



UNDERSTANDING

HODGKIN LYMPHOMA

A patient's guide to
HODGKIN LYMPHOMA



LYMPHOMA
CANADA

Lymphoma Canada wishes to acknowledge all the individuals who contributed to the content and development of this publication. Dedicated members of Lymphoma Canada's Scientific Advisory Board provided their expertise, advice, and editorial input to ensure the accuracy and relevance of the information. We thank these caring individuals; their input was invaluable. We hope this manual will provide those diagnosed with Hodgkin lymphoma with the information necessary to better understand their illness and feel confident and empowered as they continue their journey.

INTRODUCTION

Getting a cancer diagnosis is an overwhelming experience. It is perfectly normal to be shocked by the diagnosis, anxious about the future, and confused about the medical information and decisions that need to be made.

If you were recently diagnosed with Hodgkin lymphoma (HL), you probably have many questions about the disease, how it is treated and what your future will look like.

The information in this booklet is meant to act as a guide. It will help you understand the nature of HL and what to expect from treatments, including any possible side effects. The more you know about your disease, the more confident you will be in making decisions with your doctors about your care and wellbeing.

Information. Help. Hope.

You don't have to face lymphoma alone. Lymphoma Canada connects patients, their family and friends, medical professionals, researchers, volunteers, and donors to build a strong lymphoma community.

- + A community that conducts research to learn lymphoma's causes, to develop better treatments, and to find a cure.
- + A community that helps people talk about and cope with the fifth most common cancer in Canada.
- + A community that invites you to get and give support.

For more information about our educational and support programs, please visit www.lymphoma.ca or call **1.866.659.5556**.

CONTENTS

1	About Hodgkin Lymphoma	5
	Cancer	6
	The Lymphatic System	7
	Lymphoma	10
	Hodgkin Lymphoma	10
	Risk Factors	11
	Development of Hodgkin Lymphoma	12
	Types of Hodgkin Lymphoma	13
	<i>Classical Hodgkin Lymphoma</i>	13
	<i>Nodular Lymphocyte Predominant Hodgkin Lymphoma</i>	15
	Signs and Symptoms	15
2	Your Medical Team	17
	Taking an Active Role	18
	Communicating with Your Medical Team	19
	Referral to a New Doctor or Getting a Second Opinion	24
3	Diagnosis	25
	Diagnostic Tests	26
	Questions to Ask About Diagnostic Tests	31
	Staging	31
	Prognosis	33
	Questions to Ask About Your Diagnosis	34

4	Treatment	35
	Treatment Overview	36
	Before Starting Treatment	38
	What to Expect During Treatment	38
	Types of Treatment	40
	Drug Therapy	41
	Chemoimmunotherapy	44
	<i>Chemotherapy</i>	44
	<i>Antibody Therapy</i>	49
	<i>Other Targeted Therapies</i>	49
	<i>Steroids</i>	51
	Radiation Therapy	52
	Surgery	56
	Stem Cell Transplant	56
	Supportive Therapy	57
	Questions to Ask About Treatment	58
5	Relapsed or Refractory Hodgkin Lymphoma	61
6	Clinical Trials	63
7	Follow-up Care	67
	Follow-up Appointments	68
	Secondary Cancers	70
8	Medical Terms	73



ABOUT HODGKIN

LYMPHOMA

A cancer diagnosis is often overwhelming. Learning more about the disease can ease confusion and allow you to feel more in control.

Cancer	6
The Lymphatic System	7
Lymphoma	10
Hodgkin Lymphoma	10
Risk Factors	11
Development of Hodgkin Lymphoma	12
Types of Hodgkin Lymphoma	13
Classical Hodgkin Lymphoma	13
Nodular Lymphocyte Predominant Hodgkin Lymphoma	15
Signs and Symptoms	15

Lymphoma is a cancer of the blood and lymphatic system. To better understand lymphoma and how it may affect you, it helps to have a basic understanding of the lymphatic system and cancer in general.

CANCER

Cancer is the uncontrolled growth of abnormal cells.

Cells make up every part of your body: skin, hair, nails, lymph nodes, blood and body organs. To keep things running smoothly, cells grow, work, and divide in a very controlled fashion. All of these cells also eventually die.

Normally, a cell dies when it becomes too old or when it stops working properly. The immune system is also constantly monitoring cells throughout the body to identify abnormal cells and destroy them.

When damage to a cell gives it the ability to avoid death or if the immune system doesn't work properly, some cells can live longer than normal. These abnormal cells can multiply and may cause cancer.

Abnormal cells often cannot properly perform their regular job. As these abnormal cells divide, they can eventually form a solid mass called a tumour. A malignant (cancerous) tumour will continue to grow at an uncontrolled rate and can spread to other parts of the body.

Most cancers are named after the organ or the type of cell they start growing in. For example, a cancer that starts in the pancreas is called pancreatic cancer and a cancer that starts in lymphocytes is called lymphoma.

THE LYMPHATIC SYSTEM

The lymphatic system is part of your circulatory system and serves many life-preserving functions. It is made up of a network of vessels, nodes and organs that run throughout your body.

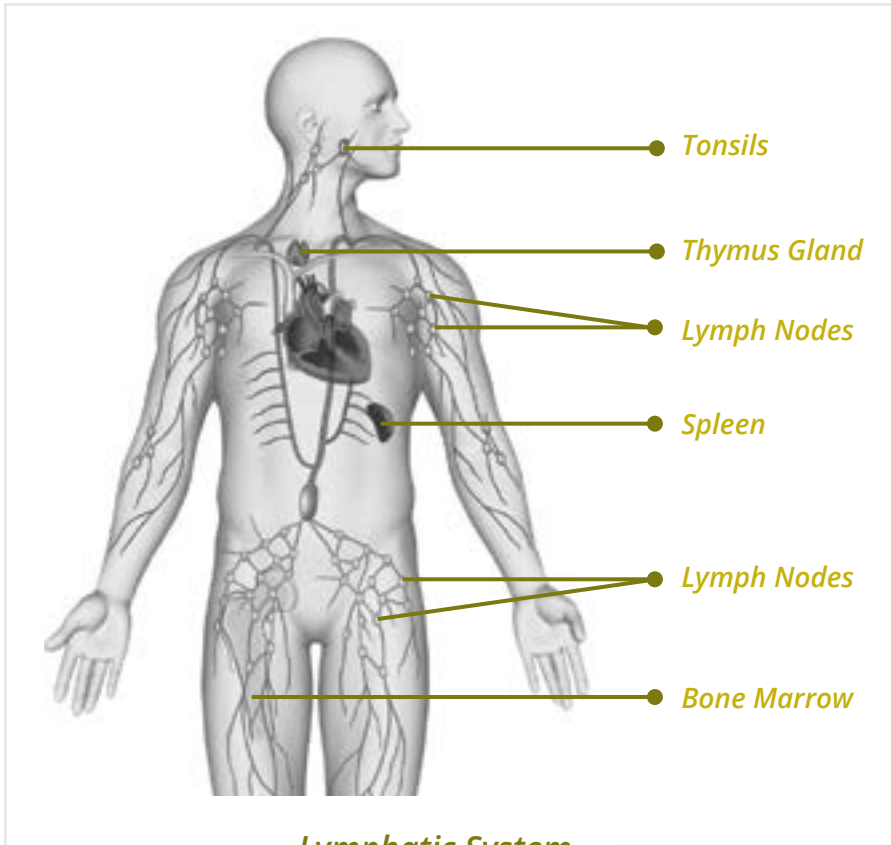
The main components of the lymphatic system are:

- + **Lymph:** the fluid that circulates within the lymphatic system.
- + **Lymphatic vessels:** vessels that circulate lymphatic fluid (also called lymph) throughout the body.
- + **Lymph nodes:** small, bean-shaped organs that filter circulating lymph. There are hundreds of lymph nodes throughout your body, often in groups, including in the neck, armpits, chest, abdomen, groin and elbows.
- + **Bone marrow:** soft, spongy tissue in the bones where blood cells are made.
- + **Spleen:** an organ in the abdomen that is involved in the production, storage and removal of blood cells.
- + **Thymus gland:** the organ where T lymphocytes develop and mature.

Two very important functions of the lymphatic system are:

1. **To defend the body against infection.** The vessels of the lymphatic system move lymph (fluid) throughout the body. As it travels through the lymphatic vessels, the lymph passes through lymph nodes, which are primarily made up of lymphocytes (a type of white blood cell). Harmful organisms, like bacteria and viruses, are trapped and destroyed by the lymphocytes in the lymph nodes. This helps keep the body free of infection.

2. **To circulate and regulate fluid levels in the body.** The small vessels of the lymphatic system absorb fluid from surrounding tissues throughout the body and return it to the bloodstream. This helps to prevent edema (swelling due to excess fluid) and keeps the fluid levels in the body and the bloodstream at healthy levels.



If a large number of foreign substances are filtered through a node or series of nodes, swelling may occur and the nodes may become tender to the touch. Most swollen nodes are a reaction to infection and are not cancerous.



WHAT ARE LYMPHOCYTES?

Lymphocytes are a type of white blood cell and are a major part of the lymphatic system. Together with other cells of the immune system, they work to fight infection and prevent disease.

Lymphocytes can be found in the blood and bone marrow; however, most of them are normally circulating in the lymphatic system. There are three main types of lymphocytes:

1

B LYMPHOCYTES (B CELLS)

B cells make antibodies to fight infections. They are called B cells because they mature in the Bone marrow.

2

T LYMPHOCYTES (T CELLS)

T cells destroy virus-infected cells and tumour cells; they also help other white blood cells carry out immune processes. They are called T cells because they mature in the Thymus gland.

3

NATURAL KILLER CELLS (NK CELLS)

NK cells destroy virus-infected cells and tumour cells.

LYMPHOMA

Lymphoma is a cancer that affects lymphocytes. Lymphoma is the uncontrolled growth of abnormal lymphocytes. Lymphoma can start in any part of the lymphatic system. Like normal lymphocytes, cancerous lymphocytes can travel through the blood and lymphatic system and spread and grow in many parts of the body, including the lymph nodes, spleen, bone marrow, and other organs.

There are two main categories of lymphoma:

1. **Hodgkin lymphoma (HL)**
2. **Non-Hodgkin lymphoma (NHL)**

NHL is approximately 8 times more common than HL – 85% of all lymphomas are NHL. The main difference between HL and NHL is the presence of Reed-Sternberg cells, detected when the tumour is examined under a microscope. A Reed-Sternberg cell is only present in HL.

Both of these major categories of lymphoma are further subdivided into several types that are different in the way they develop and spread, and in how affected patients are treated.

HODGKIN LYMPHOMA (HL)

Hodgkin lymphoma (previously called Hodgkin's disease) is a type of cancer that starts in lymphocytes. HL is named after Dr. Thomas Hodgkin, a British physician who first described the disease in 1832.

Hodgkin lymphoma (HL) is a relatively uncommon cancer. It accounts for around 0.67% of all cancers and 15% of all lymphomas diagnosed. Each year in Canada, approximately 1000 people are diagnosed with HL. HL occurs more frequently in males than females. Both children and adults can develop HL; the disease is most common in teenagers and younger adults aged 15-35 and older adults aged 55 and older.

As a result of advances in the diagnosis and treatment of the disease, over 80% of patients with HL are cured.

RISK FACTORS

Anything that increases a person's risk for contracting a disease is called a risk factor.

The reasons why people develop HL are not well understood.

There is no evidence that shows anything you have or have not done has caused you to develop lymphoma. HL is not caused by injury or by catching it from someone who has the disease. People cannot catch lymphoma from you.

Known risk factors for HL include:

- + **Age:** People who are 15-35 years or over 55 years have a higher risk of developing HL than people in other age groups.
- + **Gender:** Men have a slightly higher risk than women of developing HL, but more women than men have the nodular sclerosis subtype.
- + **Infection by Certain Viruses:** People infected with Human Immunodeficiency Virus (HIV), which causes AIDS, have a higher risk of developing HL compared with people who do not have this infection. Infection with Epstein-Barr Virus (EBV), a type of herpes virus, for a long period of time is also a risk factor for HL.
- + **Weakened Immune System:** People who have a weakened immune system because of an inherited condition, or the use of immunosuppressant drugs to prevent organ transplant rejection have a higher risk of developing HL compared with people who have a healthy immune system.

- + **Family History:** Immediate family members (siblings) of someone diagnosed with HL may have a higher risk of developing this lymphoma. It is not known if this risk is caused by genetics, or environmental conditions, or both.

It is important to remember that even if you have one or more risk factors, you will not necessarily develop HL. In fact, most people with risk factors never develop the disease and many who are diagnosed have no known risk factors.

DEVELOPMENT OF HODGKIN LYMPHOMA

Hodgkin lymphoma develops when a lymphocyte (usually a B lymphocyte) becomes abnormal (cancerous). Reed-Sternberg (R-S) cells are abnormal (cancerous) cells named after the 2 scientists, Dorothy Reed and Carl Sternberg, who provided the first conclusive microscopic descriptions of HL. Most people with HL have R-S cells, although other abnormal cell types may also be present. R-S cells attract many other inflammatory cells that make up most of the contents of the overall tumour. Having R-S cells alone does not necessarily mean that a person has HL. To confirm a diagnosis, the lymphatic tissue sample must also contain other cells and features that are characteristic of HL.

HL usually starts in the lymph nodes and may be first noticed in the neck, above or below the collarbone, under the arms, or in the chest. Lymph tissues and nodes are connected throughout the body, providing a route for cancerous lymphocytes to travel. As a result, Hodgkin lymphoma often spreads from one lymph node to another through the body. Unlike other lymphomas, HL will more often spread from one lymph node to the next in an organized and predictable way, rarely skipping areas. Hodgkin lymphoma can also spread to other areas and organs outside the lymph system.

TYPES OF HODGKIN LYMPHOMA (HL)

There are two main and distinct types of HL, based on what the cells look like under a microscope.

1. **Classical Hodgkin lymphoma** (the most common type of HL in developed countries)
2. **Nodular lymphocyte predominant Hodgkin lymphoma**

There are also a few patients where the cancer cells do not fit into either of these categories. These are then considered to be Hodgkin lymphoma unclassifiable.

Most patients respond well to treatment regardless of the type of Hodgkin lymphoma they have. A more important consideration in the choice of treatment is how widely the lymphoma has spread in your body (i.e., the stage of the disease).

CLASSICAL HODGKIN LYMPHOMA (CHL)

Classical HL is subdivided into 4 different subtypes.

1. Nodular Sclerosis

- + 60 to 70% of patients have this subtype of HL;
- + Under the microscope, the lymph nodes often contain noticeable scar tissue. Sclerosis means scarring;
- + More commonly seen in young adults;
- + Usually involves the lymph glands of the neck and chest;
- + May be “bulky” disease;
- + Most patients are cured with current treatments.

2. Mixed Cellularity

- + 20-25% of patients have this subtype of HL;
- + Under the microscope, the lymph nodes contain many R-S cells mixed with many other types of cells;
- + More common in men than women;
- + Primarily affects children and people between 55 and 74 years;
- + More commonly seen in the abdomen and/or spleen, plus other lymph nodes;
- + Most common subtype of HL that are infected with HIV.

3. Lymphocyte-rich

- + About 5% of patients have this subtype of HL;
- + Under the microscope, there are many normal lymphocytes and very few abnormal cells and R-S cells;
- + Usually diagnosed at an early stage in adults (40 to 50 years);
- + This disease has a low rate of relapse or recurrence.

4. Lymphocyte-depleted

- + This is the least common form of HL; less than 5% of patients have this subtype;
- + Under the microscope, there are very few normal lymphocytes and many R-S cells;
- + Tends to be more widespread disease at diagnosis;
- + More common in older patients and in non-industrialized countries;
- + More common in HIV-positive patients.

NODULAR LYMPHOCYTE PREDOMINANT HODGKIN LYMPHOMA (NLPHL)

Nodular lymphocyte predominant HL is rare, affecting 5% of patients diagnosed with HL. It affects more men than women and is most common amongst adults 30 to 50 years of age. This subtype is often found in the neck lymph nodes, is usually diagnosed at an early stage, and it is typically not very aggressive (it grows slowly). As researchers and clinicians learn more about NLPHL, its features are increasingly being associated with NHL.

SIGNS AND SYMPTOMS

A symptom is anything unusual in a normal body function, appearance, or sensation that a patient experiences. Patients should report all of their symptoms to their doctor or nurse.

Signs are anything unusual that doctors or nurses notice when they examine their patients.

Frequently, a diagnosis is made during a standard physical examination. Some people seek medical attention for cough and flu-like symptoms or have noticed an enlarged lymph node.

Keep in mind that 3 out of 4 people (75%) diagnosed with HL do not have any symptoms, and that none of the symptoms below are specific to HL; these symptoms are also common to other illnesses.

- + Swollen lymph node, in the neck, under the arms or in the groin. These lumps don't go away, though the size may change (get smaller or bigger);
- + Recurring fevers;
- + Unexplained itching that grows steadily worse over time;
- + Unintentional or unexplained weight loss;

- + Excessive sweating at night, enough to drench your pajamas or sheets;
- + Persistent tiredness or lack of energy;
- + Cough or feeling short of breath or chest discomfort.

Other signs and symptoms may be present depending on where the lymphoma is and how advanced the disease is.

During the visit with the doctor, you should describe all your symptoms. The doctor will ask detailed questions about medical history and perform a complete physical examination.

During the physical examination, the doctor will:

- + Check for swollen lymph nodes under the chin, in the neck and tonsil area, above the shoulders, on the elbows, in the armpits, and in the groin;
- + Examine other parts of the body to see if there is swelling or fluid in the chest or abdomen that may be caused by swollen lymph nodes;
- + Examine the abdomen to see whether any internal organs are enlarged;
- + Ask about any pain experienced;
- + Look for any weakness or paralysis that may be caused by an enlarged lymph node pressing against nerves or the spinal cord.

If a doctor suspects lymphoma after reviewing your symptoms and signs they have uncovered during the examination, they will order other tests to confirm the diagnosis.



YOUR

MEDICAL TEAM

Your team of doctors, nurses and social workers are valuable sources of support as you cope with a lymphoma diagnosis. The relationship you have with your medical team can make a big difference in how you cope with the challenges of your diagnosis and manage your care.

Taking an Active Role	18
Communicating with Your Medical Team	19
Referral to a New Doctor or Getting a Second Opinion	24

All of the professionals you see, including the specialists, make up your medical team.

The treatment of patients with HL is usually overseen by a medical oncologist (a doctor who treats cancer) or a hematologist (a doctor who treats blood cancers and other blood diseases). Depending on your medical needs, you may also see other specialists such as a radiation oncologist. You may also interact with other healthcare professionals as needed, such as an oncology nurse, nurse practitioner, physician assistant, pharmacist, psychologist, social worker, and registered dietitian. Your medical team will work together and communicate with you to plan, carry out, and monitor treatment.

TAKING AN ACTIVE ROLE

It can be very overwhelming to learn that you have cancer, and treating cancer can be a complex process. You may have many questions as you go through the different stages. Often one of the challenges is understanding the information about your disease and treatment options so you can make the best decisions, along with your doctors. It is important that you are involved in the development of your treatment plan.

Being an active participant in your cancer care can give you and your loved ones a greater sense of control over the situation. One way to become an active participant in your care is to build a good relationship with your medical team. A good partnership with your care team is based on open and effective communication. You and your doctor should trust and respect one another and work together to make the best decisions for you.

COMMUNICATING WITH YOUR MEDICAL TEAM

Even if you have a good relationship with your medical team, talking about your cancer experience can be a challenge. However, good communication with your doctors and nurses is important for many reasons. It can help with:

- + Gathering clear information about the disease;
- + Understanding your treatment options;
- + Making informed decisions about care;
- + Preparing for and managing side effects;
- + Expressing feelings and concerns;
- + Feeling more in control of the situation;
- + Feeling confident about your care.



Having a peer mentor to speak with has made a world of difference. It's the first time I have felt someone actually gets what I am thinking and feeling.

- Anonymous, patient



The following are some tips to help you communicate effectively with your cancer care team:

- + Find out what works for you.** Each person's communication style is different and what works for one may not work for another. Some people feel more in control and empowered when they know all of the details. Others find all the information to be overwhelming. Still others would prefer information they can take home and read about on their own time. Decide how much or how little information you want to know, and let your doctor know.
- + Speak up.** You know yourself better than anyone else. It's important to keep your medical team fully informed about how you are coping, and any new or unusual symptoms you may be experiencing (e.g., changes in your sleep, bowel habits, mood, appetite, memory, sexual function). Communicating your needs will give your medical team a clearer picture of your situation so they can address your needs and formulate a more individualized treatment plan.
- + Educate yourself.** Learning about cancer is like learning another language. When you understand the language, communication improves between you and your medical team. Ask your doctor if there is written information that you can take home with you. Look at www.lymphoma.ca. By having knowledge about your disease and treatment options, you will be better able to make informed decisions.
- + Keep files and records.** Staying organized is an important component of cancer care. Keep a record of your medical history, medications, test results, and symptoms. Also, keep a calendar with your medical appointments and treatment schedule. Take these records with you to your visits. The more organized you are, the better able you will be to help manage your care. Many cancer centers or hospitals also have virtual platforms to manage health

records, so you may want to sign up to help keep track of your medical history.

- + **Come prepared to appointments.** Try to write down any questions ahead of time. Ask your doctor if you can send the list before your visit. Make your questions specific and brief, and prioritize them in order of importance. Make sure that a member of the medical team reads all of your questions, because they may see some that are more important than you realize.
- + **You can get information from all members of your medical team, not just your doctor.** Oncology nurses are very well informed about cancer treatments and are a good source of information on a wide range of topics. Oncology social workers are also available to assist with practical and emotional needs from the time of diagnosis and onwards.
- + **Get help when you need it.** Remember, you are your most important advocate. Your healthcare team is there to help you. Let them. If you are dealing with troubling side effects, it is better to seek advice rather than wait to see if the symptoms become worse. Don't wait for your next scheduled appointment to contact your medical team about an important issue.

COMMUNICATING WITH YOUR DOCTORS

AT HOME

It may be helpful to keep a journal of your symptoms to help you remember what you want to discuss with your doctor during your next office visit.

Make a list of questions that you want to ask your doctor. If the questions are urgent, don't wait for your next visit; call the doctor's office to discuss your concerns.

AT YOUR NEXT DOCTOR'S VISIT

Bring your symptom journal and list of questions, and discuss them with your doctor or nurse.

Ask a family member or friend to come with you to provide emotional support and take notes. They can think of questions you may not have thought to ask, and point out changes you may not have noticed. Check with the doctor before recording any conversations.

Do not be afraid to ask questions if you do not understand something. If your doctor uses medical terms you don't understand, ask him or her to explain it in another way. If you understand better with pictures, ask to see x-rays or slides. Your doctor will want to know if you are uncertain or confused, and will explain things to you.

Clarify who should be contacted for specific sorts of questions, or for weekend support.

Ask if members of your medical team communicate by email.

Before leaving the doctor's office, make sure that you understand the next steps in your care.

Ask for written information that you can take home to help you remember what to do and learn more about your treatment.

Make the most out of virtual visits. If you have a virtual appointment with your doctor, check with your medical team how the call will be conducted. It is important to be in a safe, quiet environment, with stable Internet or cell phone reception to listen and write down what your doctor tells you.



Nobody has helped me the way you (Lymphoma Canada) have. Just being able to talk to you and sort through next steps and how to speak with the medical staff is a huge help – I really didn't know how to handle this...I was struggling with how to communicate with the doctor.

- Anonymous, patient



REFERRAL TO A NEW DOCTOR OR GETTING A SECOND OPINION

2

Receiving a lymphoma diagnosis can be overwhelming, confusing, and scary. It's important to have a good relationship with your doctor and medical care team, to ask questions and understand the treatment options available to you. Being honest with your doctor is the best way for your concerns to be addressed and to feel confident in your medical care. If you have further concerns, you may find it reassuring to ask for another doctor to confirm your diagnosis and treatment plan. This is called getting a second opinion. Seeking a second opinion from your doctor may be best for you, but also can delay the start of your treatment. Your family doctor, oncology nurse or social worker may be able to help in addressing your concerns or seeking a second opinion.



DIAGNOSIS

Understanding how Hodgkin Lymphoma is diagnosed and what it means will help you make the best decisions about your treatment and wellbeing.

Diagnostic Tests	26
Questions to Ask About Diagnostic Tests	31
Staging	31
Prognosis	33
Questions to Ask Your Doctor About Your Diagnosis	34

A number of different examinations and tests are usually required to diagnose HL and determine how much the disease has spread.

It is important for your doctors to have as much information about your cancer as possible to decide the best treatment option for you.

At times, just about everyone will have to wait to have tests or to get the results. This can cause anxiety for you and your loved ones. It helps to ask your doctor or nurse how long your test results will take. If you have not heard anything in the timeframe they gave you, call your doctor's office or clinic to check if your results are back.

3

DIAGNOSTIC TESTS

You may have the following tests. Not all testing is required. Your medical team will determine what tests are needed.

Biopsy: A biopsy is one of the most important steps in diagnosing the type of HL. It involves the removal of a sample of tissue (cells), usually performed by a surgeon. Doctors may use a CT scan to guide them to the area of interest. The type of biopsy done depends on where in the body the sample needs to be taken from. The removed tissue is then sent to the pathology lab where it is looked at under a microscope. The biopsy is often called a tissue diagnosis (meaning the diagnosis is made through an examination of the tissue or cells). You may need more than one biopsy to make an accurate lymphoma diagnosis.

Immunophenotyping: When a sample of cells is collected, sometimes doctors will order a test called immunophenotyping. This involves identifying and staining specific proteins expressed on lymphoma cells and analyzing them under a microscope. This can help doctors identify the type of Hodgkin lymphoma from the sample collected.

BIOPSY TYPE	DESCRIPTION OF TEST
Excisional or Incisional Biopsy	<p>A surgeon cuts through the skin to remove an entire lymph node (excisional biopsy) or a large portion of tissue (incisional biopsy).</p> <p>If the lymph node is close to the skin surface, the procedure can be done under local anesthesia to numb the area. If the lymph node is in the chest or stomach, the patient is sedated and the surgeon removes the tissue.</p>
Core Needle Biopsy	<p>A large needle is inserted into a lymph node suspected to be cancerous and a small tissue sample is withdrawn.</p> <p>A needle biopsy can be done under local anesthesia and stitches are usually not required.</p>
Bone Marrow Aspiration and Biopsy	<p>This may be necessary to determine if the lymphoma has spread to the bone marrow. For an aspiration, a thin hollow needle is inserted into the bone (usually the hip bone) and a small amount of liquid (marrow) from the bone is removed. Even with the numbing local anesthetic, this procedure can be painful for a few seconds while the marrow is withdrawn.</p> <p>For the biopsy, the area is frozen and a slightly larger needle is inserted into the bone (usually the hip bone) to take out a small piece of bone and marrow. This procedure does not require any stitches.</p>
Pleural or Peritoneal Fluid Sampling	<p>This is used to find out if the lymphoma has spread to the chest or abdomen where it can cause liquid to accumulate. The liquid is called pleural fluid when found inside the chest and peritoneal fluid when found inside the abdomen. A small needle is inserted and a syringe is used to remove a sample of the liquid.</p>

Although examining the tissue under the microscope is often enough to diagnose HL, other tests may be needed to assess your lymphoma and overall health.

Blood tests: Blood tests to find out how many normal and abnormal types of blood cells are in your blood.

- + **Complete blood count (CBC).** The CBC is a test that measures how many blood cells are in your blood. It measures how many red blood cells, white blood cells and platelets there are. The numbers of the different blood cells are often talked about as the 'counts'. A person with lymphoma may have a high number of lymphocytes. There may also be lower numbers of red blood cells, neutrophils and platelets.

Blood tests may be done to ensure your kidneys are working properly. As kidney function decreases, the level of urea and creatinine in the blood may increase, and low levels of certain dissolved salts in the blood may indicate the kidneys are not working. Liver tests (LTs) are blood tests used to assess the general state of the liver or biliary system (to see if there is damage or inflammation).

Heart and lung function tests: These tests are done to see if the lymphoma has reduced the ability of your lungs or heart to work properly and to see if you are healthy enough to have certain treatments. An echocardiogram uses ultrasound to take images of your heart so the doctor can see it beating and pumping blood. A multigated acquisition (MUGA) scan is a test using a radioactive tracer (called a radionuclide) and a special camera to take pictures of your heart as it pumps blood to see how well your heart pumps with each beat, at rest and/or while you exercise. Pulmonary Function Tests (PFT) are a group of tests that measure how well your lungs work.

CT scan/CAT scan: CT stands for computed tomography and CAT stands for computerized axial tomography. A CT scan is a series of detailed X-ray pictures that give a 3-dimensional (3D) picture of the body. Patients

with HL might have CT scans of the neck, chest, abdomen, and pelvis to find out how many lymph nodes are involved, how large they are, and whether internal organs are affected by the disease. Before a CT scan, you may be asked to drink a contrast liquid and/or get an intravenous injection of a contrast dye that will more clearly outline abnormal areas in the body.

X-ray: Low dose radiation beams are used to provide images of the inside of the body.

MRI (magnetic resonance imaging): A technique used to obtain three-dimensional images of the body. An MRI is similar to a CT scan, but an MRI uses magnets and radiofrequency waves instead of X-rays. An MRI can provide important information about tissues and organs, particularly the nervous system.

PET (positron emission tomography) scan: This test is a way to visualize cancer in the body. While CT scans show the size of a lymph node, PET scans show if the cancer is still active in the lymph node. Radioactive glucose (a sugar molecule used as the energy source for cells) is injected into the body and is taken up by cells that are very active, such as some types of cancer cells. A scanner is then used to visualize the areas of the body where the radioactive glucose is concentrated. PET scans can help determine how much disease is present (staging) and how well it is responding to treatment.

CAUTIONS ABOUT INTERPRETING LAB REPORTS

Some patients like to view their written or virtual lab reports; when doing so, it is important to carefully review the findings of your laboratory tests and imaging scans with your doctor. You may have many results that are not reported as “normal” or in the “normal range”. This is common for many patients. The clinicians looking after you will review all of the important results with you.

Please remember these results are not reported for the public, they are provided to the team looking after you that have appropriate medical knowledge to interpret them.

Only a biopsy is definitive.

Tests can be reported as “normal” even though lymphoma may be present.

Tests may be reported as “abnormal” even though lymphoma is not present.

Other conditions may mimic HL.

The interpretation of tests, such as imaging studies and scans, can be difficult in some situations and needs to be made in the context of the disease and the patient.

3

QUESTIONS TO ASK ABOUT DIAGNOSTIC TESTS

1. Why is this procedure necessary and can the information be obtained in another way?
2. How and where is this procedure done?
3. What are the possible risks, complications, and side effects?
4. Do I have to do anything to prepare for the procedure?
5. How long will the procedure take? Will I be awake? Will I feel pain?
6. How long will it take for me to recover from the procedure?
7. Should anyone else be present when I have the procedure? Will I need someone to take me home afterward?
8. When will I know the results and when will we talk about them?

STAGING

HL is staged based on the findings from your lab and imaging tests. Knowing the stage of your HL helps your doctor determine the extent of your disease and monitor its progression over time.

The stage is determined by:

- + The number and location of lymph nodes affected;
- + Whether the affected lymph nodes are above, below or on both sides of the diaphragm (the large, dome-shaped muscle under the ribcage that separates the chest from the abdomen);
- + Whether the disease has spread to the bone marrow or other organs such as the liver.

There are four main stages:

- + In stages I and II, the cancer is limited to one or two areas of the body (early stage). In stages III and IV, the cancer is more widespread (advanced stage).

The most common method for staging HL is called the Ann Arbor Staging System.

ANN ARBOR STAGING SYSTEM

STAGE	WHAT IT MEANS
I	Localized disease: one group of lymph nodes affected.
II	Two or more groups of lymph nodes are affected but they are all in the chest or all in the abdomen.
III	Two or more groups of lymph nodes are affected in both the chest and the abdomen with or without involvement of a nearby organ.
IV	Widespread disease: lymphoma is in multiple organs or tissues (e.g., bone marrow, liver or lungs) and may also be in the lymph nodes.

Your doctor may also add a single letter to the stage:

A generally means the patient has not experienced any troublesome symptoms.

B means the patient has experienced one or more of the following symptoms:

- + Unexplained weight loss of more than 10% in the six months before diagnosis;

- + Unexplained, intermittent fevers with temperatures above 38°C (100.4°F);
- + Drenching night sweats (requiring pajamas or bed sheets to be changed).

X means patient has a tumour in the chest that is at least one-third as wide as the chest, or tumours in other areas are at least 10 cm (4 inches) wide. This is called bulky disease. Patients with bulky disease usually need more intensive treatment than patients without bulky disease.

PROGNOSIS

Prognosis is the medical term used to describe how the disease will progress and the likelihood of recovery. It is often one of the first things that patients ask their doctor. A prognosis is usually based on information gathered from hundreds or thousands of other patients who have had the same disease. This information provides doctors with a general idea of what to expect when a patient is diagnosed with HL. It also helps guide them on the kind of treatments that have been most successful in treating HL.

However, it is important to remember that no two patients are alike and that information from large groups of people does not always accurately predict what will happen to a particular patient.

There is an International Prognostic Score (IPS/IPI) for HL based on the results of various tests, as well as your age and the stage of your disease. Your doctor will interpret all of these factors and give you this information if you wish.

QUESTIONS TO ASK YOUR DOCTOR ABOUT YOUR DIAGNOSIS

The questions below may be helpful in starting a discussion with your doctor so you understand your cancer.

1. What type of Hodgkin lymphoma do I have? May I have a copy of the report from the pathologist?
2. What is the stage or extent of my cancer? Where are the tumours?
3. What is my prognosis, as you view it?
4. How will this cancer affect my life? My work? My family?
5. What changes should I expect to happen (to my appetite, appearance, energy levels, etc.)?
6. What adjustments should I make to my everyday life?
7. How much experience do you have in treating my type of lymphoma?



Defer major decisions until you have had time to adjust to your diagnosis and understand your situation.

- Mary Jon, patient





TREATMENT

This section includes information to help you understand your treatment options, as well as a list of questions you may wish to ask your medical team.

Treatment Overview	36
Before Starting Treatment	38
What to Expect During Treatment	38
Types of Treatment	40
Drug Therapy	41
Chemoimmunotherapy	44
Chemotherapy	44
Antibody Therapy	49
Targeted Therapy	49
Steroids	51
Radiation Therapy	52
Surgery	56
Stem Cell Transplant	56
Supportive Therapy	57
Questions to Ask About Treatment	58

Research-based information gathered from thousands of people around the world who have had HL helps guide the doctor in recommending the best treatment for you.

Remember, however, that no two people are the same. In helping you make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Although each person is different and each response to therapy is unique, knowing someone who has been through the same treatment and who may have had similar concerns can be a source of great comfort. If you are interested in talking to and learning from people who have had similar experiences, you should ask your oncologist, hematologist, oncology nurse, or the oncology social worker about any one-on-one mentoring programs or support groups in your area or contact Lymphoma Canada for more information (www.lymphoma.ca/resources/support)

4

TREATMENT OVERVIEW

The type of treatment you have will depend on:

- + Your age;
- + Your general health or fitness;
- + Any other illnesses you have;
- + The exact type, stage and grade of your HL.

Your doctors will take all these factors into account when planning your treatment. The following charts provide an overview of the treatment options and possible outcomes for HL.

Please talk to your doctor about what may come next in your treatment. You should be aware of possible future therapies and discuss them with your doctor early on in your treatment journey.

HOW WILL MY HL BE TREATED?

What will my treatment be?

Chemotherapy or
Chemoimmunotherapy

Radiation therapy

Immunotherapy

Stem cell transplant

Clinical trials

What happens
after treatment?

Regular follow-up visits
with oncologist

Remission / Cure

Relapse

BEFORE STARTING TREATMENT

Before treatment starts, be sure to tell your medical team about any medicines, vitamins, herbs or different healing approaches that you may be using.

You may wish to consider obtaining an advanced directive before starting treatment. Advance directives are legal documents that describe what you want for your future medical care, in the event that you become physically or mentally unable to speak for yourself. They take effect only if you become unable to make your own decisions. There are two types of advance directives: a living will, which is a set of written instructions about your wishes for your medical care; and a power of attorney, where you choose someone you trust to make your healthcare and financial decisions for you. If you need advice about creating these documents, please ask a doctor, social worker or lawyer.

WHAT TO EXPECT DURING TREATMENT

Each patient responds differently to treatment. It is important to understand what to expect with your treatment, possible side effects, and any effects on quality of life, such as lifestyle, emotions and financial issues.

Doctors talk about results of treatment using certain terms that you may want to become familiar with. They include:

- + **Primary therapy:** Also called front-line or first-line therapy. This is the first treatment given after a cancer diagnosis. If a patient requires more treatment, subsequent treatment may be referred to as second-line, third-line, etc.
- + **Complete response:** A term which means that all signs of the cancer have disappeared following treatment. This does not mean the cancer is cured but it is undetectable using current laboratory testing.

- + **Cure:** The term used when no signs or symptoms of the disease have been present for a certain period of time and the tumour is gone. The longer a patient is in remission (absence of signs or symptoms of cancer), the higher the likelihood of a cure.
- + **Partial response:** Also called partial remission. The term used when a cancer has decreased in size by half or more but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.
- + **Minimal Residual Disease (MRD):** The term used when a minute number of cancer cells remain either during or after treatment.
- + **Stable disease:** The term used when the cancer does not get better or worse following treatment.
- + **Disease progression:** A worsening of the disease despite treatment. The term is often used interchangeably with the term treatment failure.
- + **Refractory disease:** A cancer that does not respond to treatment or that relapses very soon after treatment is completed.
- + **Relapse:** The return of cancer after a period of improvement. HL may recur in the same area as the original tumour or it may relapse in another body area.

TYPES OF TREATMENT

There are many different types of treatments for your HL. Your doctor may recommend one or more of the types of treatment listed below:

- + Drug therapy
 - + Chemotherapy
 - + Antibody Therapy
 - + Other Targeted Therapies
 - + Steroids
- + Radiation Therapy
- + Surgery
- + Stem cell transplant
- + Supportive therapy

Early-stage HL (stages I and II) is usually treated with a short course of chemotherapy followed by a course of involved field radiation. This type of radiation treats only the lymph nodes that are enlarged and limits the damage to healthy tissue in the area. In patients that are not good candidates for chemotherapy, radiation alone can be an effective therapy.

People with advanced-stage disease (stages III and IV) are usually treated with combination chemotherapy (chemotherapy involving a number of different drugs).

The approach to treatment for nodular lymphocyte predominant HL has evolved over the past twenty years. Many experts believe the disease can be treated the same way as classical HL with similar results. Some experts advocate a different treatment approach.

For the majority of individuals with HL, treatment will result in the cancer being cured.

Before your treatment starts, you will be given information about what to expect from the treatment you will have and how to take care of yourself during treatment.

DRUG THERAPY

Powerful anticancer drugs may be used in your treatment.

Drug therapy may be used to:

- + Bring about a complete remission;
- + Prevent the cancer spreading;
- + Slow the growth of the cancer or kill cancerous cells;
- + Relieve symptoms.

Make sure you get patient information sheets for each of the drugs you will receive. These sheets explain what the drugs are, what their side effects are and which side effects require immediate treatment.

Side Effects

Many people are frightened by the side effects of drugs. However, it is important to understand that:

- + Not all patients who receive drug therapy experience side effects;
- + Side effects are not always severe, they can be mild;
- + Different drugs have different side effects;
- + There are many effective treatments that can reduce side effects or prevent them from happening altogether.

Everyone reacts to drug therapy differently. Even people of similar age and health can experience different side effects from treatment.

Most side effects are short-lived, but some can last for a few weeks or months after treatment has finished. Occasionally, side effects can be permanent. Some side effects can start long after treatment has finished. These are called late-effects. Your doctor will talk to you about any effects before you start treatment.

Depending on the side effects you experience from drug therapy and how strongly you feel them, you might not be able to maintain your usual level of activity during treatment. You might need to set aside more time for rest and healing.

To learn more about side effects of various treatment options visit Lymphoma Canada's Side Effect Fact Sheet: https://www.lymphoma.ca/wp-content/uploads/2022/03/LymphomaCanada_SideEffectsOfLymphomaAndCLLTreatments_V6.pdf



You have no idea how much I appreciate Lymphoma Canada's assistance. You are an amazing valuable resource and sounding board and that is exactly what I needed to unrattle me.

- Rob, patient





DID YOU KNOW?

Not all drugs that are approved by Health Canada are publically funded. Each province and territory has their own publically funded prescription drug program. The drug coverage provided by each province can vary a lot, and each province decides who is eligible for each type of coverage.

WHO PAYS FOR DRUGS IN CANADA?

Once a drug is approved for use in Canada, there are two ways patients can have their medicines and treatments paid for:

1

Public Insurance: provided through provincial and territorial governments.

2

Private Insurance: provided through employers or purchased individually.

Patients also have the option to pay for the drug themselves. In certain circumstances, programs are available to help a patient pay for the costs of drugs, if they meet criteria.

Since there are some medications that are only funded through private insurance plans, it's very important to tell your doctor if you have private insurance. Ask your doctor if your treatment is covered by public health insurance, and find out what other treatment options exist if you have private insurance.

Funding and access to lymphoma therapy varies across Canada.

CHEMOIMMUNOTHERAPY

CHEMOTHERAPY

Chemotherapy is a type of treatment that includes a drug or combination of drugs to kill cancer cells. A combination of drugs may be prescribed to improve the chances for success as each drug kills the cancer in a different way. If chemotherapy is given in combination with antibody therapy it is called chemoimmunotherapy.

Chemotherapy works to prevent the cancerous cells from multiplying and to remove or reduce the number of cancerous cells in the body.

How chemotherapy works

Chemotherapy is a systemic therapy, which means it affects the whole body. Chemotherapy targets and kills cells that grow and divide quickly, such as cancer cells. Because of how they work, chemotherapy drugs can also have the same effect on normal cells that divide quickly, like hair, nails, and the cells in your mouth and digestive tract. This is why chemotherapy can cause side effects including hair loss, diarrhea, nausea and vomiting.

Cancer is often described as being either chemosensitive or chemoresistant.

- + **Chemosensitive** means that the cancer is responding to chemotherapy and the chemotherapy treatment is effective in killing the cancer cells.
- + **Chemoresistant** means that the cancer does not respond to chemotherapy and an alternate treatment is required. If this happens, another drug therapy is usually offered.

How chemotherapy is given

Each dose of chemotherapy kills only a percentage of cancer cells. For this reason, chemotherapy is often given in multiple doses in order to destroy as many cancer cells as possible.

Chemotherapy treatment is usually followed by a period of rest and recovery. Together, each period of treatment and non-treatment is called a chemotherapy cycle. Chemotherapy drugs may be given once per cycle or on multiple days per cycle, depending on your treatment plan. The full course of chemotherapy (the total number of cycles) may take several months. The actual number of cycles of chemotherapy you receive will depend on the type and stage of your HL as well as your age and overall health.

A typical treatment session will involve having blood tests and a visit with your oncologist or nurse, followed by your chemotherapy.

Some drugs are given by mouth as capsules or pills. Other drugs are given by needle directly into a vein (intravenous or IV infusion).

If you are going to receive intravenous chemotherapy, your doctor may recommend having a venous catheter inserted. A venous catheter (a small, flexible plastic tube) is a device that is put into a vein to make it easier to give medication. There are different types but each device works in the same way. The one chosen for you will depend on the normal practices at your hospital.

Common side effects of chemotherapy

Chemotherapy does often cause side effects, though the severity varies person-by-person and by type of drug. Medications to prevent side effects may be given prior to, alongside or after chemotherapy treatment. Potential side effects from chemotherapy include:

- + Decreased Blood Cell Production:** Blood cells, including red blood cells, white blood cells and platelets, are continually being produced in the bone marrow. Because these cells are always dividing, they are also targeted by chemotherapy, so the number of all blood cells can be reduced. This is called myelosuppression.

It is important to be aware of the symptoms of myelosuppression. If you notice these symptoms, tell your doctor immediately.

TYPE OF MYELO-SUPPRESSION	POSSIBLE SIGNS AND SYMPTOMS	WHAT CAN BE DONE?
Anemia – decrease in the number of red blood cells	<p>Feeling tired and weak.</p> <p>Shortness of breath.</p> <p>Lightheadedness.</p>	<p>Injections may be given to help boost the bone marrow production of red blood cells.</p> <p>Red blood cell transfusions might be required for severe anemia.</p>
Neutropenia – decrease in the number of neutrophils, a type of white blood cell that fights infections	<p>More frequent and/or serious infections or the recurrence of old viruses, like shingles.</p> <p>Fever; sore throat; rash; diarrhea; redness, pain or swelling around a wound.</p>	<p>Chemotherapy might be delayed or the dose reduced.</p> <p>Antibiotics may be prescribed.</p> <p>Injections might be given to boost the bone marrow production of neutrophils (G-CSF).</p>
Thrombocytopenia – decrease in the number of platelets	<p>Increased bruising.</p> <p>Excessive bleeding from cuts, nosebleeds and bleeding gums.</p>	<p>Avoiding blood-thinning medications, such as aspirin, might be recommended.</p> <p>Platelet transfusion might be necessary in severe cases.</p>

- + **Hair loss:** Also called alopecia. This is a common side effect of chemotherapy and can affect the hair of the scalp, eyebrows, eyelashes, arms, legs and pelvic region. Some people may lose all their hair and some may only experience thinning of their hair. Hair loss or thinning usually begins gradually, within two to three weeks of your first chemotherapy treatment. This can be a very distressing side effect for patients. However, not everyone experiences hair loss and most people have a normal amount of hair within six months after their final chemotherapy treatment. The new hair may be curlier than your hair was initially but usually will revert back to your original texture in 1-2 years. If your hair loss is distressing to you, the cancer centre staff will be able to connect you to places that specialize in wigs for cancer patients.
- + **Mouth sores or sore throat:** Also called mucositis. Infections of the mouth and throat may occur. If you have a persistently sore mouth or throat you should tell your doctor.
- + **Nausea and vomiting**
- + **Diarrhea**
- + **Fatigue:** Severe fatigue can be a symptom of anemia and should be mentioned to your doctor.
- + **Chemo brain:** Various treatments may impair your cognitive function which can lead to something known as “chemo-brain”, “brain fog”, or “cancer-related cognitive disorder”. You may notice difficulties concentrating, paying attention, remembering new things, recalling old memories or saying the right words. For most patients, these symptoms will get better in the months following the completion of treatment. If you continue to experience these symptoms, discuss them with your doctor.
- + **Changes in taste:** Chemotherapy can often alter the taste of foods. Familiar foods can taste different (called dysgeusia) or food flavours

can taste less intense than normal (hypogeusia). Taste changes are usually temporary and disappear once your chemotherapy treatment is finished.

- + **Loss of appetite**
- + **Nerve damage:** Chemotherapy may cause damage to the nerves in your limbs. This is known as peripheral neuropathy. Very rarely, you may also experience late onset of nerve damage to your organs. Symptoms of nervous system damage include: changes in perception of temperature, pain, or pressure on your skin; feelings of numbness, tingling, or “pins and needles” in your hands and feet; sudden sharp or stabbing pains; loss of sensation of touch; problems with balance or difficulty walking; clumsiness; trouble with fine motor movements such as picking up objects or buttoning clothes; hearing loss; jaw pain; constipation; postural hypotension (feeling dizzy, light headed, or faint when standing up from sitting or lying down). Be sure to talk to your doctor about any of these symptoms that you experience. Symptoms should improve over time.
- + **Bone complications:** Treatment may cause a bone complication referred to as avascular necrosis. This term refers to bone tissue damage due to a lack of blood supply. The most common bones that are affected are the knees, hips, and shoulders. Be sure to tell your doctor if you feel any symptoms of increased pain and stiffness in the hips or other bones.
- + **Sexual Issues:** For women, chemotherapy may leave you with temporary or permanent damage to your ovaries leading to hormonal changes or menopausal changes. This may cause hot flashes, vaginal tightness, and vaginal dryness. Ask your doctor about treatment options. For men, chemotherapy may lower your testosterone levels and/or damage blood flow to the penis, resulting in various sexual concerns such as the inability to keep a firm

erection (also known as erectile dysfunction), penile pain, or difficulty reaching orgasm. Many men find it difficult to discuss their sexual concerns with others; however, your doctor, or a specialist in sexual health, can help you overcome these issues. It is also important that partners practice safe sex and use a condom during treatment to ensure none of the chemotherapy chemicals are passed to your partner.

TARGETED THERAPY

Targeted therapy is a category of treatments that target specific genetic or cellular markers or pathways, which contribute to the growth of cancer. Blocking these survival pathways leads to cancer cell death while limiting damage to healthy cells. Not all lymphomas have the same targets, therefore molecular or genetic testing is required to determine which treatment option is best to treat your lymphoma. Monoclonal antibodies are a common targeted therapy used for advanced-stage Hodgkin lymphoma.

ANTIBODY THERAPY

Antibodies are proteins in our blood that fight infections. They are made naturally by our lymphocytes when we get an infection. They stick to proteins on the surface of bacteria and viruses and tell our body to get rid of them.

Lymphoma cells also have proteins on their surface, and antibodies can be made in a laboratory to recognize these proteins. The man-made antibody sticks to the target protein on the lymphoma cell. This marks the cell so that the immune system will kill the cell. Antibody therapy is sometimes known as 'immunotherapy' because the medical name for an antibody is 'immunoglobulin'. Antibody therapies are under clinical investigation.

Antibody therapy can be used on its own or in combination with chemotherapy, which is called chemoimmunotherapy.

New antibody therapy drugs combine the antibody to target the lymphoma cell with a strong chemotherapy drug to kill it, into one drug (unlike previous therapies where the antibody therapy is administered separately from the chemotherapy). This type of drug is called an antibody-drug conjugate.

Antibody therapy can also be combined with radiation therapy which delivers a dose of radiation directly to the lymphoma cell. These are called radioimmunotherapies.

Antibody therapies are given by needle directly into a vein (IV infusion) or under the skin (subcutaneous).

Common side effects of antibody therapy

Antibody therapies can cause some side effects. In general, the side effects are milder than those of chemotherapy. Most of the side effects from antibody therapy are minor and short-lived, lasting only during the actual treatment and for a few hours afterwards (often referred to as 'infusion related reactions'). The chances of experiencing infusion related reactions decrease with each treatment received because the patient adjusts to the treatment and, as treatment continues, there are fewer lymphoma cells to kill.

Sometimes, patients will experience an allergic reaction to the antibody therapy at the time of infusion. Patients are monitored closely during their treatment sessions for signs of allergic reaction, including itching, rash, wheezing and swelling. If these symptoms occur, the treatment is slowed down or stopped for a short time until the symptoms go away. Medications (antihistamines and acetaminophen) are commonly given before treatment to avoid allergic reactions.

The most common side effect is:

- + Flu-like symptoms (fever, chills, sweating).

Less common side effects include:

- + Nausea;

- + Vomiting;
- + Shortness of breath;
- + Low blood pressure;
- + Fatigue;
- + Headache;
- + Infection.

STEROIDS

Steroids are an important part of many chemotherapy regimens for lymphoma. These steroids are not the same as those that are banned in athletics.

Steroids can be used to help kill the cancer cells and make chemotherapy more effective; reduce some of the side effects of chemotherapy; combat any allergic reactions you may have to other drugs you are receiving as part of your treatment; combat low blood; reduce swelling, pain, and other symptoms of inflammation. Steroids may be given in combination with chemotherapy drugs or they may be given alone. Steroids are usually given in pill form though you may also receive a steroid in an IV, liquid, cream or ointment.

Common side effects of steroids

These medicines may have side effects, including:

- + Insomnia;
- + Increased appetite;
- + Mood/personality changes: You may feel more angry, sad, or anxious than normal. You may also feel that you are more emotional than before;

- + Weight gain;
- + Water retention.

Less common side effects including:

- + Raised blood pressure;
- + Increased risk of picking up infections;
- + Sugar in the urine and higher than normal sugar levels in the blood.

Steroids are often used for short periods of time, so you may not experience any of these side effects.

RADIATION THERAPY

Radiation therapy (also called radiation or radiotherapy) is a local therapy meaning that it only treats the area of the body where the cancer is located. Radiation therapy is often combined with chemotherapy.

Radiation therapy uses high-energy X-rays, like those used to take pictures but in much higher doses, to kill cancer cells. The X-rays cause damage to the cell's DNA (the genetic material of the cell) which makes it impossible for the cancer cell to repair itself, so the cell dies.

Radiation does not only affect cancer cells. Healthy cells in the area will be killed off as well. Care is always taken to plan the treatment properly and ensure that other areas of the body are affected as little as possible. Healthy areas are shielded from the radiation with lead shields similar to the ones you wear at the dentist when receiving an X-ray. Lead blocks the path of any stray radiation beams and prevents them from affecting normal cells.

A radiation field is the area of the body marked to receive the radiation therapy. The skin may be marked with tiny tattooed ink dots to ensure that the correct area receives the therapy each time. Radiation is usually confined to lymph nodes or the area immediately surrounding the lymph

nodes. The radiation field is different in each person and depends on many factors including the extent of the disease.

You must lie completely still during the treatment. Often a mould is created or props are used to minimize movement. The actual treatment lasts only for a few minutes and causes no pain or discomfort.

Radiation therapy is usually given in a day clinic. Radiation treatments are delivered by a radiation therapist. You may have to visit the hospital as many as five times per week during a course of radiation therapy. Each dose of radiation is called a fraction and the radiation oncologist prescribes the total number of fractions for your specific treatment.

Side effects of radiation therapy

Although the radiation treatments are painless, there may be some associated side effects. The side effects are usually limited to the area of the body receiving the radiation and may vary based on the targeted site. The radiation dose commonly used in lymphomas is less than the radiation dose used in solid cancer. Because of this, lymphoma patients are less likely to experience significant side effects compared to patients receiving higher radiation dosages.

This kind of radiation does not make you radioactive. There is no risk to those close to you.

Short-Term Side Effects

The area of skin that was exposed to the radiation may become red, irritated, itchy and flaky. Moist areas like the mouth may be more severely affected and may require treatment. It often looks and feels as though the area is sunburned and the skin may begin peeling. The skin reactions are usually short-lived and diminish over a few weeks.

Following radiation therapy you may find that foods you previously enjoyed no longer appeal to you. You may also not feel as hungry as you normally do.

Report side effects to your medical team as many side effects can be treated. If side effects are severe, your doctor may adjust your radiation treatment.

Radiation to the Head and Neck (areas affected can include the scalp, mouth and throat)

- + **Hair loss (on the scalp or anywhere the radiation is targeted):** Hair loss from radiation is not like the general hair loss that occurs with chemotherapy. If the radiation was targeted at the head, a patch of hair loss may occur on the head. If the radiation was targeted at a specific lymph node in the groin area, there may be a loss of hair in the groin region. The hair loss is usually temporary; however, with high doses of radiation it may be permanent.
- + **Dry mouth & throat irritation:** After radiation therapy in the area of the mouth, saliva production may be decreased and patients may experience a dry mouth, also called xerostomia. Throat irritation may also occur from the decreased saliva or direct effects from radiation to that area.

Radiation to the Chest (areas affected can include the esophagus and breasts)

- + **Difficulty swallowing:** You may experience difficulty swallowing due to a dry mouth, or because the radiation has affected the esophagus which is involved in swallowing.

Radiation to the Abdomen

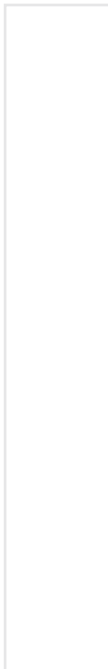
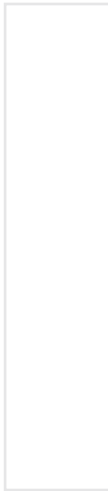
- + **Nausea:** Nausea may occur after the first radiation treatment.
- + **Diarrhea**

Long-Term Side Effects

It is possible for radiation to cause long-term side effects. The risk of long-term side effects is less than in the past due to the refinement of

the radiation therapy process. The following table outlines the possible effects of radiation given to different areas of the body. It is important to discuss these risks with your doctor if you feel concerned.

TREATMENT AREA	POSSIBLE LONG-TERM EFFECT	WHAT YOU CAN DO
Pelvis or groin	Infertility	<p>Ensure that the testes/ovaries are shielded from radiation if they are not the target of the treatment.</p> <p>If you have not yet had children, talk to your doctor about the risks associated with having children after radiation therapy and the possibility of harvesting eggs or sperm prior to treatment.</p>
Chest and breasts	<p>Breast cancer</p> <p>Heart disease/ stroke</p>	<p>Long-term breast cancer screening is very important.</p> <p>This is more likely if you also had chemotherapy that also affects the heart.</p>
Skin	Skin cancer	<p>Long-term skin cancer screening is very important.</p> <p>Protect your skin from the sun by using sunscreen and minimizing exposure.</p>
Neck	Thyroid problems, including cancer	Discuss the risks with your doctor and have your thyroid checked on a regular basis.



SURGERY

Surgery may be an option, if the lymphoma appears localized (confined to one area). During surgery the cancerous area may be removed along with any surrounding tissue that might contain cancer cells. At times your surgeon may not be able to determine how much of an area has to be removed until the surgery is in progress.

STEM CELL TRANSPLANT

Hematopoietic stem cells are a group of cells which are immature and can grow and change into any type of cell found in the blood - red blood cells, white blood cells or platelets.

Hematopoietic stem cells can be found in the bone marrow (the spongy material inside the large bones of the body that is responsible for blood cell production), circulating blood (also called peripheral blood) and umbilical cords.

Stem cells, because they divide rapidly, can be killed off by chemotherapy and radiation therapy. Therefore, the doses of chemotherapy and radiation therapy used to treat lymphoma are limited due to the risk of damaging these stem cells. Patients with lymphoma that is difficult to treat or resistant to standard therapy may benefit from chemotherapy or radiation therapy given in very high doses (myeloablative therapy). However, this can potentially destroy all stem cells and leave the patient at very high risk for infection.

To combat this problem, the patient receives a rescue with stem cells which is commonly called a transplant. After myeloablative therapy, they will receive stem cells they have previously stored from themselves (autologous transplant) or stem cells from a compatible donor (allogeneic transplant) to replenish those destroyed by high dose chemotherapy.

If your doctor feels that it is possible you may eventually need a transplant, they will discuss it with you during your treatment planning.

Peripheral Blood Stem Cell Transplant and Bone Marrow Transplant:

The difference between a peripheral blood stem cell transplant and a bone marrow transplant is where the hematopoietic stem cells are taken from. In bone marrow transplants, the stem cells are taken from the bone marrow in the operating room. In peripheral blood stem cell transplants (PBSCTs), medications are given to allow the stem cells to move from the marrow into the circulating blood where they can easily be collected using a filtering machine. The blood is removed from the donor through a needle in one arm, passed through the machine that collects the stem cells, then the remaining blood is returned to the donor. PBSCTs are now more commonly performed than bone marrow transplants, as the procedure is easier and the body is able to regenerate new stem cells faster.

4

SUPPORTIVE THERAPY

Supportive therapies are often given to prevent or treat HL symptoms and/or treatment side effects.

Supportive care for HL can include:

- + Antibiotics to treat infections caused by bacteria or fungi;
- + Vaccinations;
- + Blood transfusions or growth factors to increase red blood cell counts;
- + Growth factors to increase white blood cell counts (G-CSF).

QUESTIONS TO ASK ABOUT TREATMENT

GENERAL QUESTIONS

1. What is the goal of treatment? Do you hope to cure or control the cancer?
2. What are my treatment choices? Which do you recommend for me? Why?
3. Do I need more than one type of treatment? What are the expected benefits of each type of treatment?
4. What are the names of the drugs I will be given? What are they for and what will each one do?
5. How will we know if the treatment is working?
6. What are the chances that the treatment will be successful?
7. How will treatment affect my life? My work? My family?
8. Are new treatments being studied? Would a clinical trial be appropriate for me?
9. Who will manage my treatment program?
10. Where can I go for more information?

PRACTICALITIES OF TREATMENT

1. How often will I need to come in for treatment or tests?
2. What if I miss a treatment?
3. If I get radiation therapy, how will it be given to me? Is it painful?
4. How long will my treatments last?

5. Are there any special foods I should or should not eat?
6. Can I drink alcoholic beverages?
7. Should I still take the other drugs I am on?
8. Is it okay to continue with the supplements I am currently taking?
9. What costs will I encounter? What should I do if I can't afford it?
10. Who should I call if I have questions? What is the best time to call?
11. What should I do to try to stay healthy and strong during my treatment?
12. Can I come for my chemotherapy treatments alone or do I need assistance?

SIDE EFFECTS OF TREATMENT

1. What are the possible risks or side effects of treatment? How serious are they?
2. Can the side effects be managed?
3. What symptoms or problems should I report right away?
4. How long will the effects of treatment last?

THE FUTURE

1. What are the chances that my cancer may return after remission? What are the signs?
2. What life changes should I plan for in regards to my work, family, etc.?
3. Will I still be able to have children after treatment?

A photograph of a male doctor in a white lab coat with a stethoscope around his neck, standing in a hospital or clinic. He is looking towards a man and a woman who are standing together. The man is wearing a blue button-down shirt and has his arm around the woman's shoulder. The woman is wearing a maroon top. They appear to be in a conversation. The background is a brightly lit room with a window and a door.

RELAPSED OR REFRACTORY

HODGKIN LYMPHOMA

Most patients undergoing treatment for Hodgkin lymphoma will respond well to treatment. If your disease returns or doesn't respond to initial treatment, more treatment may be necessary.

Relapsed HL means that the disease has returned after responding to treatment.

This is sometimes also called a recurrence. Refractory HL means that your disease does not respond to a specific treatment or that the response to the treatment does not last very long.

If this does occur, there are usually ways to get the cancer under control. The first step may involve another biopsy to confirm the diagnosis of lymphoma and ensure that the lymphoma at this point is the same type of lymphoma that had been treated previously. Depending on the results of this biopsy and staging tests, treatment options will be outlined by your medical team. These might involve using more chemotherapy or using more intensive or high-dose chemotherapy followed by a stem cell transplant or trying a new therapy through a clinical trial. There may still be curative options.

If neither cure nor remission is possible, the aim is to relieve symptoms. This is called palliative treatment. You may consider taking part in a clinical trial to help evaluate a new treatment or combination of treatments.

5



Lymphoma Canada has been a lifeline for me. From the very day of our son's diagnosis, through treatment, and even now as we deal with the aftermath, you have been an incredible support through the most trying time in our lives.

- Anonymous, parent of patient





CLINICAL

TRIALS

Clinical trials are research studies that involve people. Understanding what they are can help you decide if a clinical trial might be an option for you.

Research is constantly underway to develop new treatments and to improve existing ones.

A major part of developing new treatments involves clinical trials – carefully planned research studies that are conducted with patients in order to test new medications or new treatment approaches. The new treatment is usually compared with an existing treatment to determine if the outcome is more beneficial for patients.

A clinical trial can test many aspects of treatment, including the safety and effectiveness of new medications, the addition of new medications to standard treatments and potential new methods of administering standard treatments.

The protocol of a clinical trial is examined and approved by ethics committees and must meet rigorous government and medical standards. A significant amount of careful, detailed research is conducted on the new medication before it reaches the stage where it is tested on patients.

There are different types of trials in which a patient may participate. They are listed in the following table:

TRIAL TYPE	MAJOR DIFFERENCES
Phase I	<p>Tests for safety and appropriate dose of a new treatment (does not compare it with another treatment).</p> <p>Increased risk of side effects.</p> <p>Usually includes only a small number of patients who often have advanced disease that has not responded to current treatments.</p>
Phase II	<p>Tests for side effects and efficacy of new treatment (does not compare it with another treatment).</p> <p>Larger number of patients than a phase I trial.</p>
Phase III	<p>Further tests the new treatment on large numbers of patients once the phase II trial has shown the treatment to be effective and safe.</p> <p>The new treatment is compared with a standard treatment to determine if the outcome is more beneficial for patients (randomized controlled trial).</p>
Phase IV	<p>Further study of the treatment after the treatment has been licensed for use in standard practice.</p>

Patients who choose to take part in a clinical trial must give informed consent. This means that they are aware of the potential benefits and associated risks and are a willing participant. No patient should feel pressured to participate in a clinical trial. Furthermore, once a patient is in a trial they have the right to leave it at any time without explanation. Leaving a trial will in no way affect the attitude of your medical team, and you will still receive the best current standard treatments.

To learn more about clinical trials currently available in Canada and around the world, please visit www.lymphoma.ca/resources/clinicaltrials



FOLLOW-UP

CARE

Follow-up care after treatment is an important part of cancer care. Follow-up for HL is often shared among cancer specialists and your family doctor. Your healthcare team will work with you to decide on follow-up care to meet your needs.

Follow-up Appointments	68
Secondary Cancers	70

Your care after treatment will depend, to a large extent, on the type of lymphoma you had or have, what type of treatment you received, and how you responded to treatment.

Once you have completed active treatment, you will likely be given a follow-up care plan to monitor your progress and recovery as well as to watch for a potential recurrence.

FOLLOW-UP APPOINTMENTS

It is very important to go to all of your follow-up appointments. Your schedule of visits and the tests and procedures that you will undergo during follow-up are tailored to your individual situation.

Your follow-up appointment may include any combination of the following:

- + Physical exam:** for careful examination of the size and firmness of lymph nodes;
- + Blood tests:** to assess your recovery, potential after-effects of treatment and general health;
- + Imaging tests:** such as CT, PET, or other imaging scans to measure the size of any remaining tumour masses if internal lymph nodes or other internal organs are or were affected. Routine CT or PET scans are typically not performed in patients who are otherwise well with no symptoms potentially related to cancer.

Your doctor will also tell you to watch for specific signs or symptoms of recurrence. Having ongoing or new symptoms can be alarming for people who have been through cancer. The fear of recurrence is real and commonly experienced by patients. There are a number of ways that you can deal with this fear. Remember that even though new

symptoms may be concerning, not all issues that arise will be cancer-related. However, it is still important to bring anything that concerns you to the attention of your medical team – don't ignore them. Let your medical team know about them right away – you do not have to wait until your next scheduled appointment.

Furthermore, almost all cancer treatments have side effects. Some may last for a few weeks to months, but others can last several years, especially in patients on continuous therapy. Use the time during your follow-up appointments to talk to your medical team about any changes or problems you notice and any questions or concerns you have about your health during and after treatment.

Notes from your previous clinic visits should have automatically been sent to your family doctor but you may wish to check with your lymphoma medical team to make sure this happened. Do not be afraid to be an advocate for your care and facilitate the process of ensuring that all of your records have been sent to your family doctor.

It is very important that your family doctor is and continues to be up-to-date on the following:

- + All medications that you are currently taking (including over-the-counter medicines such as pain relievers, laxatives, nutritional supplements, vitamins, minerals and herbal therapies);
- + All of the specialists you are still seeing and why;
- + All your future screening tests and how often these should be scheduled;
- + Your feelings, fears or concerns about anything that may affect your recovery including symptoms or changes that you are experiencing that cause you to worry;
- + Any lifestyle changes you make, such as quitting smoking or changing your diet or exercise routine.

In addition, you may start to see new or additional doctors such as a dentist, neurologist, physiotherapist or naturopath for other health-related issues. Keep in mind that if you change doctors, have a new doctor or are under the care of several different doctors, you may be the only one who has your complete health history. For this reason, it is important to keep up-to-date records of all the medical care you receive for lymphoma and other conditions because future decisions about your care may depend on what treatment you received in the past.

As part of life after diagnosis and potential treatment, there is a realization that life may never return to the normal that you were accustomed to before you were diagnosed. You are now faced with creating a new normal for yourself.

Part of this process involves re-evaluating personal relationships and professional and financial goals. For help with this process, please visit www.lymphoma.ca/life-beyond/

SECONDARY CANCERS

A secondary cancer is a new cancer, which is different from the lymphoma you were initially treated for, that develops after treatment for lymphoma. It may develop as a late effect of your initial treatments, such as chemotherapy and radiation.

All patients who have been treated for lymphoma have a higher risk than the general population of developing a secondary cancer. This increased risk continues for up to 20 years after treatment.

The most common secondary cancers include:

- + Lung cancer;
- + Brain cancer;
- + Kidney cancer;

- + Bladder cancer;
- + Breast cancer (especially for women who had radiation therapy to the chest prior to the age of 35);
- + Cancer of the digestive organs;
- + Melanoma (skin cancer);
- + Myelodysplasia;
- + Leukemia;
- + Other lymphomas.

Therefore it is very important to remain vigilant and attend all of your required follow-up appointments to get the best care and surveillance during and after lymphoma treatment.

Speak with your medical team about what the best care plan is for you to screen for these secondary cancers and about ways to lower the risk of a secondary cancer as well as the signs or symptoms to watch for. It is also recommended to use sun screen to reduce exposure to UV light, avoid tanning beds, quit smoking if you are a smoker and undergo regular screening for breast, prostate and colorectal cancer.

A close-up photograph of a silver stethoscope with a white rubber bulb, resting on a white surface. In the background, a medical book with a white cover and some text is visible. The stethoscope's chest piece is in the foreground, and the tubing loops around it. The lighting is bright, creating soft shadows.

MEDICAL

TERMS

Absolute neutrophil count (ANC): The number of mature neutrophils in the bloodstream.

ABVD: A combination chemotherapy treatment that consists of four individual chemotherapy drugs (adriamycin, bleomycin, vinblastine and dacarbazine). ABVD is one of the most common chemotherapy regimens used in Hodgkin lymphoma.

Acute: Sudden onset of disease or symptoms.

Adjuvant therapy: Anti-cancer treatment given after the primary treatment to increase the chance of remission.

Advanced disease: Disease that has spread from the original site, often to multiple locations.

Allogeneic stem cell transplant: A procedure where a patient receives stem cells from the bone marrow or peripheral blood of a compatible donor.

Alopecia: Loss of hair, either from the head or elsewhere on the body. Alopecia during cancer treatment most commonly occurs as a side effect from chemotherapy and is almost always temporary. Hair will re-grow once chemotherapy treatment is finished.

Anemia: A condition where the number of red blood cells is below the normal limit. The most common symptoms associated with anemia include fatigue, weakness and shortness of breath.

Ann Arbor Staging System: Describes the extent to which lymphoma has spread within the body. There are four main stages: I, II, III & IV. For additional information, see page 32.

Antibody: A protein that attaches to the surface of bacteria, toxins or viruses so they can be identified and destroyed by the immune system. For additional information, see page 50.

Antiemetic: A medication that reduces or prevents nausea and vomiting.

Antigen: A molecule that causes the immune system to produce antibodies against it. See *antibody*.

Antinauseant: A medication that reduces or prevents nausea and vomiting.

Antipyretic: A medication that reduces fever.

Apheresis: A process in which the blood is passed through a machine that separates out one particular part or type of cell and returns the remainder to circulation.

Autologous stem cell transplant: A type of bone marrow or stem cell transplant where the patient receives their own cells instead of those from a donor.

Axilla (axillary): Refers to the area under the arm (armpit).

B cell (B lymphocyte): A type of white blood that helps the body fight disease and infection.

B symptom: Symptoms that some people may experience with lymphoma. B symptoms include fever, night sweats and weight loss. They are often associated with more advanced disease.

Benign tumour: A tumour that is not cancerous and does not spread. Benign tumours can grow large enough to impact surrounding tissues.

Biologic therapy: Treatments that stimulate the patient's immune system to fight infection or disease. Also called immunotherapy.

Biopsy: Removal of a small piece of the tumour for examination under a microscope. A biopsy is an effective method of determining whether a tumour is malignant (cancerous) or benign (non-cancerous).

Blood cell: A general term that describes the three major cell types that circulate in the blood: red blood cells, white blood cells and platelets.

Bone marrow: The material inside the large bones of the body that produces red blood cells, some white blood cells and platelets. The bone marrow contains immature forms of these cells, called stem cells, which can be harvested for transplant.

Bone marrow aspiration and biopsy: A test routinely done to determine whether the cancer has invaded the bone marrow. In both tests a needle is inserted into the bone to remove a sample of the marrow. For additional information, see page 27.

Bone marrow transplant: See *stem cell transplant*.

Bone scan: A procedure where the bones of the body are viewed. The patient is injected with a radioactive substance that is absorbed into the bones allowing them to be viewed during a scan. The procedure is performed to determine if the cancer has spread to the bones.

Bulky disease: If you have a tumour in the chest that is at least one-third as wide as the chest, or if tumours in other areas are at least 10 cm (4 inches) wide, this is called bulky disease.

Cancer: Uncontrolled growth of abnormal cells.

Carcinogen: A substance that is known to cause cancer.

Catheter (see also venous catheter): A device, usually a flexible tube, which is used to transport medications into the body (through a vein) or take fluids (e.g., urine) out of the body.

Cell: The building block of all living tissues, it is the most basic structural and functional unit of life.

Central line: An intravenous catheter that is inserted into a large vein, usually in the neck or near the heart. It is used to administer medication or withdraw blood.

Chemosensitive: A term used to describe a tumour that responds to chemotherapy.

Chemoresistant: A term used to describe a tumour that does not respond to chemotherapy.

Chemotherapy: Treatment with drugs that targets and kills cells that grow and divide quickly, such as cancer cells. For additional information, see page 44.

Chemotherapy cycle: A cycle includes each period of treatment and the non-treatment period of rest and recovery afterwards. Chemotherapy for HL usually requires multiple cycles.

Chemotherapy course: The total number of required chemotherapy cycles.

Clinical trial: A research study performed on volunteer patients under strictly controlled conditions to evaluate a new treatment. The ultimate goal is to find the most effective, least toxic treatment for a specific disease.

Combination chemotherapy: The use of a number of drugs together to treat cancer. Each drug kills the cancer in a different way, so a combination of chemotherapy drugs can be more effective than a single drug in destroying the cancer.

Complete blood count (CBC): A routine blood test used to determine the number of blood cells (red blood cells, white blood cells and platelets) in the bloodstream. A CBC is commonly done during a normal check-up with a doctor, and is often done during cancer treatment to monitor blood cell levels.

Complete response: Also called complete remission, it means that all signs of the cancer have disappeared following treatment.

CT scan or CAT scan: CT stands for computed tomography and CAT stands for computerized axial tomography. Both tests are a series of X-rays that provide detailed, three-dimensional images of the inside of the body.

Cure: The term used when no signs or symptoms of the disease have been present for a certain period of time. The longer a patient is in remission (absence of signs or symptoms of cancer), the higher the likelihood of cure.

Debulking: Treating cancer to reduce the size of the tumour. Debulking is usually achieved via surgery or radiation.

Diaphragm: The thin, dome-shaped muscle below the heart and lungs that separates the chest from the abdomen.

Disease progression: A term used to describe a worsening of the disease despite treatment. The term is often used interchangeably with treatment failure.

DNA (deoxyribonucleic acid): The building block for all genetic material. It is a molecule inside cells that carries genetic information.

Dose intensity: The total amount of a drug delivered to a patient in a certain period of time. The ultimate goal is to reach the highest dose possible where the side effects remain at an acceptable level.

Drug resistance: Occurs when cancer cells do not respond to drug therapy.

Durable remission: The term used to describe cancer that has been in remission for many years.

Dysgeusia: An altered sense of taste.

Dysphagia: Difficulty in swallowing.

Echocardiogram: An imaging technique where an ultrasound machine is used to visualize the heart. Some chemotherapy medications can affect the heart.

Edema: Swelling caused by excessive amounts of body fluid.

Epstein-Barr virus (EBV): A common virus that remains dormant in most people. It causes infectious mononucleosis and has been associated with certain cancers, including Hodgkin lymphoma.

Erythrocyte: Red blood cell

Etiology: The cause(s) of disease. The cause of HL is not known.

Extranodal disease: A term describing lymphoma that has spread to tissues outside of the lymphatic system.

Fatigue: Excessive tiredness and lack of energy, with a decreased capacity for daily activities.

Febrile neutropenia: Neutropenia (low white blood cell count) accompanied by fever and other signs of infection. If left untreated, febrile neutropenia can lead to serious infections, which may be life threatening and/or cause you to stay in the hospital.

Fraction: A single dose of radiation.

G-CSF: See *granulocyte colony stimulating factor*.

Gallium (radioisotope) scan: An imaging technique to detect cancer. Gallium is a chemical taken up by some cancer cells. In this procedure, a safe amount of radioactive gallium is injected into the patient, after which the patient undergoes an X-ray procedure where the radioactive gallium makes the tumour(s) visible. Gallium scans are performed in the nuclear medicine clinic in the hospital.

Genes: Made up of DNA and found in all cells, genes contain the information to determine an individual's unique characteristics.

Gene therapy: The introduction of DNA into a patient to treat a disease. The new DNA usually contains a functioning gene to correct the effects of a disease-causing mutation.

Genetic mutation: A permanent change to the normal sequence of a gene. Genetic mutations may cause certain cancers.

Graft-versus-host-disease (GVHD): A complication that can occur after a patient has received a bone marrow or stem cell transplant from a donor (an allogeneic transplant). The immune cells from the donor (the graft) attack the patient's organs and tissues, impairing their ability to function, and increasing the patient's risk of infection.

Granulocyte colony stimulating factor (G-CSF): A type of growth factor that makes the body produce white blood cells to reduce the risk of infection.

Hemoglobin: A protein in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide from the tissues back to the lungs.

Hematologist: Doctor specializing in diseases of the blood.

Hepatosplenomegaly: Abnormal enlargement of both the liver and spleen.

Hodgkin lymphoma: One of the two main types of lymphoma, Hodgkin lymphoma is primarily distinguished from NHL by the presence of Reed-Sternberg cells.

Hyperkalemia: High blood potassium.

Hyperphosphatemia: High blood phosphorus.

Hyperuricemia: High blood uric acid.

Hyperviscosity: Abnormal thickening of the blood.

Hypocalcemia: Low blood calcium.

Hypogeusia: A loss of the sense of taste.

Immune system: The body's defense system against infection and disease.

Immunoglobulin: Also called an antibody, it is any protein that is used by the immune system to identify and neutralize harmful agents, such as bacteria and viruses.

Immuno-oncology (IO): A therapy that activates your immune system to attack your cancer.

Immunosuppression: Suppression of the immune system due to the side effects of medications.

Immunotherapy: Treatments that stimulate the patient's immune system to fight infection or disease. Also called antibody therapy or biologic therapy. For additional information, see page 50.

Induction therapy: Cancer treatment used as the first step towards shrinking the tumour(s). If necessary, induction therapy is followed by additional therapy to treat the remaining cancer cells/tumours.

Intravenous (IV): Administered into a vein.

IVIg: Intravenous immunoglobulin (IVIg) is a blood product used to treat patients who have an increased risk of infection due to antibody deficiencies.

Leukapheresis: A laboratory procedure in which white blood cells are separated from a sample of blood.

Leukopenia: A low level of white blood cells. Since white blood cells are the main cells of the immune system, low levels leave a person at increased risk of infection.

Localized disease: A cancer that is contained in a certain area of the body and has not spread throughout the body.

Local therapy: Treatment that only affects a small area of the body.

Lymph (lymphatic fluid): The watery fluid contained in lymphatic vessels. Lymph circulates lymphocytes throughout the lymphatic system.

Lymph nodes: Small, bean-shaped organs that filter the lymphatic fluid and remove any foreign invaders. There are hundreds of lymph nodes throughout the body. The major lymph node clusters are found in the neck, under the arms, and in the chest, abdomen and groin.

Lymph node biopsy: Either a section of a lymph node or the entire lymph node is removed (by a surgeon) for examination under a microscope.

Lymphadenopathy: Swelling or enlargement of the lymph nodes due to infection or cancer.

Lymphatics: Lymphatic vessels and channels that carry lymphatic fluid and lymphocytes throughout the body.

Lymphatic system: The network of lymphatic vessels, lymph nodes and other organs that transport lymphocytes throughout the body to fight infection and disease. The lymphatic system also regulates fluid in the body. For additional information, see page 7.

Lymphoblast: An immature lymphocyte (B cell or T cell).

Lymphocytes: A type of white blood cell found in the lymphatic system and the bloodstream. Lymphocytes fight infection and disease and are an important part of the immune system.

Lymphoma: Cancer of the lymphocytes.

Lymphoid: Pertaining to lymphocytes or the lymphatic system.

Maintenance therapy: Extended treatment, usually given after the original treatment has brought the cancer under control. It is done to prevent the disease from relapsing or to keep the cancer in remission.

Malignant: A malignant tumour is a cancerous tumour. They can invade surrounding tissue and spread to other areas of the body. Benign tumours are not invasive and do not spread.

Mediastinum: The mediastinum is the area at the centre of the upper chest, located behind the breastbone, containing the heart and blood vessels.

Metastasis: The spread of cancer within the body from the original tumour site to other sites or organs.

Minimal residual disease (MRD): The term used when small numbers of cancer cells remain either during or after treatment.

MRI (magnetic resonance imaging): A technique used to obtain 3 dimensional images of the body. While similar to a CT scan, an MRI uses magnets instead of X-rays.

Mucositis: Inflammation of the lining of the digestive tract, most commonly of the mouth, causing painful sores.

Myeloablative chemotherapy: High-dose chemotherapy that destroys the bone marrow. This is performed prior to a bone marrow or stem cell transplant.

Myelosuppression: A reduction in bone marrow activity resulting in decreased red blood cells, white blood cells and platelets.

Nausea: A sensation characterized by an urge or need to vomit.

Neutropenia: A reduction in the number of neutrophils, the white blood cells that fight bacterial infection. This may put a patient at a higher risk of infection.

Neutrophils: The most common type of white blood cell in the body essential in fighting infections.

Non-Hodgkin lymphoma (NHL): A group of related cancers that affect lymphocytes. There are many different kinds of NHL and although they have similarities, they differ in many ways including how they develop and how they are treated.

Night sweats: Extreme sweating during sleep at night.

Oncologist: A doctor who specializes in the treatment of cancer. There are different types of oncologists who specialize in certain treatments including medical oncologists (specializing in chemotherapy), radiation oncologists (specializing in radiation therapy) and surgical oncologists (specializing in cancer surgery).

Oncology: The branch of medicine that focuses on the diagnosis and treatment of cancer.

Palliative: Treatment that is designed to relieve symptoms rather than cure disease.

Pancytopenia: Deficiency of all three types of blood cells (red cells, white cells, platelets).

Partial remission: Also called partial response. The term used when a tumour has decreased in size by half or more, but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.

Pathologist: A doctor who specializes in identifying diseases by examining and studying cells under a microscope.

Peripheral blood: Blood circulating in the blood vessels and heart as opposed to the bone marrow.

Peripheral blood stem cell transplant (PBSCT): See *Stem cell transplant*.

Performance status: A term describing how well a patient is able to perform daily tasks and activities.

Peripheral neuropathy: Altered nerve sensations in the hands and feet, including numbness, tingling and weakness as a result of nerve damage.

PET scan (positron emission tomography): A way to visualize cancer in the body. Radioactive glucose (a sugar molecule used as the energy source for cells) is injected into the patient and is taken up preferentially by cells with high metabolic activity, such as cancer cells. A scanner is then used to visualize the areas of the body where the radioactive glucose is concentrated.

Pleural effusion: A collection of fluid inside the chest cavity around the lungs.

Plasma cell: The main function of plasma cells is antibody production. They play an important role in the defense against infection and disease.

Primary therapy: The first treatment given after a patient is diagnosed with cancer.

Prognosis: The prediction of the outcome of the cancer and the likelihood of recovery.

Radiation field: The area of the body that receives radiation therapy.

Radiation oncologist: A type of oncologist (cancer specialist) specializing in treating cancer with radiation therapy.

Radiation therapy or radiotherapy: A type of therapy where high-dose radiation beams (X-rays) are carefully focused on a tumour site. Exposure to the X-ray beams kills the cancer cells. For additional information, see page 66.

Radioimmunotherapy: A radioactive molecule (a molecule that emits radiation and is capable of killing cancer cells) is attached to an antibody so that the radiation is delivered specifically to lymphoma cells.

Reed-Sternberg cell: A type of cell found in Hodgkin lymphoma but not in non-Hodgkin lymphoma (NHL).

Refractory disease: A cancer that does not respond to treatment or that relapses very soon after treatment ends (for example within 6 to 12 months).

Regimen: The administration of a specific combination and dose of cancer medications following an arranged schedule.

Relapse: The return of cancer after a period of improvement. HL may recur in the same area as the original tumour or it may relapse in another body area.

Remission: A patient is said to be in remission if the tumour has diminished by half or more (partial remission) or is undetectable

(complete remission). Remission does not necessarily imply that the cancer has been cured.

Salvage therapy: Treatment that is used when the cancer has not responded to standard treatments or after the cancer has relapsed.

Secondary cancer: A secondary cancer is a new cancer, which is different from the lymphoma you were initially treated for that develops after treatment for lymphoma. It may develop as a late effect of your initial treatments, such as chemotherapy and radiation.

Side effect: Secondary effect caused by cancer treatment. Side effects can be short-term (disappear quickly), long-term (last for a longer period of time) or a late-effect (develop months or years after treatment has ended). There are many effective treatments that can reduce side effects or prevent them from happening altogether.

Single-agent chemotherapy: Chemotherapy treatment that utilizes only one chemotherapy drug.

Spleen: An organ that is an important part of the lymphatic system. The spleen is located in the top left-hand corner of the abdomen, below the ribcage. The spleen is involved in lymphocyte production and storage, and also works to store and filter the blood and remove aging blood cells from the circulation.

Splenectomy: Surgery to remove the spleen.

Splenomegaly: Abnormal enlargement of the spleen.

Stable disease: A term used when the cancer does not get better or worse following treatment.

Stage: Describes the extent to which a cancer has spread within the body. For additional information, see page 31.

Standard therapy: Treatment that has been proven effective and is widely used as primary therapy for cancer.

Stem cell: A precursor cell produced in the bone marrow that gives rise to all different kinds of blood cells (red blood cells, white blood cells and platelets).

Stem cell transplant: A procedure that replaces stem cells destroyed by high-dose chemotherapy and radiation with healthy stem cells. For additional information, see page 58.

Subcutaneous (SC or SQ): Under the skin.

Supportive therapy or supportive care: Therapy given to prevent or treat lymphoma symptoms and/or treatment side effects.

Systemic: Affecting the entire body.

Tattoo: In radiation therapy, the term used for the ink markings made on the body to clearly outline the radiation field. This ensures that the appropriate area is targeted for radiation and that the same area is treated each time.

T cell (T lymphocyte): A type of white blood cell that recognizes and destroys abnormal cells (such as virus-infected cells and cancer cells) and plays an important role in fighting infection. They are called T cells because they mature in the thymus.

Thrombocytes: Also called platelets. They are small pieces of cell that help blood clot and stop bleeding.

Thrombocytopenia: A lower than normal level of platelets in the blood. Platelets are important in blood clotting and a shortage may result in increased bleeding or bruising.

Thymus gland: A gland that is part of the lymphatic system where T cells complete their development. The thymus is located behind the sternum (breastbone) in the chest.

Tissue: A group of cells that work together to perform a specific function in the body.

Toxicity: Any unwanted side effect of medication. Common toxicities of cancer treatments include hair loss, nausea and vomiting.

Treatment failure: A worsening of the cancer despite treatment. The term is often used interchangeably with the term disease progression.

Tumour: An abnormal mass of dividing cells that serves no useful bodily function. Tumours can be either benign (non-cancerous) or malignant (cancerous).

Tumour burden: Refers to the number of cancer cells, the size of a tumor, or the amount of cancer in the body.

Ultrasound: Ultrasound imaging uses sound waves to produce pictures of the inside of the body.

Venous catheter: A device, usually a flexible tube, which is used to give medications into the body (through a vein) or take fluids (e.g., urine) out of the body.

Xerostomia: A reduction in the production of saliva resulting in a dry mouth. It can be a side effect of cancer treatment.

X-ray: Radiation beams that are used in two ways: in low doses to provide images of the inside of the body for diagnostic purposes and in high doses to treat cancer (radiation therapy).



When you donate to Lymphoma Canada, you help provide free information and services for Canadians affected by lymphoma. A gift of \$10 allows us to produce one Patient Resource Manual, which helps support newly diagnosed patients and their families.

GENERAL INFORMATION

Title	First Name	Last Name	
Address		Suite/Apt.	
City		Province	Postal Code
Phone Number	Email		

Yes, I would like to receive Lymphoma Canada's e-newsletter and other e-updates.

I WOULD LIKE TO DONATE A ONE-TIME GIFT OF:

\$10 \$20 \$50 \$100 Other:

*A tax receipt will be issued for donations of \$10 and over.

PAYMENT INFORMATION

<input type="radio"/> Visa	<input type="radio"/> Mastercard	<input type="radio"/> Amex	Card Number
Expiry Date	Name on Card	Signature	

PLEASE RETURN THIS FORM TO:

Lymphoma Canada | 6860 Century Avenue, Suite 202 | Mississauga, ON | L5N 2W5



LYMPHOMA
CANADA

www.lymphoma.ca | info@lymphoma.ca

Charitable Registration Number: 87346 1040 RR0001 | HLP001



Monthly giving ensures a reliable source of funds to help promote early detection, find new and better treatments, help patients access those treatments, and ultimately find a cure.

GENERAL INFORMATION

Title	First Name	Last Name	
Address		Suite/Apt.	
City		Province	Postal Code
Phone Number		Email	

Yes, I would like to receive Lymphoma Canada's e-newsletter and other e-updates.

I WOULD LIKE TO DONATE A MONTHLY GIFT OF:

\$10/month \$20/month \$30/month \$50/month

Other:

*A tax receipt will be issued for donations of \$10 and over.

PAYMENT INFORMATION

<input type="radio"/> Visa	<input type="radio"/> Mastercard	<input type="radio"/> Amex	Card Number
Expiry Date	Name on Card	Signature	

By signing this form, you agree to waive your right to receive pre-notification of any debits under the Pre-Authorized Debit agreement. To request a change, hold, or cancellation of your gift detailed above, please contact Lymphoma Canada at 1-866-659-5556 at least 7 days prior to your next scheduled donation. For more information, visit www.cdnpay.ca

PLEASE RETURN THIS FORM TO:

Lymphoma Canada | 6860 Century Avenue, Suite 202 | Mississauga, ON | L5N 2W5



LYMPHOMA
CANADA

www.lymphoma.ca | info@lymphoma.ca

Charitable Registration Number: 87346 1040 RR0001 | HLPRM01

While Lymphoma Canada (LC) has made every effort to confirm the accuracy of the information contained herein, it makes no representation or warranty with respect to the accuracy, completeness, usefulness or appropriateness of such information. Statistical data is taken from Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2022. Toronto, ON: Canadian Cancer Society; 2022 or from The Surveillance, Epidemiology, and End Results (SEER) Program. The information in this manual has been based on current medical knowledge at the time of production, however, the management of lymphoproliferative disorders is a fast-changing field such that the accuracy of the information may become outdated over time. LC does not assume any liability for any such deficiency or any damage or harm incurred directly or indirectly from such information. The information herein cannot substitute for medical advice and LC advises patients to contact their physician regarding the information presented and its relevance to each patient's unique situation. This patient guide is supported through unrestricted educational grants from: BeiGene, Incyte, Janssen, Kyowa Kirin, Mallinckrodt Pharmaceuticals, Novartis, and Seagen.



6860 Century Avenue, Suite 202 | Mississauga, ON L5N 2W5

Telephone 905.858.5967 Toll Free 1.866.659.5556

General inquiries info@lymphoma.ca Website lymphoma.ca

All material copyright © 2023 Lymphoma Canada



LYMPHOMA
CANADA