

Hodgkin Lymphoma (HL)

Lymphoma Australia
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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.**

Introduction

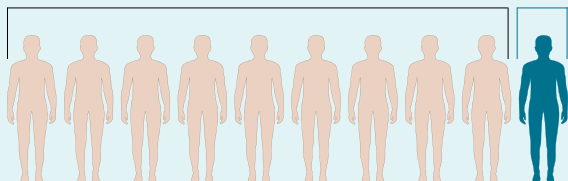
Hodgkin Lymphoma (HL) is a type of blood cancer. Most people with HL have a fast growing (aggressive) lymphoma, but for some people it may grow more slowly. It is most common in young people aged 15-29 years, or older people aged over 70 years. Many people with HL will be cured after treatment.

The Australian Institute of Health and Welfare (AIHW) suggests approximately 803 people will be diagnosed with HL in Australia during 2021. It is expected this will include 98 children and teenagers. This means about 1 in 10 people diagnosed with any type of lymphoma, will have a subtype of Hodgkin's Lymphoma.

LYMPHOMA DIAGNOSIS

Non-Hodgkin Lymphoma

Hodgkin Lymphoma

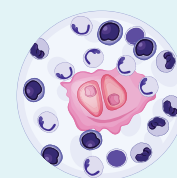
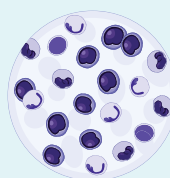


HL affects a type of white blood cell called B-cell lymphocytes (B-cells). B-cells fight infection and diseases to keep you healthy. They remember infections you had in the past, so if you get the same infection again, your immune system can fight it more effectively. Sometimes these cells become larger than they should and can look different to your healthy B-cells. They will not work as effectively to fight infections and disease.

HODGKIN LYMPHOMA

Normal cell

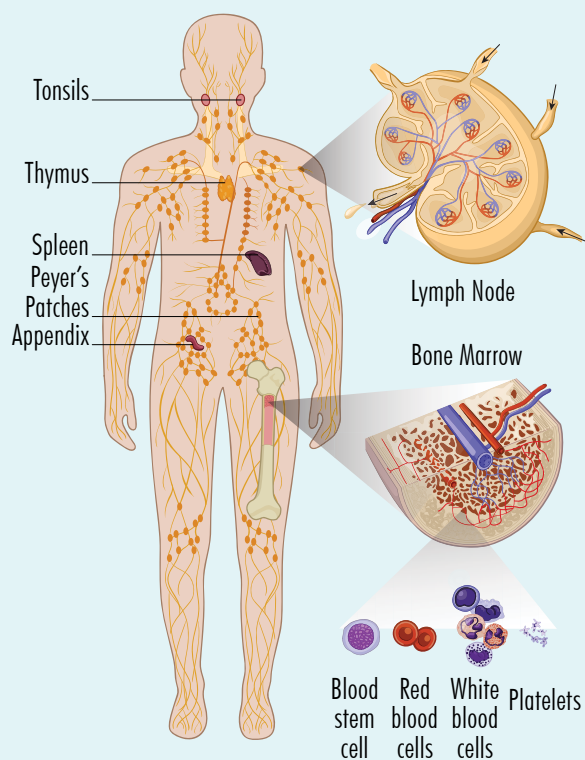
Reed Sternberg cells



When this happens, the cells become cancerous lymphoma cells. You may hear them called "Reed-Sternberg cells". As well as Reed-Sternberg cells, you may have other abnormal cells too, but it is the

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LYMPHATIC SYSTEM



Reed-Sternberg cells that help doctors diagnose Hodgkin Lymphoma instead of non-Hodgkin lymphoma. Those with non-Hodgkin lymphoma do not have Reed-Sternberg cells.

B-cells are made in your bone marrow (the spongy part in the middle of your bones), but live in your spleen and your lymph nodes. They can travel through your lymphatic system, to any part of your body to fight infection or disease. Because of this, HL can also develop in any part of your body.

The first symptom you might experience with HL is a swollen lymph node in your neck, armpit, groin or abdomen. You may also have a swollen spleen. Your spleen is an organ that filters your blood and keeps it healthy. It is on the left side of your upper abdomen near your stomach (tummy). When your spleen gets too big, it can put pressure on your stomach and make you feel full, even if you haven't eaten very much.

Other symptoms you might get include:

- feeling unusually tired (fatigued)
- feeling out of breath
- bruising or bleeding more easily than usual
- blood in your poo (this can happen if you have HL in your stomach or bowels)
- infections that don't go away, or keep coming back (recurrent)
- sweating at night more than usual
- losing weight without trying
- a new lump in your neck, under your arms, your groin, or other areas of your body (this is caused by lymphoma cells gathering in your lymph node and

making it grow larger). These lumps may or may not hurt, depending on where they are.

- B-symptoms

SWOLLEN LYMPH NODE



Diagnosis and Staging

Your doctor may suspect you have lymphoma when they get your blood test results, X-ray, other scan results, or do a physical exam. But to diagnose HL, you will need a biopsy. A biopsy is a procedure to remove part, or all of an affected lymph node or bone marrow. The biopsy is then checked by scientists in a laboratory to see if there are changes that help the doctor diagnose HL.

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

Lymphoma cells can travel to any part of your body so, if you have HL your doctor

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.

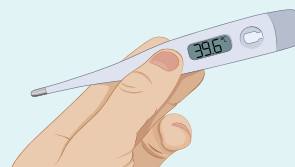
Contact your doctor as soon as possible if you get B-symptoms.



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.

will organise more tests to check if it is anywhere else. These tests are called “staging” and may include:

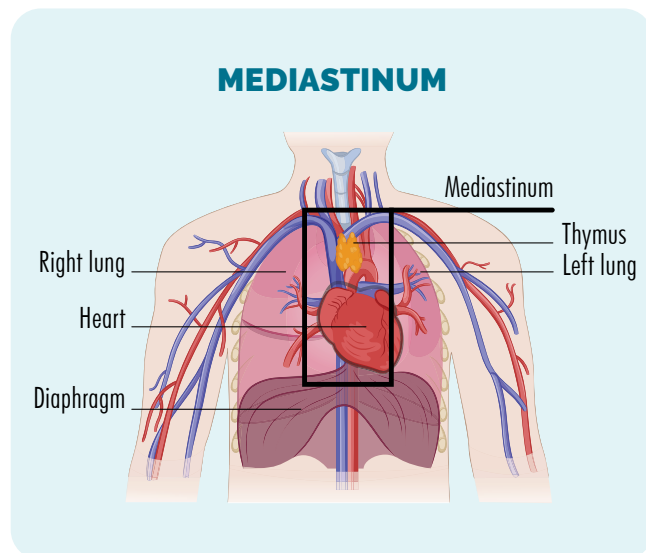
- Blood tests
- Positron emission tomography (PET) scan
- Computed tomography (CT) scan
- Bone marrow biopsy (Your doctor will use a needle to take a sample of marrow from the middle of your bone - usually hip, but sometimes the sample may be taken from a different bone. This will be done with local anaesthetic.

Types of classical Hodgkin Lymphoma (cHL)

There are two main types of HL – classical HL and Nodular Lymphocyte Predominant HL. If you have been diagnosed with Nodular Lymphocyte Predominant HL – please see our factsheet [here](#). If you have been diagnosed with a subtype of classical HL (cHL), please read on. The sub-types of classical HL are:

Nodular sclerosis cHL – This is the most common type. For every 10 people diagnosed cHL, around 6-8 of you will have nodular sclerosis cHL. It usually develops deep in the middle of your chest (mediastinum), but can also develop in your spleen, lungs, bone or bone marrow. Rarely it can develop in your liver.

Mixed cellularity cHL – This is the second most common subtype of cHL, and is more common in older adults and in men, but can still affect others too. It usually



develops in lymph nodes just under your skin deep in the fatty tissue, but can also develop in your spleen, bone marrow, liver and other organs.

Lymphocyte rich cHL – This subtype, is usually found earlier than other subtypes of cHL and usually develops in your lymph nodes just under your skin deep in the fatty tissue.

Lymphocyte depleted cHL – This is a very rare subtype of cHL. It usually develops in lymph nodes that are deep in your abdomen (tummy) area – these are called retroperitoneal lymph nodes. It can also develop in your organs such as liver, pancreas, stomach and bowel.

Your doctor is able to diagnose which subtype you have by looking at your blood and biopsies under a microscope, or from the report they get from pathology. If you

don't already know, ask your doctor what subtype you have.

Before you start treatment

Before you start treatment you will also need to have some baseline tests done. These can include blood tests to check how well your liver and kidneys are working, scans on your heart, or lung function tests. These are to make sure that you are well enough to have treatment without it causing you to become too unwell. Throughout your treatment you will have regular blood tests which will be compared to these baseline tests. You may also have further lung tests and heart scans to make sure that the treatment has not caused any damage to your organs.

Fertility – some cancer treatments can make it harder to fall pregnant, or to get somebody pregnant. If you (or your child) are planning to have children later in life, talk to your doctor about how to preserve your fertility.

Starting treatment can feel overwhelming, and even knowing what questions to ask can be difficult. To help get you started, we have put together some questions you may like to consider asking. Click [here](#) to download our **Questions to ask your Doctor** factsheet or scan the QR code at the end of this document.

Treatments

There are a lot of different treatments available for HL. The best treatment for you will depend on many factors including your age, your overall health, if you have an early or advanced stage HL, if you've had treatment before and how well it worked for you. Your doctor will be able to explain why they think a particular type of treatment is the best option for you. Some of the different types of treatment include:

Radiation/Radiotherapy - Radiation therapy is a cancer treatment that uses high doses of radiation to kill lymphoma cells and shrink tumours. Before having radiation, you will have a planning session. This session is important for the radiation therapists to plan how to target the radiation to the lymphoma, and avoid damaging healthy cells. Radiation therapy usually lasts between 2-4 weeks. During this time, you will need to go to the radiation centre everyday (Monday-Friday) for treatment.

*If you live a long way from the radiation centre and need help with a place to stay during treatment, please talk to your doctor or nurse about what help is available to you. You can also contact the Cancer Council or Leukemia Foundation in your state and see if they can help with somewhere to stay.

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 Hodgkin 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) – Given as an infusion at a cancer clinic or hospital. MABs attach to the lymphoma cell and attract other disease fighting white blood cells and proteins to the cancer so your own immune system can fight the HL.

Immune checkpoint inhibitors (ICIs) – Given as an infusion at a cancer centre or hospital. ICIs work to improve your own immune system, so that your own body can fight the cancer. They do this by blocking some of the protective barriers lymphoma cells put up, that make them invisible to your immune system. Once the barriers are removed, your immune system can see and fight the cancer.

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. For more information on these treatments, please see our [Oral Therapies Fact Sheet](#).

Stem-cell transplant – to learn more about stem cell transplants please see our factsheets

- Transplants in Lymphoma
- Allogeneic stem cell transplants
- Autologous stem cell transplants

Chimeric antigen receptor therapy (CAR T-cell therapy) – Please see our factsheet for more information on CAR T-cell therapy

All factsheets are available on our [website here](#). If you do not have access to a computer and would like a paper copy, please call us on 1800 359 081 or email us at enquiries@lymphoma.org.au.

Starting treatment

The first time you start treatment it's called first-line treatment. Once you finish your first-line treatment, you may not need treatment again.

First-line treatment

Radiation treatment (Radiotherapy) - This may be with or without chemotherapy. If you need to start treatment, you may have more than one medicine, including several different types of chemotherapy and a monoclonal antibody or immune checkpoint inhibitor. When you have these treatments, you will have them in cycles. That means you will have the treatment,

then a break, then another round (cycle) of treatment. First-line treatments may include:

ABVD – a combination of chemotherapy medicines called doxorubicin, bleomycin, vinblastine and dacarbazine.

Escalated BEACOPP – combination of chemotherapy medicines called bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine and procarbazine. You will also be given a steroid medicine called prednisolone. You will not be given all these medications on one day, but you will have them all over 8 days. You will have the steroid for 2 weeks, then a break, and then start your next cycle

*If you have one of these treatments with **bleomycin**, you should not have high-flow oxygen in the future. If you do it may cause some scarring in your lungs. Instead, if you need help breathing you may have medical air or other alternatives. If you have ever had bleomycin – even just one dose, you will need to tell all doctors and nurses that you **cannot have high flow oxygen** (some hospitals may put oxygen down as an allergy. Although it is not a true allergy, it may be put down as one, just as a reminder). In some cases, your doctor may still order oxygen for you if the benefit of having it outweighs the risk.

You may also be eligible for a clinical trial – ask your doctor about these.

Second-line treatment

Many people are cured with their first-line treatment but for some, first-line treatment may not work as well as hoped. This is called “refractory” disease. Others may have a good result from the first-line treatment, but after months or years, the HL may come back. This is called a “relapse”. If you have refractory or relapsed HL you may need treatment again. This is called second-line treatment. Second-line treatment can include:

- High-dose chemotherapy and then a stem cell transplant
- Different types of chemotherapy
- A monoclonal antibody or immune checkpoint inhibitor
- Radiotherapy
- Or you may also be eligible for a clinical trial – Ask your doctor about these

Further information on different treatment protocols can be viewed [here](#).

What happens if I don't respond to treatment?

If you don't respond to your treatment for HL, your doctor may want to do more tests on your lymphoma cells.

Grey Zone Lymphoma (GZL) is another, very rare, and hard to diagnose subtype of lymphoma. It is sometimes misdiagnosed as HL because it looks, and behaves so much like HL.

Your doctor may do more tests to see if your lymphoma cells have too much of a protein called CD20, while also having the usual characteristics of classical HL. If you have too much of the CD20 protein on your lymphoma cells, you may have Grey Zone Lymphoma instead of HL. You can find more information on Grey Zone Lymphoma at our webpage [here](#).

Clinical Trials

Clinical trials are important to find new medicines, or combinations of medicines to improve treatment of HL in the future. They can also offer you a chance to try a new medicine, combination of medicines or other treatments that you would not be able to get outside of the trial. Some clinical trials for HL are looking at CAR-T cell therapy to see if this may be effective for people with HL. If you are interested in participating in a clinical trial, ask your doctor what clinical trials you are eligible for. You can also read our '[Understanding Clinical Trials](#)' Fact Sheet to find a clinical trial.

Follow Up

Finishing treatment can be a time of mixed emotions. You may feel relieved and excited, or you may feel worried and scared. You may even alternate between all of these emotions. This is very normal. However, you will not be alone. You will continue to see your specialist team on a regular basis, and be checked for any

signs and symptoms of your lymphoma relapsing, and your doctor will also want to make sure you're not having any side effects from your treatment. Your doctor will let you know how often they want to see you, however the longer time you are in remission the less often they will need to see you.

If you have any concerns or worries please contact your healthcare team or contact our lymphoma care nurses on 1800 953 081. You can also email us on nurse@lymphoma.org.au.

Summary

- Hodgkin Lymphoma is unique from non-Hodgkin because of the presence Reed-Sternberg cells.
- HL is a type of blood cancer affecting B-cell lymphocytes. B-cells are specialised immune cells that fight infection and disease and live mostly in your lymphatic system.
- Hodgkin Lymphoma is very treatable and even advanced stage 4 HL can be cured in many people.
- There are different subtypes of HL. If you do not know your subtype - ask your doctor.
- Talk to your doctor about preserving your fertility before you start treatment.
- Report any concerns to your treating team - your doctor and nurses.

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 www.lymphoma.org.au 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 [Lymphoma Down Under](#) (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 www.cancer.org.au 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](#).

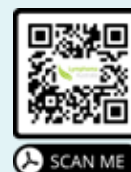
WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

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

Questions to ask your doctor



Definitions



Health Translations



Hodgkin Lymphoma Website



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.

