.

Rarely, some indolent lymphomas can "transform" into another, more aggressive type of lymphoma. If this happens, you will need to start treatment.

Aggressive – Aggressive means the lymphoma is growing quickly. You may notice symptoms such as a lump come up

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.

Contact your doctor as soon as possible if you get B-symptoms.



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.



within days or weeks and it does not go away. If you have an aggressive lymphoma you will need to start treatment soon after you are diagnosed. However, unlike indolent lymphomas, many (but not all) aggressive lymphomas can be cured.

Symptoms of lymphoma

Symptoms of lymphoma can vary between subtypes, and depend on where in your body the lymphoma is growing. However, some symptoms are more common in most lymphomas and include:

- B-symptoms (see picture on page 3)
- Swollen lymph nodes A lump you can see or feel – usually in your neck, armpit or groin. But you can have swollen

SYMPTOMS OF LYMPHOMA Psychological (fatigue, loss of appetite) Systemic Lymph Nodes (weight (enlargement) loss, loss of apetitite, Lungs fever and (shortness of night sweats) breath, cough) Diaphragm Liver Spleen (enlargement) (enlargement) Kidney (Nephrotic Muscle syndrome) (muscular weakness) Bone and joints Bone marrow (pain or (involvement) tenderness)

- lymph nodes anywhere in your body.
- Difficulty getting over infections, or infections that keep coming back
- Itchy skin
- Fatigue extreme tiredness not improved after a rest or sleep
- Unintended weight loss
- Fevers and/or chills
- Night sweats
- Rash or spots on your skin
- Unusual bleeding or bruising

How is lymphoma diagnosed?

Sometimes it can take a while to diagnose lymphoma because many of the symptoms are similar to other more common causes such as stress, infections or anaemia. Your doctor will often try to rule out some of these more common causes before testing for lymphoma.

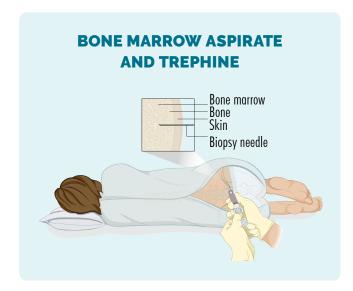
In some cases, you may have a scan or test for some other reason, which shows swollen lymph nodes or other signs that you may have lymphoma. In this case your doctor may do more tests, or refer you to a specialist doctor called a haematologist or oncologist – who specialises in treating patients with lymphoma.

Types of biopsy you may need

You will need a biopsy to diagnose lymphoma. The type of biopsy you have will depend on where the suspected lymphoma is, but can include:



- Core needle biopsy a needle is used to take a part of tissue from your lymph node.
- Excisional biopsy a surgical procedure to remove the whole lymph node.
- Incisional biopsy a surgical procedure to remove part of the lymph node.
- Bone marrow biopsy a surgical procedure where your doctor uses a needle to remove some of your bone marrow.



The biopsy will then be checked by a histopathologist for signs of lymphoma. The histopathologist may also do other tests on the biopsy to check for any genetic changes or proteins that may give information about how quickly the lymphoma is growing, and the best type of treatment for you.

Types of scans you may need

Depending on your subtype of lymphoma, you may also have one or more of the following scans to check for lymphoma in different parts of your body.

PET scan - PET scans provide an image of the inside of your whole body, and lights up areas that are affected by lymphoma. You will be given an injection of a radioactive medicine that any cancerous cells absorb, making them stand out on the PET scan. It takes around 30-60 minutes to do, but you should allow at least 2 hours for the appointment over all.



 CT scan - A CT scan is a scan that can look at the inside of your body and give a 3D image. It is usually used when only a certain part of your body needs to be seen, such as your chest or abdomen.
 They can provide an image of your body from front to back and top to



bottom. Scans are often used to check for tumours, swollen lymph nodes and other conditions.

- MRI MRI scans use magnets and radio waves to create a picture of the inside of your body. It is similar to a CT scan in that you will lay on a bed and be moved in and out of the MRI machine. However, MRI scans can take longer, and depending on what part of your body is being scanned, can take 15 90 minutes (1 and half hours). It is also a very noisy scan as the magnets move around inside the machine.
- Ultrasound An ultrasound is a scan that uses sound waves to make a picture.
 The ultrasonographer (person doing the ultrasound) will put some gel over the area being checked, and use a wandlike device to run over your skin, which sends sound waves into your body. As the waves bounce back it creates a picture of the inside of your body.

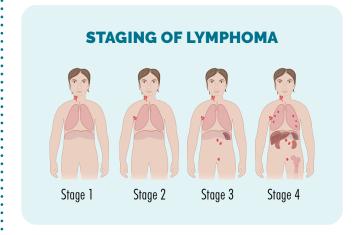
Staging

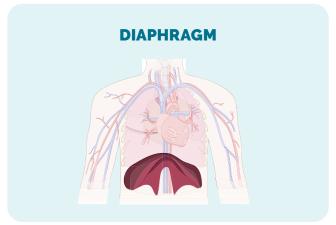
Staging looks at where the lymphoma is in your body. Early-stage lymphomas are only on one side of your diaphragm. For example, all your affected lymph nodes are above or all below the diaphragm . Stage 1 and 2 are early-stage lymphomas.

Late-stage lymphomas have areas of lymphoma on both sides of your diaphragm. Stage 3 and 4 are advanced stage lymphoma. Stage 4 includes having lymphoma on both sides of your

diaphragm, and in an area outside of your lymphatic system such as your liver, lungs, bone marrow or bone.

Unlike other cancers, some advanced stage lymphomas can often be cured. Please ask your doctor about your own chances of being cured from your lymphoma.





Treatment for Lymphoma

The type of treatment you get will depend on many factors including:

- The subtype of lymphoma you have.
- Whether it is early or late-



stage lymphoma.

- If you have any genetic mutations in your lymphoma cells.
- Your overall health and well-being.
- If you have ever had treatment for lymphoma before.
- Your personal preferences once you have all the information you need.

Below is an overview of different treatment options that may be offered to you to treat your lymphoma.

Watch and Wait

Watch and wait is often used when you have an indolent lymphoma. It is a good way to start, because it means your lymphoma is not causing any harm, and your own immune system is keeping it under control. Your doctor will actively monitor your progress and your lymphoma. If it starts to grow or cause symptoms, you will likely start treatment. About 1 in every 5 people with an indolent lymphoma will never need treatment.

Surgery - can be used to completely remove the lymphoma.

Antibiotics – some lymphomas called Marginal Zone Lymphoma feed off certain infections. If you have one of these types of lymphoma, you may be given antibiotics to kill the infection which will cause the lymphoma cells to starve and die.

Radiation/radiotherapy

Radiotherapy is a treatment that uses high doses of radiation to kill cancer cells and shrink tumours. If you are having radiotherapy you will have a planning session before you start which helps the radiation therapists work out how to target the radiation to your lymphoma and avoid damaging nearby healthy tissue. It is usually given every day Monday to Friday and can last between three and five weeks. You may or may not have radiation treatment with chemotherapy.

If you live far away from the radiation centre and you need help with accommodation, talk to your doctor or nurse about what help is available to you. You can also contact the Cancer Council or Leukaemia Foundation in your state to see if they can help with somewhere to stay.

Targeted therapy – taken as a tablet either at home or in hospital. Targeted therapies attach to the lymphoma cell and block signals it needs to grow and produce more cells. This stops the cancer from growing and causes the lymphoma cells to die off.

Chemotherapy (chemo)

Chemotherapy are types of medications that kill fast-growing cells. Because they kill fast-growing cells, they can be very effective at treating lymphoma. Unfortunately, chemotherapy cannot tell the difference between healthy cells and



lymphoma cells, so you can get unwanted side-effects from chemo. These can include hair loss, a sore mouth, nausea and vomiting, diarrhea or constipation.

Monoclonal antibody (MAB) (including immune checkpoint inhibitors)

MABs are a type of treatment that help your own immune system to fight the lymphoma more effectively. They are given by a drip, and move through your bloodstream to the lymphoma cells and attach to these cells. By attaching to the lymphoma cells, MABs attract your own immune cells to the lymphoma so they can begin to attack.

Stem cell transplants

Stem cell transplants are used to replace your bone marrow with healthy stem cells that can become different types of blood cells. It involves several steps where your own stem cells are collected during a procedure called apheresis, and stored until you can get them back. You will then have high dose chemotherapy to kill off your bone marrow, before getting your stem cells back. You can learn more about stem-cell transplants at our website https://www.lymphoma.org.au/lymphoma/treatments/stem-cell-transplants/

CAR T-cell therapy

CAR T-cell therapy is a type of immunotherapy that enhances your immune system so it can recognise, and

destroy cancerous lymphoma cells more effectively. It uses your own immune T-cell lymphocytes, which are collected in a procedure called apheresis. The T-cells are then bound to a CAR – (chimeric antigen receptor), which is specifically designed to attach to antigens on your lymphoma cells. The CAR- T cells are then returned to you, better able to fight your lymphoma. You can learn about CAR T-cell therapy here https://www.lymphoma.org.au/lymphoma/treatments/chimeric-antigen-receptor-car-t-cell-therapy/.

Clinical Trials

Clinical trials are an important way to learn new and better ways to treat lymphoma or manage side-effects to improve your quality of life. They can provide you with an opportunity to try new medicines, or new combinations of medicines that you otherwise would not have access to. However, there is no guarantee that a clinical trial will give you a better outcome than standard treatment. If you are interested in joining a clinical trial, ask your doctor if you are eligible. Or you can see our clinical trials factsheet here or scan the QR code at the end of this document.

Important things to note

- You will need a biopsy to diagnose lymphoma – In some cases, you may need more than one biopsy.
- There are many different types of lymphoma – Ask your doctor what subtype you have.



- Lymphoma is grouped into Hodgkin and Non-Hodgkin Lymphoma and can be indolent or aggressive.
- Some indolent lymphomas do not need treatment.
- Treatment will depend on your individual circumstances, so make sure you talk to your doctor about the best options for you.
- Some advanced stage aggressive lymphomas can be cured.
- If you have an indolent lymphoma, you may have it for the rest of your life, but many people live well with it.
- Report any symptoms especially B-symptoms to your doctor.

Glossary

Aggressive – fast-growing.

Indolent – slow-growing.

Immune system – includes the lymphatic system, antibodies, all white blood cells and physical barriers such as our skin, stomach acids and mucous membranes – all which work together to keep infection and disease out of our bodies.

Lymphatic system – a part of our immune system that includes lymph nodes, spleen, thymus, lymphatic vessels, lymph and other tissue to fight infection and disease.

Lymphocytes – a type of white blood cell that fights infection and disease. They can be B-cell lymphocytes or T-cell lymphocytes (including Natural killer (NK) cells). Lymphocytes live mostly in our lymphatic system, but can also travel to any part of our body. Some B-cell lymphocytes also make antibodies to fight infections.

Lymphoma – Cancer of lymphocytes.

For a more indepth glossary please <u>click here</u> or scan the QR code at the end of this document.

Resources and support

Lymphoma Australia offers a wide range of resources and support for people living with lymphoma or CLL, and their carers. How to access our resources:

- Visit our website <u>www.lymphoma.org.au</u> for more information.
- Phone our Lymphoma Care Nurse Hotline on 1800 953 081.
- Email our Lymphoma Care Nurses nurse@lymphoma.org.au
- Booklet: Understanding Non-Hodgkin Lymphoma (NHL)
- Downloadable information: Visit our website, or give us a call if you would like some more information on a variety topics related to lymphoma
- Join our Facebook page
 <u>Lymphoma Down Under</u> (make sure you complete all the membership questions when you join).

Cancer Council offers a range of services, including free counselling, to support people affected by cancer, including



patients, families and friends. Services may be different depending on where you live. You can contact them at <u>www.cancer.org.au</u> or by phone on 13 11 20.

Medicare Australia: Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan is funded by Medicare and can provide you with up to 10 sessions with a registered psychologist. More information can be found here.

WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

Canteen provides support for young people aged 12-25 years who have cancer, or, who have a parent with cancer. Find out more at their website here www.canteen.org.au.

Health Translations: A collection of health related information collected by the Victorian Government with resources in different languages. You can visit their website at www.healthtranslations.vic.gov.au.

Useful links

<u>Understanding your lymphatic and immune systems</u>

What is lymphoma

Symptoms of lymphoma

Types of lymphoma

Understanding clinical trials



Bone marrow biopsy



CAR T-cell webpage



Definitions



Factsheets



Questions to ask your doctor





Stem_cell



Tests_diagnosis_staging



Treatments_website



Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this document is accurate and up-to-date. However, this information is intended for educational purposes only and does not substitute for medical advice. If you have any concerns about your health or wellbeing, please contact your treating team.



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Notes

