## **Hodgkin Lymphoma (HL)**

Lymphoma Australia Fact Sheet

#### 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.

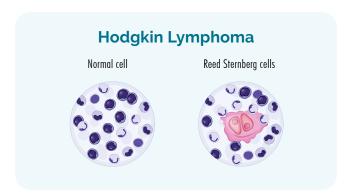
Lymphoma Diagnosis

Non-Hodgkin Lymphoma

Hodgkin Lymphoma

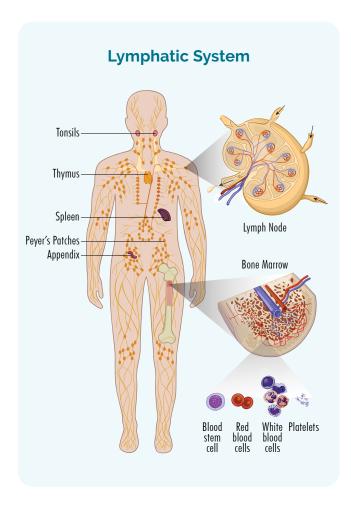
HL affects a type of white blood cell called B-cell lymphocytes (B-cells). B-cells fight infection and diseases to keep you healthy. They remember infections you had in the past, so if you get the same infection again, your immune system can fight it more effectively. Sometimes these cells become larger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

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 Reed-Sternberg cells that help doctors diagnose Hodgkin Lymphoma instead of



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non-Hodgkin lymphoma. Those with non-Hodgkin lymphoma do not have Reed-Sternberg cells.

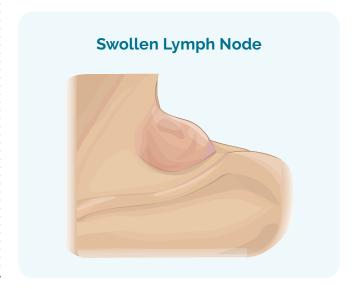
B-cells are made in your bone marrow (the spongy part in the middle of your bones), but live in your spleen and your lymph nodes. They can travel through your lymphatic system, to any part of your body to fight infection or disease. Because of this, HL can also develop in any part of your body.

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.

### **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.

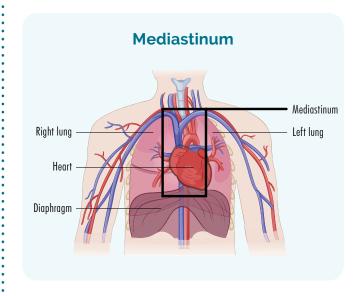
Lymphoma cells can travel to any part of your body so, if you have HL your doctor will organise more tests to check if it is anywhere else. These tests are called "staging" and may include:

- 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 <a href="here">here</a>. 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.

## Questions for your doctor before you start treatment

- 1. What tests have been done? What tests still need to be done before treatment?
- 2. Can you explain these results to me?
- 3. What treatment will work best for me based on these results?
- 4. What is the intent of this treatment?

- (eg. Will I be cured)
- 5. How long will I be at the hospital/ cancer center on treatment days? How often?
- 6. Do I have any other choices?
- 7. What are the best treatments that are available for my HL, even if they're not available in Australia?
- 8. What are the main, and the worst side effects of this treatment?
- 9. What clinical trials am I eligible for?
- 10. Will I need to have time off work? If yes, can I see a social worker to help me arrange finances?
- 11. What support services are available to help me cope with my diagnosis and learn strategies to avoid stress and talk to my family and friends about my diagnosis and treatment
- 12. If you are the parent of a child with HL you may like to ask what support is available for your other children or, for schooling and tutoring for you child while they have, and recover from treatment

## Additional Questions if you live in rural Australia

- 13. Can I have my appointments and treatment close to home?
- 14. Is telehealth an option for me?
- 15. How long will I need to be away from home for treatment?
- 16. How often will I need to come to the city (or be away from home)?
- 17. What financial, accommodation and



travel assistance is available to me?

18. Is there a social worker who can help me arrange these things?

#### **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 able to explain why they think a particular type of treatment is the best option of 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) – These medications might be taken as a tablet or be given as a drip (infusion) into your vein (into your bloodstream) blood at a cancer clinic or hospital. Chemo kills fast growing cells so can also affect some of your good cells that grow fast.

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 - 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 <u>here</u>.

# 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 <a href="here">here</a>.

#### **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**

You will still see your doctor for blood tests and scans after your treatment ends. Your doctor will check you for signs and symptoms of HL coming back, and for side-effects you may have from your treatment.

## **Resources and support**

**Lymphoma Australia** offers a wide variety of resources and support for people with lymphoma and their carers. Please visit our website <a href="www.lymphoma.org.au">www.lymphoma.org.au</a> for further information. Lymphoma Australia Fact sheets and booklets include:

Booklet: What you need to know about lymphoma



## **Hodgkin Lymphoma (HL)**

- Lymphoma subtypes
- Understanding Clinical Trials
- Emotional impact of a lymphoma diagnosis and treatment
- Fear of cancer recurrence and anxiety

Visit the <u>Lymphoma Australia YouTube</u> <u>Channel</u> for presentations and interviews on a variety of topics about lymphoma subtypes, management and supportive care.

Contact the Lymphoma Nurse Support Line on 1800 953 081, email: nurse@lymphoma.org.au or join the private Facebook group: Lymphoma Down Under.

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