

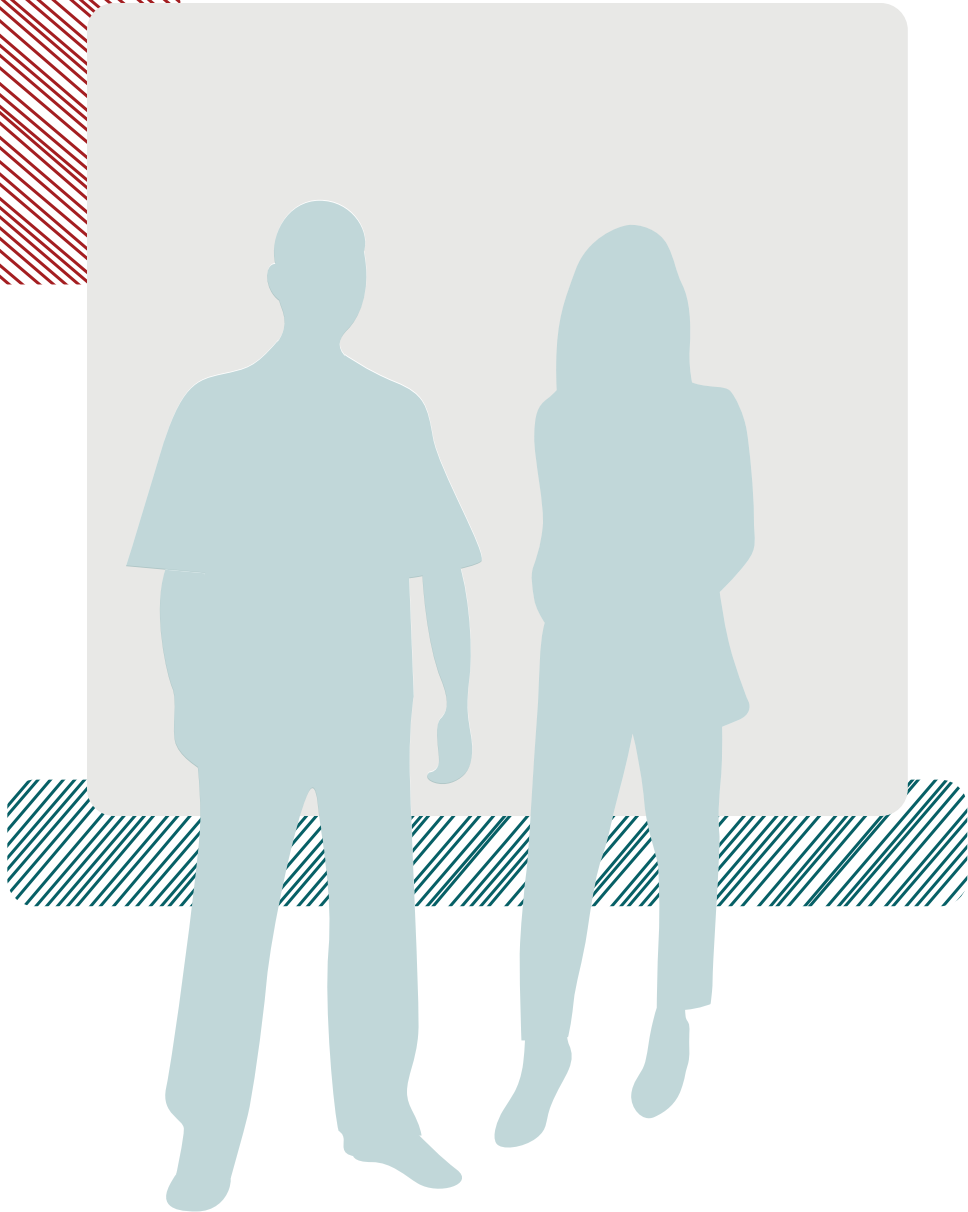
## Understanding and managing **Hodgkin lymphoma (HL)**



## What is this booklet for?

This booklet was designed to answer some questions you may have about HL. It summarizes the treatment options that are available in Canada. It can also serve as a starting point for discussions with your doctor, so that you can decide together what is best for you.

Once you have a better understanding of each treatment option, you can stay informed and take an active role in your HL treatment process.



# What is HL?

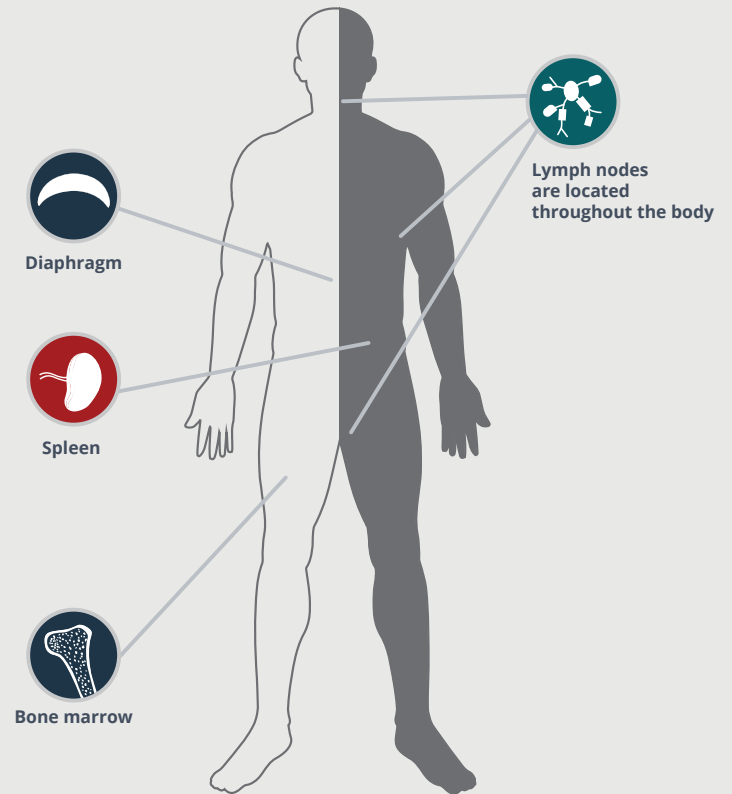
“**Lymphoma**” is a general term for a group of blood cancers that originate in the **lymphatic system**. The lymphatic system is part of the body’s immune system.

It is made up of tissues and organs that produce, store and carry white blood cells throughout the body to fight infections and diseases.

- **HL is a cancer that starts in lymphocytes**, which are a type of white blood cell found mostly in the lymphatic system.
- When a normal lymphocyte undergoes a change (mutation), the abnormal cell (referred to as a “**lymphoma cell**”) begins to multiply.
  - Lymphoma cells may then build up in one or more lymph nodes or in other lymphoid tissues and organs, such as the spleen.
  - They may form a mass (tumour), invade neighbouring tissues, or travel from one group of lymph nodes to the next.
  - Over time, the lymphoma cells can also spread to tissues and organs outside the lymphatic system.

DNA is the material that carries all the information about how our bodies look and function. Each piece of information is carried on a different section of the DNA and these sections are called “genes.” Genes tell a cell how to make a specific protein, which is used by the cell to grow and survive. DNA is organized into tightly coiled thread-like bundles called “chromosomes” that contain thousands of genes. Some changes, called “mutations,” can happen in your genes.

## HL and the lymphatic system



HL is one of the most curable forms of cancer.

It is estimated that in 2022, 1,050 Canadians will be diagnosed with HL.

# What are the types of HL?

There are **2 types** of HL:

- Classical HL (**CHL**)
- Nodular lymphocyte-predominant HL (**NLPHL**)

Let's look at them in some detail.



CHL	NLPHL
<ul style="list-style-type: none"><li>• Most people with HL (<b>about 95 out of 100</b>) have CHL</li><li>• CHL can be recognized by large lymphocytes called <b>Reed-Sternberg cells</b></li></ul>	<ul style="list-style-type: none"><li>• This type of HL is very <b>rare</b></li><li>• Only about <b>5 out of 100</b> people with HL have NLPHL</li><li>• While CHL is known for Reed-Sternberg cells, NLPHL is known for having "<b>popcorn-shaped</b>" cells</li></ul>
<p><b>Subtypes:</b></p> <p><b>Nodular sclerosis HL (NSHL):</b></p> <ul style="list-style-type: none"><li>• Most common type (about <b>60% to 70%</b> of all cases) of HL</li><li>• Most often seen in <b>teens and young adults 15 to 34 years of age</b></li></ul> <p><b>Mixed cellularity HL (MCHL):</b></p> <ul style="list-style-type: none"><li>• Second most common type (about <b>25%</b> of all cases) of HL</li><li>• Most often seen in <b>children and in adults 55 to 74 years of age</b></li><li>• More common in <b>men</b></li></ul> <p><b>Lymphocyte-rich classical HL (LRHL):</b></p> <ul style="list-style-type: none"><li>• Accounts for about <b>4%</b> of all cases</li><li>• Usually develops in lymph nodes in the <b>neck</b>, in the <b>armpits</b> and above the <b>collarbone</b></li></ul> <p><b>Lymphocyte-depleted HL (LDHL):</b></p> <ul style="list-style-type: none"><li>• Least common type (only about <b>1%</b> of all cases) of HL</li></ul>	<ul style="list-style-type: none"><li>• Most common in <b>adults 30 to 50 years of age</b></li><li>• More common in <b>men</b></li><li>• Usually starts in lymph nodes in the <b>neck, underarm or groin</b></li><li>• Usually <b>slow growing (indolent)</b> and diagnosed at an early stage</li><li>• <b>Most people don't have symptoms</b> other than enlarged lymph nodes</li></ul>

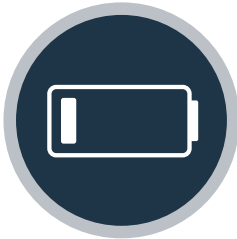
# What are the signs and symptoms of HL?

The signs and symptoms of HL can be similar to other less serious diseases. Some people have no symptoms and their disease is uncovered during a routine medical examination. The **most common and early sign of HL** is **painless swelling in one or more of your lymph nodes**. Some of the signs and symptoms that you may experience are listed below:



## Large masses in the upper part of the body, usually in the neck or upper chest

- When your lymph nodes are enlarged or swollen



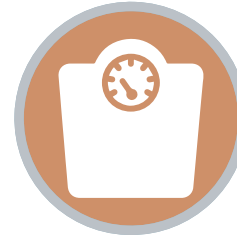
## Fatigue and shortness of breath

- When your body is using more energy



## Fevers and drenching night sweats

- Possibly a response from your immune system



## Weight loss

- When you are eating less or using more energy



## Generalized skin itchiness

- This is a less frequent symptom

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# What are the possible tests for HL?



## Blood tests

A complete blood count (CBC) measures the components of the blood, including counts of white blood cells, red blood cells, and platelets. A CBC is done to help rule out an infection. It also gives doctors a baseline to check against future blood cell counts taken during and after treatment.



## Lymph node biopsy

A biopsy of an enlarged lymph node is needed to diagnose HL. The most common type of biopsy is called an “**excisional biopsy**,” in which the whole lymph node is typically removed (excised).

- If the lymph node is just under the skin, the biopsy procedure is usually simple and can sometimes be done with a numbing medication (local anesthetic).
- If the lymph node is inside the chest or abdomen (stomach area), you may be sedated or receive general anesthesia.

The removed lymph nodes are tested using a process called **immunohistochemistry (IHC)**. Using a microscope, this test looks for proteins on the surface of cells. A diagnosis can be made depending on which proteins can be seen (and not seen) using this technique.



## Imaging tests

Imaging tests like computed tomography (CT) and positron emission tomography (PET) scans take pictures that let your doctor see where your HL is, how it has spread, what size it is, and if other organs are involved.

## CT scan

- A CT scan uses special x-ray equipment to take multiple images of areas inside the body from different angles.
- People with HL may have CT scans of all the areas where lymph nodes are present, which could include the neck, arms, chest, abdomen and pelvis, to identify areas of disease involvement.

## PET-CT scan

- This procedure combines a PET scan with a CT scan to obtain a more detailed image of areas inside the body than either scan can produce alone.
- A PET scan is an imaging technique that produces a 3D image of functional processes in the body.

**PET scans play a very important role in the management of HL. It is common to have more than one PET scan during the course of treatment. They are used to see how well the cancer is responding to treatment.**

## Magnetic resonance imaging (MRI) scan

- The scanners for MRIs use powerful magnetic fields and radio waves that are processed by a computer to create detailed cross-sectional images (slices) of the body.
- These images can then be displayed on a video monitor and also saved on a disk for future analysis.
- While MRI scans are rarely used to diagnose HL, they may be **used for close examination of the spinal cord or the brain if a doctor is concerned that the disease may have spread to these areas.**

# What are the stages of HL?

Identifying the stage of your disease is an important step to planning your treatment. In HL, the stage refers to the **number of lymph nodes that are affected, as well as their location in the body**. It does not determine how well you will respond to treatment.

Your doctor will determine the stage of your disease using tests that were described on pages 10-11. Knowing the stage of the disease helps figure out:

- Which lymph nodes are larger than normal
- Whether your disease affects organs other than your lymph nodes
- If you have large masses of tumours

Now let's take a look at the various stages of HL.

<b>Stage I</b>	Involves swelling in one lymph node or in a group of adjacent nodes.
<b>Stage II</b>	Involves two or more lymph nodes on the same side of your diaphragm.
<b>Stage III</b>	Involves lymph nodes on both sides of your diaphragm.
<b>Stage IV</b>	Is found in areas of the body beyond the lymph nodes, such as the lungs, spleen, liver, bones, or bone marrow.

About **75%** of people with NLP HL have **stage I disease at diagnosis**. It is rare for people with NLP HL to have disease involvement outside of the lymph nodes.

The following letters may be added to your stage:

<b>Category A</b>	Means you are showing no symptoms.
<b>Category B</b>	Means you have symptoms like fevers, drenching night sweats, and unexpected weight loss.
<b>Category E</b>	Means your lymphoma has spread to areas or organs outside of your lymph nodes or to tissues near your major lymphatic areas.
<b>Category X</b>	Means your testing has shown large masses of lymphocytes (the term "bulky disease" is used when a single mass measures more than 10 cm).

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# How is HL treated?

## Factors affecting treatment choice for HL

Discuss your treatment options with your doctor to make sure you understand the benefits and risks of each approach. Your treatment plan is based on:

- Age and overall health status
- HL subtype
- Stage

After considering the above factors and assessing the stage of HL, your doctor will recommend one or more of the treatment options listed on pages 16–18.

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# What treatment options are available for HL?

Not everyone with HL receives the same treatment. Various factors (listed on the previous page) will help your doctor determine the treatment that is most appropriate for you. Speak with your doctor to help you make informed decisions.

Now let's take a closer look at the available HL treatment options.





# Treatment options for HL based on type

## CHL

### Chemotherapy

- Different types of chemotherapy drugs work in different ways to eliminate lymphoma cells or stop new lymphoma cells from forming.
- In many cases more than one chemotherapy drug is used.
- It is usually given in treatment cycles.
- Generally, a treatment cycle is 3 or 4 weeks long.
- Some chemotherapy drugs are given by intravenous (IV) infusion (injected slowly into a vein).

### Radiation therapy

- This is also called “**external beam therapy.**”
- It selectively treats the lymph nodes where the cancer started and the cancerous masses near those nodes.
- With a special machine, carefully focused beams of radiation are directed at the cancer.
- The size of the targeted area is restricted to minimize radiation exposure to adjacent, uninvolved organs.

### Monoclonal antibody therapy

- This is a type of targeted therapy.
- When the body’s immune system identifies something harmful, such as bacteria or a virus, it produces antibodies, which are proteins that help fight infection.
- Monoclonal antibodies are a type of protein made in the laboratory that can only attack a specific target, typically a substance on cancer cells.
- This targeting can reduce damage to normal, healthy cells.

### Immunotherapy

- Immune checkpoint inhibitors are a type of immunotherapy.
- Checkpoints are molecules found on T cells, a type of white blood cell.
- T cells circulate throughout the body looking for signs of infection and diseases, including cancer.
- When a T cell comes across any type of cell, it looks for certain proteins on the cell’s surface.
- If the T cell determines that it is a normal, healthy cell, it moves on to check other cells.
- If the proteins indicate that the cell is foreign or cancerous, the T cell attacks it.
- But cancer cells can sometimes send misleading signals to these checkpoints, telling the T cells that they are not harmful.
- **Checkpoint inhibitors work by blocking the signals that cancer cells send to T cells.**
- When the signals are blocked, it is more likely the T cells will distinguish the cancer cells from healthy cells and begin an attack.

### Stem cell transplantation (SCT)

- Stem cells are basic cells produced by the bone marrow that can turn into different types of blood cells.
- It is not used as an initial treatment, but may be recommended for those who do not respond to treatment or when the disease returns after disappearance of the signs and symptoms.
- The goal of SCT is to cure the cancer by destroying the lymphoma cells with high doses of chemotherapy.
- These high doses of chemotherapy, however, can severely damage the stem cells in the bone marrow.
- SCT allows doctors to give high doses of chemotherapy and then replace the damaged stem cells with healthy stem cells.

## Treatment options for HL based on type

### NLPHL

- NLPHL tends to progress more slowly than CHL, so the treatment approach is usually different.
- One option for some people is the **active surveillance** approach, in which the person is closely monitored for disease progression without getting any treatment until symptoms appear or begin to change.
- Another option for **early-stage NLPHL** is the use of **radiation therapy** alone.

**Joining a clinical trial can be a good option for you. A clinical trial is a type of research that studies a test or treatment in people. It gives people access to healthcare options that otherwise wouldn't be available. Ask your medical team if there is an open clinical trial that is right for you.**

## What else should you know about your HL treatment?

### Treatment side effects

- When you begin your treatment for HL, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan.
- Most side effects improve or resolve once your treatment ends.
- New drugs and therapies can help control side effects, such as nausea and vomiting.

Speak to your doctor if you are experiencing side effects.

### Medical follow-up

- Medical follow-up is important after treatment for HL.
- Once you complete your initial treatment, you will undergo more imaging tests to determine how your body has responded to treatment and whether further investigations or treatments are needed.
- If your scans show that your lymphoma is in remission, you will go for occasional follow-up visits, where your doctor will do a physical exam and blood tests.

See your doctor to get follow-up care for possible early detection of heart disease, secondary cancers, fertility issues, thyroid problems, trouble concentrating, and chronic fatigue.



# What questions should you ask your doctor?



Being an active participant in your cancer care can give you and your family a greater sense of control. One way to achieve this is by building a relationship with your medical team based on open communication.

Consider bringing this list of questions to your next doctor's appointment.

## Diagnosis

- What type of cancer do I have? From what type of cell did it form? Is this cancer common?
- What tests do you recommend for me?
- Where will the tests take place? How long will the tests take?
- How do I prepare for testing? How will the test be done? What can I expect?
- What is the cancer stage? Does this stage mean the cancer has spread far?

## General treatment

- Can I just carefully monitor the cancer?
- Should I start treatment now? Why or why not?
- What should I do to be ready for treatment?
- How do my age, health, and other factors affect my options?
- What are my treatment options?
- Which one do you recommend for me? Why?
- What is the treatment frequency?
- How often will you test my blood to see how treatment is working?
- What should be avoided or taken with caution while receiving treatment?
- What are my chances that the cancer will return?

## Side effects of treatment

- What are the possible risks or side effects of my treatment? How serious are they and what should I report right away?
- What can be done to prevent or relieve the side effects of treatment?

## Other considerations

- Can treatments be taken at home?
- How will treatment affect my daily activities?
- What if I miss a treatment?
- Are there any limits on what I can do?
- Should I still take the other medications I am on?
- Is it okay to continue with the supplements I am currently taking?
- What costs will I encounter?
- In cases of emergency, how can I reach your office on nights, holidays, or weekends?

**Be sure to write down any questions you have that are not on this list. For instance, you might want information about how you'll feel so that you can plan your work schedule. Or you may want to ask about qualifying for clinical trials.**

## What resource is available to you?



Visit our website to learn more about HL and its treatment.

**bloodcancers.ca**

For more information, never hesitate to contact us. We're here to help you!

**1 833 222-4884**

**info@bloodcancers.ca**

Please download the LLS Health Manager™ app by visiting

**bloodcancers.ca/health-manager-app**

You can use this app to note down any questions that you may have to bring to your next doctor's appointment.



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