



UNDERSTANDING NHL

A patient's guide to
NON-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, Nursing Advisory Board and Patient & Family Advisory Committee 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 non-Hodgkin lymphoma with the information necessary to better understand their illness and feel confident and empowered as they continue on 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 non-Hodgkin lymphoma (NHL), 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 NHL 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**.

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ABOUT NON-HODGKIN LYMPHOMA (NHL)

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

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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.

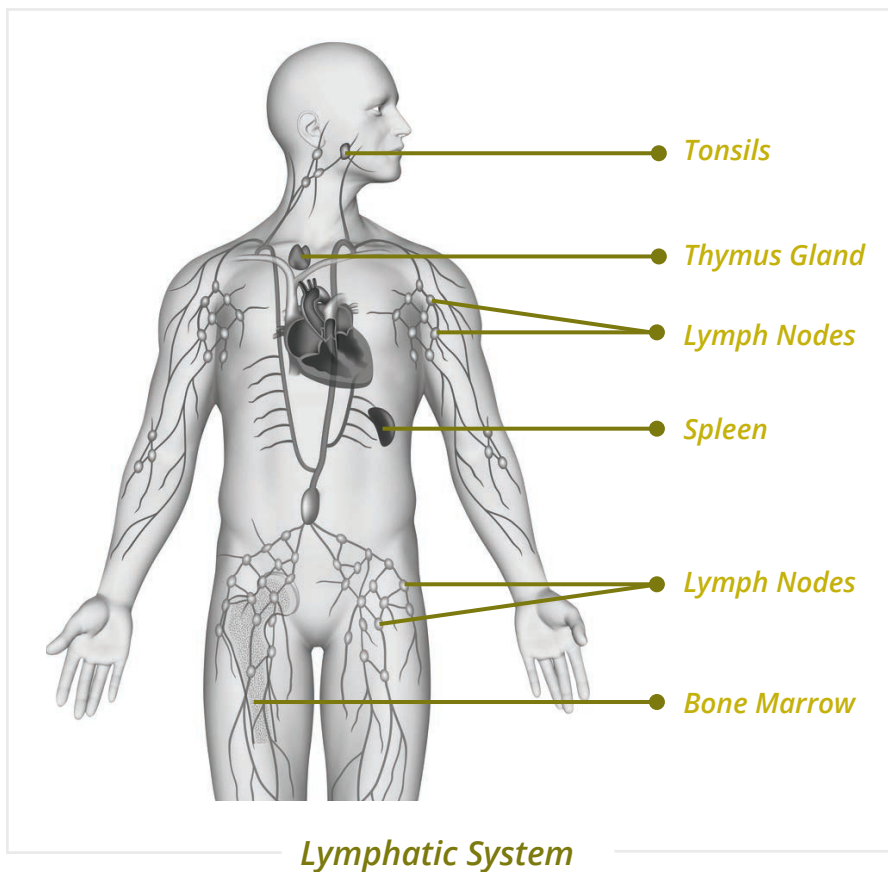
The main components of the lymphatic system are:

- + **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 Hodgkin lymphoma.

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.

NON-HODGKIN LYMPHOMA (NHL)

NHL is not a single disease but rather a group of over 80 closely related cancers that affect the lymphocytes.

While the different types of NHL share many common features, certain characteristics set them apart from each other, including:

- + How they look when examined under a microscope;
- + Genetic characteristics and other molecular features;
- + How and where they grow in the body;

- + The symptoms they cause;
- + How patients should be treated.

HOW COMMON IS NHL?

NHL is the fifth most common cancer diagnosed in Canada. Men are diagnosed slightly more often than women. NHL may develop in children and young adults, but most people diagnosed with NHL are age 50 and older.

RISK FACTORS

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

The reasons why people develop NHL are not well understood.

There is no evidence that shows anything you have or have not done has caused you to develop lymphoma. NHL 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 NHL include:

- + **Age:** People over the age of 60 have a higher risk of developing NHL than people in other age groups.
- + **Gender:** NHL is more common in men than women.
- + **Infection by Certain Viruses:** People infected with Human Immunodeficiency Virus (HIV), which causes AIDS, or human T cell leukemia/lymphoma virus type 1 (HTLV-1) or hepatitis C have a higher risk of developing NHL compared with people who do not have these infections.

- + **Weakened Immune System:** People who have a weakened immune system because of an inherited condition, splenectomy, an autoimmune disease, or the use of immunosuppressant drugs to prevent organ transplant rejection have a higher risk of developing NHL compared with people who have a healthy immune system.
- + **Bacteria:** Infection with the bacteria *Helicobacter Pylori*, which may cause stomach ulcers, can increase the risk of developing lymphoma in the stomach lining.
- + **Chemical Exposure:** People who have been exposed to certain chemicals such as benzene, certain pesticides or herbicides, and some chemotherapy drugs used to treat other cancers or autoimmune disease are at increased risk of developing lymphoma.

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

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.

There are many types of NHL, each of which has its own unique symptoms. There are symptoms which are common among many

types of NHL. Some patients do not experience any symptoms. Keep in mind that none of the symptoms below are specific to NHL; 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;
- + Severe or frequent infections;
- + Easy bruising or bleeding;
- + Unintentional or unexplained weight loss;
- + Excessive sweating at night, enough to drench your pajamas or sheets;
- + Rash or itching;
- + Persistent tiredness or lack of energy;
- + Headache and/or blurry vision;
- + Swollen stomach and or abdominal pain;
- + Numbness and or tingling in hands and/or feet;
- + Cough or feeling short of breath or chest discomfort.

Other signs and symptoms may be present depending on the type of NHL, 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.

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

The treatment of NHL 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 healthcare needs, you may also see other specialists such as a radiation oncologist or surgeon. You will also interact with other healthcare professionals such as an oncology nurse, nurse practitioner, radiation therapist, physician assistant, pharmacist, 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.

- + **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

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.



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

Patients must be comfortable with their doctor and the approach that they take. If you are not comfortable, you should discuss your concerns. Confidence in your medical team often leads to confidence in treatment. If you do not feel that the team is a good match, you should ask your family doctor or specialist for a referral to another specialist.

Even if you have a good relationship with your doctor, you may want to seek a second or third opinion before beginning therapy. The purpose of the second opinion is to make sure that the suggested treatment plan is reasonable and the best choice for your particular case.

Most doctors understand the value of a second opinion when facing a major decision. It doesn't necessarily mean you have to change doctors. And, when you are able to talk with several experts about the disease, it can help you feel more confident knowing you have explored every possible resource to receive the best available care. You can discuss how to get a second opinion with your specialist or your family doctor.

If your doctor is recommending immediate treatment, ask if it would be okay to briefly delay the start of treatment to give you extra time to get a second opinion.



DIAGNOSIS

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

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Doctors need the results of various tests to determine if you have NHL. Getting a diagnosis can sometimes take a while.

It is important for your doctors to have as much information about your cancer as possible. This helps them to work out the stage of your cancer. The stage of the cancer will help your doctor decide which treatment is best 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.

DIAGNOSTIC TESTS

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

- + Biopsy;
- + X-ray;
- + CT or CAT scan;
- + MRI;
- + PET scan;
- + Heart & lung function tests;
- + Blood tests;
- + Immunophenotyping;
- + Cytogenetic analysis;
- + Other laboratory tests.

Biopsy: A biopsy is one of the most important steps in diagnosing the type of NHL. It involves the removal of a sample of tissue (cells), usually performed by a surgeon. The biopsy may be done by a doctor called an interventional radiologist with the procedure being done with the help of a CT (computed tomography) scan or ultrasound. 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).

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>

BIOPSY TYPE	DESCRIPTION OF TEST
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>
Lumbar Puncture (Spinal Tap)	<p>This may be used to see if the lymphoma has spread to the cerebrospinal fluid (CSF), the liquid found in the brain and spinal cord. Most types of NHL do not spread to the CSF.</p> <p>A thin needle is inserted into the lower back and a small sample of fluid is removed.</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>

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

CT scan/CAT scan: CT stands for computed tomography and CAT stands for computerized axial tomography. These scans provide detailed X-ray pictures giving a 3-dimensional (3D) picture of the body. Patients with NHL might have CT scans of the neck, chest, abdomen or 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, the patient 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.

MRI (magnetic resonance imaging): A technique used to obtain 3-dimensional (3D) 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.

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.

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 smear examination.** A sample of your blood will be examined under the microscope to determine whether lymphoma cells are present. Flow cytometry uses a machine that looks for certain substances on or in cells that help identify what types of cells they are (markers).

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).

Immunophenotyping: Immunophenotyping distinguishes between different types of cells. This test detects markers that help to distinguish what type of lymphocyte is involved (B cells or T cells or NK cells) or what part of the lymph tissue the lymphoma is originating from. This can be done by tests called immunohistochemistry (IHC) or flow cytometry.

Cytogenetic analysis: Chromosomes are long strands of DNA, the genetic material of a cell. Healthy human cells have 23 pairs chromosomes. Some lymphomas and other types of cancer have too few or too many chromosomes, or other defects. In cytogenetic analysis, chromosomes from lymphoma cells are examined for abnormalities.

One type of chromosomal abnormality is called a translocation – which happens when part of a chromosome breaks off from its normal location and becomes attached to another chromosome. The results of these tests may help doctors determine the best course of treatment.

Other laboratory tests: For example, urine tests.

CAUTIONS ABOUT INTERPRETING LAB REPORTS

Some patients like to review their written lab reports; when doing so, it is important to carefully review the findings of your laboratory tests and imaging scans with your doctor.

Your blood tests must be looked at as a trend over time and not in isolation.

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 NHL.

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.

Often, follow-up tests are needed to clarify the results.

QUESTIONS TO ASK YOUR DOCTOR ABOUT A BIOPSY OR OTHER DIAGNOSTIC PROCEDURES

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?

CLASSIFYING NHL

Your medical team needs to determine the exact type, or classification, of NHL you have as this helps doctors decide on the best treatment for you. Find out more in the section Types of Non-Hodgkin Lymphoma.

STAGING

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

The most common method for staging lymphoma is the Ann Arbor Staging System. Certain subtypes of NHL may be staged using a different system.

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.

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).

ANN ARBOR STAGING SYSTEMS

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 patients 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. Patients with bulky disease usually need more intensive treatment than patients without bulky disease.

GRADE

Doctors also determine the grade of the lymphoma.

The grade is determined by the type of NHL. This information helps to decide the treatment approach.

The following grades are often used to describe NHL:

Low-grade: indolent (or slow-growing) NHLs;

Intermediate- or high-grade: aggressive (or fast-growing) NHLs.

	INDOLENT NHL (slow-growing; low-grade)	AGGRESSIVE NHL (fast-growing; intermediate or high-grade)
Proportion of NHL cases	40% to 50%	50% to 60%
Cancer growth rate	Slow	Fast
Symptoms	<p>Tumour grows very slowly and patients often do not show symptoms until late in the disease.</p> <p>No symptoms at diagnosis is common.</p>	Patients usually experience symptoms which prompt a doctor's visit.
Treatment timing	<p>Often does not require immediate treatment. The watch and wait approach is often used.</p> <p>Treatment may be required and is usually effective at shrinking tumours and giving the patient a disease-free period, called remission.</p> <p>Some patients never need treatment.</p>	Immediate, more intensive treatment is required.

Prognosis	<p>Respond well to treatment.</p> <p>Relapse is common and subsequent treatment is often required.</p> <p>Currently, indolent NHL is largely incurable but patients often live for a long time and enjoy a good quality of life.</p>	<p>Show an excellent response to treatment and patients can often be cured.</p>
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Sometimes low-grade, indolent NHL will transform into an intermediate or high-grade, aggressive lymphoma and the patient will require more urgent, intensive treatment.

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 NHL. It also helps guide them on the kind of treatments that have been most successful in treating NHL.

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.

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.

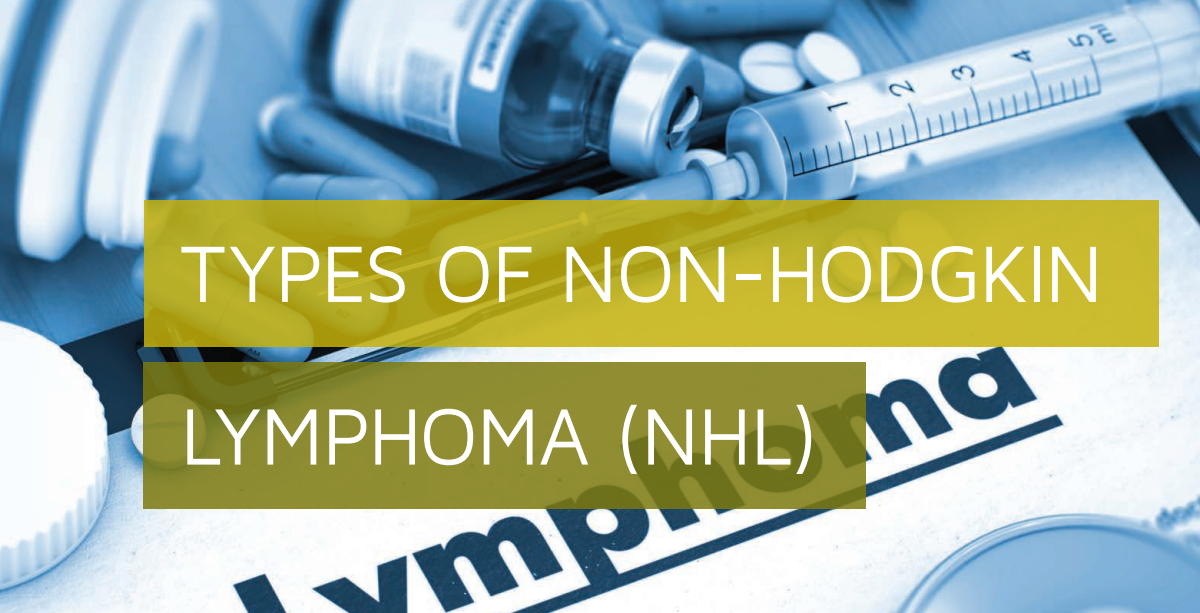
1. What type of non-Hodgkin lymphoma do I have? May I have a copy of the report from the pathologist?
2. What is the stage or extent of my cancer? Where are the tumours?
3. What is my prognosis, as you view it?
4. How will this cancer affect my life? My work? My family?
5. What changes should I expect 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





TYPES OF NON-HODGKIN LYMPHOMA (NHL)

There are over 80 different subtypes of lymphoma. Knowing your NHL subtype will help you talk to your doctor about your lab and imaging tests as well as your treatment options.

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Anaplastic Large Cell Lymphoma (ALCL)	49
Lymphoblastic Lymphoma	50

| There are more than 80 subtypes of lymphoma

Not all are mentioned in this book. If you don't see the type you have here, check with your doctor or nurse to see if they have used a different name for a lymphoma that is included here or if there is a lymphoma listed that is very similar to the one you have.

More information on different subtypes is available at www.lymphoma.ca/NHL.

COMMON TYPES OF NHL

INDOLENT NHL (slow-growing; low-grade)	AGGRESSIVE NHL (fast-growing; intermediate - or high-grade)
<ul style="list-style-type: none">+ Follicular lymphoma+ Chronic lymphocytic leukemia (CLL)+ Small lymphocytic leukemia (SLL)+ Marginal zone lymphoma+ Waldenstrom macroglobulinemia (lymphoplasmacytic lymphoma)	<ul style="list-style-type: none">+ Diffuse large B cell lymphoma (DLBCL)+ Double hit lymphoma+ Mantle cell lymphoma+ Burkitt lymphoma+ Gray zone lymphoma+ Peripheral T cell lymphomas+ Anaplastic large cell lymphoma+ Lymphoblastic lymphoma

COMMON TYPES OF INDOLENT NON-HODGKIN LYMPHOMA

FOLLICULAR LYMPHOMA

Follicular lymphoma is the most common type of indolent (slowgrowing) NHL, comprising 20% to 30% of all NHLs. Follicular lymphoma typically affects middle-aged or older adults.

Follicular lymphoma grows slowly in most cases and causes few symptoms in the early stages. The most common sign of follicular lymphoma is painless swelling in the lymph nodes of the neck, armpit or groin. Sometimes more than one group of nodes is affected. Often treatment is not required until symptoms develop. By the time symptoms develop, patients often have advanced-stage disease. Follicular lymphomas can transform into a more aggressive form of NHL, usually a diffuse large B cell lymphoma.

Follicular NHL usually responds quite well to treatment. However, there is a risk that it will return. If the lymphoma returns, treatment may be given again, or the patient may return to a period of watch & wait. The disease can often be brought under control again. This pattern may repeat itself over many years.

CHRONIC LYMPHOCYTIC LEUKEMIA (CLL) / SMALL LYMPHOCYTIC LYMPHOMA (SLL)

Chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL) are really two forms of the same disease. The same kind of cell has become cancerous in both. The difference is where the cancer cells are found. In CLL, most of them are in the blood and bone marrow; in SLL they are mainly in the lymph nodes and spleen.

CLL and SLL is mainly seen in people over the age of 70 and it is more common in men.

CLL is staged differently than other types of NHL, usually using a system called the Rai Staging System (classic or modified).

To find out more about CLL and SLL, please see **Understanding CLL and SLL: A Patient's Guide to Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma** or www.lymphoma.ca/CLL.

MARGINAL ZONE LYMPHOMAS

Marginal zone lymphomas account for approximately 10% of all NHL cases. Marginal zone lymphomas typically affect older adults.

Marginal zone lymphomas can be categorized according to the area affected:

1. Mucosa-associated lymphatic tissue lymphoma (MALT) starts in the mucosa, which is a soft, moist tissue layer that protects and covers organs in different parts of the body. The most common place for MALT lymphomas to develop is the stomach and they are called gastric MALT lymphoma. Less commonly it can develop outside the stomach, in the small bowel, salivary gland, thyroid gland, tear glands, or lungs. Many patients diagnosed with MALT outside of the stomach have an autoimmune disease.
2. Splenic marginal zone lymphoma (SMZL) usually starts in the spleen and can also be found in the bloodstream. Fatigue is a common symptom.
3. Nodal marginal zone lymphoma (NMZL) usually forms in the lymph nodes. Most often seen in older adults but can occur in children, usually boys.

WALDENSTROM MACROGLOBULINEMIA

Waldenstrom macroglobulinemia (WM) is a rare form of B cell lymphoma, making up 1% to 2% of all NHL cases. Dr. Jan Waldenström first described the condition in 1948. It typically affects older adults. WM is a type of lymphoplasmacytic lymphoma where there is an overproduction of a certain type of protein called IgM. If there is no abnormal IgM the disease is called lymphoplasmacytic lymphoma, not WM. A large amount of IgM in the bloodstream causes thickening (hyperviscosity) of the blood, resulting in symptoms such as nosebleeds, headaches, dizziness, confusion, hearing loss and blurry vision. Anemia (low red blood cells) is common; lymph nodes may be enlarged, as may the liver and spleen.

Symptoms are not usually obvious in the early stages of the disease and the disease is often found by chance when getting a routine blood test or an examination for another reason.

Waldenstrom macroglobulinemia may be treated with plasma exchange/plasmapheresis (a procedure to thin out the blood if high levels of IgM have made the blood thick). Stem cell transplants may be considered in younger patients.

CUTANEOUS LYMPHOMA

Lymphoma in the skin is known as cutaneous lymphoma. It can develop from either B cells or T cells, but the most common type is a T cell lymphoma called mycosis fungoides. Cutaneous lymphomas are most common in men between 50 and 70 years of age, but they can affect men and women of all ages.

Cutaneous lymphomas can appear as small, raised, red patches on the skin, often on the breasts, buttocks, skin folds and face. These patches often look similar to eczema or psoriasis, and there may be hair loss in the affected area. Patients in later stages may have ulcerating tumours (open sores) that appear on the skin.

Patients often have several years of eczema-like skin conditions before the diagnosis is finally established.

In addition to chemotherapy, the therapies used to treat cutaneous lymphomas include:

- + **PUVA:** Also called photochemotherapy, this treatment is used if large areas of skin are affected. PUVA consists of a drug called psoralen plus ultraviolet A (UVA) light. Psoralen makes the skin more sensitive to the healing effects of the UVA light. The treatment is similar to sitting under a sunlamp and may be given several times a week.
- + **UVB therapy:** Ultraviolet B (UVB) light slows the growth of the cancerous cells in the skin. This treatment does not include the use of a drug to make the skin more sensitive.
- + **Radiation therapy:** Local radiation may be used if only one or two small areas of skin are affected. A type of radiation treatment called total skin electron beam treatment may be used to treat the entire surface of the skin. It is only given once and then may be followed up with further PUVA treatments if needed.
- + **Photopheresis:** This treatment involves passing the patient's blood through a machine where it is exposed to ultraviolet light.

COMMON TYPES OF AGGRESSIVE NON-HODGKIN B CELL LYMPHOMA

DIFFUSE LARGE B CELL LYMPHOMA (DLBCL)

Diffuse large B cell lymphoma (DLBCL) is an aggressive B cell NHL and is the most common type of NHL, comprising 30% to 40% of all cases. The average age of diagnosis for DLBCL is 57 years, but this cancer can also affect younger people and children.

DLBCL can develop in people who have been diagnosed with an indolent (slow-growing) lymphoma.

The most common symptom of DLBCL is a painless swelling in the neck, armpit or groin caused by enlarged lymph nodes. It may be in one location or spread throughout the body. Patients may experience weight loss, fever and night sweats. About 50% of patients have organ involvement at the time of diagnosis, usually the digestive (gastrointestinal) tract and bone marrow.

Not all DLBCLs are the same and this type can be broken down into further subtypes.

The most common subtypes are:

- + DLBCL not otherwise specified (NOS) is the most common group;
- + Germinal centre B cell (GCB) DLBCLs get their name because they develop from lymphoid cells residing in the germinal centre of the lymph node;
- + Activated B cell (ABC) DLBCLs develop from B cells that are in the process of differentiating from germinal center B cells to plasma cells. ABC DLBCL is associated with a poorer outcome than GCB DLBCL;
- + Primary mediastinal B cell lymphoma arises from a thymic B cell. This disease occurs predominantly in girls and young women and shares many clinical features with classic Hodgkin lymphoma of the nodular sclerosis type (CHL-NS);
- + Double-hit lymphomas (DHL) affecting approximately 5% to 10% of patients (described next) and double-expressor lymphomas (DEL), which overexpress MYC and BCL2 protein, are aggressive DLBCLs and are also associated with a poor prognosis.

You can find out more about DLBCL subtypes at www.lymphoma.ca/DLBCL.

This type of NHL is very sensitive to treatment and a large percentage of patients with DLBCL can be cured.

DOUBLE HIT LYMPHOMA (DHL)

Double hit lymphoma (DHL) describes patients whose lymphoma tumours have mutations in two significant genes, where most lymphoma patients have a mutation in only one. Currently found primarily in diffuse large B cell lymphoma (DLBCL), DHL is a relatively rare subtype. It occurs in approximately 5-10% of NHL patients. Generally, these lymphomas are aggressive, developing rapidly and requiring early treatment. Identifying these types of lymphoma from other B cell lymphomas can be difficult and testing is often complex.

DHL is a research focus, in the hopes of improving outcomes.

BURKITT LYMPHOMA

Burkitt lymphoma is a very aggressive (high-grade) form of NHL that affects both children (usually aged 5-10 years) and adults (usually aged 30-50 years), with males affected more frequently than females. It is named after Dr. Denis Burkitt, who first wrote about this type. The disease can be associated with viral infection such as the human immunodeficiency virus (HIV). Burkitt lymphoma accounts for 30% to 40% of all childhood lymphomas.

The most common symptoms of Burkitt lymphoma are swollen lymph nodes and abdominal swelling and/or pain. Burkitt lymphoma may also affect other organs such as the eyes, ovaries, kidneys, central nervous system and glandular tissue such as breast, thyroid or tonsil. Burkitt lymphoma in children often affects the jaw, in the areas where permanent teeth are forming.

Although Burkitt lymphoma has a very aggressive course, survival rates with treatment are approximately 80%. Burkitt lymphoma often involves the central nervous system (CNS) so patients with Burkitt lymphoma may need to have treatment that can reach their CNS. Drugs may be given intrathecally (directly into the cerebrospinal fluid).

GRAY ZONE LYMPHOMA

Gray zone lymphoma is a rare type of lymphoma. It is called “gray zone” lymphoma because it has some characteristics of Hodgkin lymphoma and some characteristics of large B cell lymphoma, but cannot be assigned specifically to either type. The clinical characteristics and treatment of gray zone lymphoma have yet to be defined because of its recent identification and rarity.

MANTLE CELL LYMPHOMA (MCL)

Mantle cell lymphoma is rare and most commonly affects men over the age of 50 years. Mantle cell lymphoma may follow an indolent or slow-growing course but usually is an aggressive disease and is treated as an aggressive lymphoma.

The most common symptom is a painless swelling in the neck, armpit or groin, caused by enlarged lymph nodes. Often, patients with mantle cell lymphoma have many lymph nodes, one or more organs, and the bone marrow involved. The gastrointestinal tract is commonly affected.

Treatment is often initially successful. However, mantle cell lymphoma frequently relapses and becomes difficult to treat. While treatments are available for this type of lymphoma patients are often encouraged to participate in clinical trials so they can receive newer treatments that are not yet on the market and to improve knowledge of this uncommon lymphoma type.

COMMON TYPES OF AGGRESSIVE NON-HODGKIN T CELL/NATURAL KILLER CELL LYMPHOMA

PERIPHERAL T CELL LYMPHOMAS (PTCLS)

Peripheral in this case means the T cells developed in parts of the body outside of the thymus gland. PTCL refers to a large number of different T cell lymphomas that together affect 5-10% of all patients diagnosed with NHL. PTCL usually affects adults over the age of 50. It occurs slightly more often in men.

The most common symptoms include swollen, enlarged lymph nodes in many areas of the body and an enlarged liver and spleen (hepatosplenomegaly). Skin may also be affected.

There are many distinct sub-types of PTCLs. They include:

1. Adult T cell leukemia/lymphoma (ATLL) commonly causes high levels of calcium in the blood, known as 'hypercalcaemia'. It can also sometimes cause serious problems with the heart and kidneys so must be treated quickly. ATLL is also likely to affect the CNS (the brain and spinal cord), especially if it relapses.
2. Subcutaneous panniculitis-like T cell lymphoma is often confused with a condition called panniculitis, an inflammation of fatty tissue in the body. Patients may feel bumps under the skin (subcutaneous nodules) which can progress to open, inflamed sores.
3. Hepatosplenic gamma delta T cell lymphoma usually shows up as cancerous T cells present in the liver, spleen and bone marrow. It is quite difficult to diagnose.
4. Enteropathy-type intestinal T cell lymphoma is linked to celiac disease (a gluten-sensitive intestinal disease). The lymphoma grows in the small bowels.

5. Nasal-type NK/T cell lymphoma used to be called angiocentric lymphoma and is more common in Asia and South America. It most frequently affects the nose and sinuses.
6. Angioimmunoblastic T cell lymphoma. Angio refers to blood vessels, which often grow in an abnormal pattern in this disease. The most common symptoms include generalized swollen lymph nodes (called lymphadenopathy), fever, weight loss, skin rash and high levels of antibodies in the blood.
7. PTCL, unspecified is the most common PTCL subtype in North America. It represents all of the PTCLs not classifiable as a specific subtype.

The response to treatment is not often as effective in PTCLs as it is in other aggressive NHL types. As a result, stem cell transplantation is sometimes considered an early treatment option.

ANAPLASTIC LARGE CELL LYMPHOMA (ALCL)

Anaplastic refers to the appearance of the lymphoma cells. ALCL is rare. Patients with ALCL are typically young, with an average age of 33 years, with 70% of patients being male.

ALCL can occur in two different forms:

1. A systemic type, meaning in organs in the body (aggressive).
2. A primary cutaneous type, where it occurs only in the skin (less aggressive). Patients may go into remission without treatment, but the remissions are followed by relapses. Primary cutaneous ALCL is associated with a rare, non-cancerous condition called lymphomatoid papulosis (LyP).

Patients with ALCL are divided into 2 groups, depending on whether or not a protein called anaplastic lymphoma kinase (ALK) is found on the cells. ALK positive patients (have the protein ALK) respond well to

chemotherapy, putting most patients in long-term remission or cure. A majority of ALK negative patients (do not have the protein ALK) will relapse within 5 years and are treated more aggressively, often with transplant.

LYMPHOBLASTIC LYMPHOMA

Lymphoblastic lymphoma can appear in both B cells and T cells but is much more common in T cells (which are affected in 80% of all lymphoblastic lymphomas). Lymphoblastic lymphoma mainly affects children and adolescents. A second peak of occurrence is seen over 40 years of age. Males are affected more than females.

Breathing difficulties often result from a large mass in the mediastinal area (the centre area of the upper chest), as well as fluid accumulation around the lungs. This type of NHL can spread to the central nervous system (the brain and spinal cord).

Young patients whose disease is in one area have an excellent prognosis. Adults with later stage disease may be offered stem cell transplantation as part of their initial treatment plan. Most people with LBL also have chemotherapy treatment to the brain and spinal cord (the CNS).



I didn't know where to turn to...But now there's the Lymphoma Canada website which has all the information you need.

- Daniel, patient





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Research-based information gathered from thousands of people around the world who have had non-Hodgkin lymphoma 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/support)

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WATCH AND WAIT

If your NHL is slow growing and not causing you serious symptoms, you likely will not have treatment right away. This approach is called ‘watch and wait’ or ‘watchful waiting’ or ‘active monitoring’.

Watch and wait is a strategy where doctors monitor you closely, but do not treat you until symptoms appear or change.

This does not mean your cancer is being ignored by your medical team. During the watch and wait period, you will meet regularly with your cancer specialist to monitor changes in your disease and overall health. At these appointments, your doctor will examine you and do blood tests. They will also ask how you are feeling and about any symptoms you have. Patients in watch and wait should report disease symptoms, most notably fever, night sweats and unexplained weight loss.

The results of exams and blood tests over time will help your doctor determine if you need treatment and the type of treatment you should have.

Understandably, many people worry their lymphoma will get worse if they don't have treatment. It is natural to want treatment if you have cancer. Studies comparing watch and wait with early treatment have shown there is no benefit to early treatment for patients with asymptomatic indolent lymphoma. Furthermore, some patients will never need treatment for their lymphoma. And with watch and wait, you can avoid the side effects of treatment until it is needed.

TREATMENT OVERVIEW

NHL often responds very well to modern treatments.

The major goals of NHL treatment include:

- + Cure (if possible);
- + Bringing about prolonged remission (cancer-free period);
- + Reducing the number of cancer cells;
- + Minimizing the number of lymph nodes and/or organs affected;
- + Preventing the development of symptoms and relieving existing ones;
- + Improving the patient's quality of life.

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 NHL.

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 NHL. The sequence of treatment in lymphoma is important because, in some cases, the first treatment you get may affect your next treatment (if it becomes necessary). 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.



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



AGGRESSIVE NON-HODGKIN LYMPHOMA TREATMENT

HOW WILL MY NHL BE TREATED?

What will my treatment be?

Chemotherapy (with or without antibody therapy)

Radiation (with or without chemotherapy or antibody therapy)

Steroid therapy

Surgery

Clinical trial

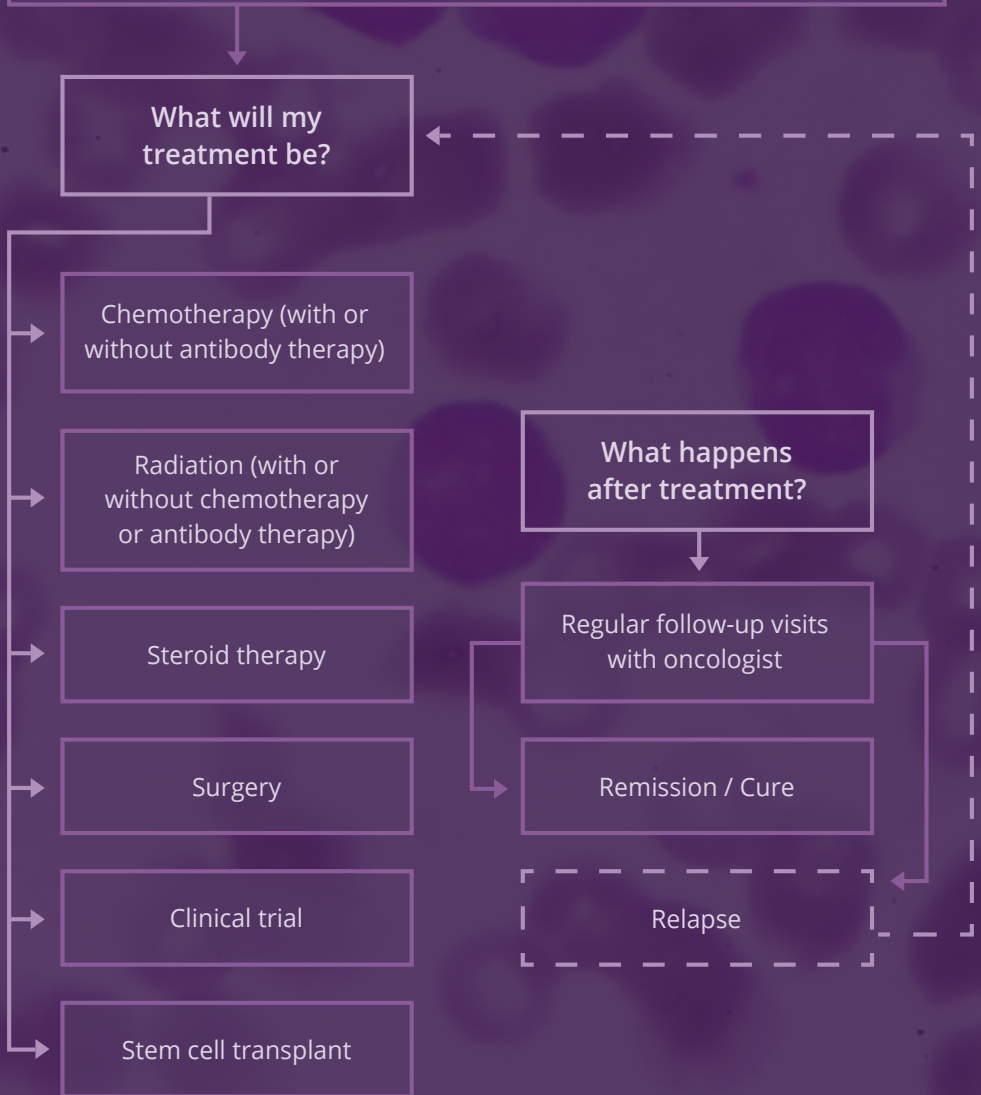
Stem cell transplant

What happens after treatment?

Regular follow-up visits with oncologist

Remission / Cure

Relapse



INDOLENT NON-HODGKIN LYMPHOMA TREATMENT

HOW WILL MY LYMPHOMA BE TREATED?

Watch and Wait

How long until I get treatment?

If signs or symptoms of progressive disease never appear, treatment may never be needed

Treatment will begin when signs or symptoms of progressive disease appear

Primary (first line) Therapy

What will my treatment be?

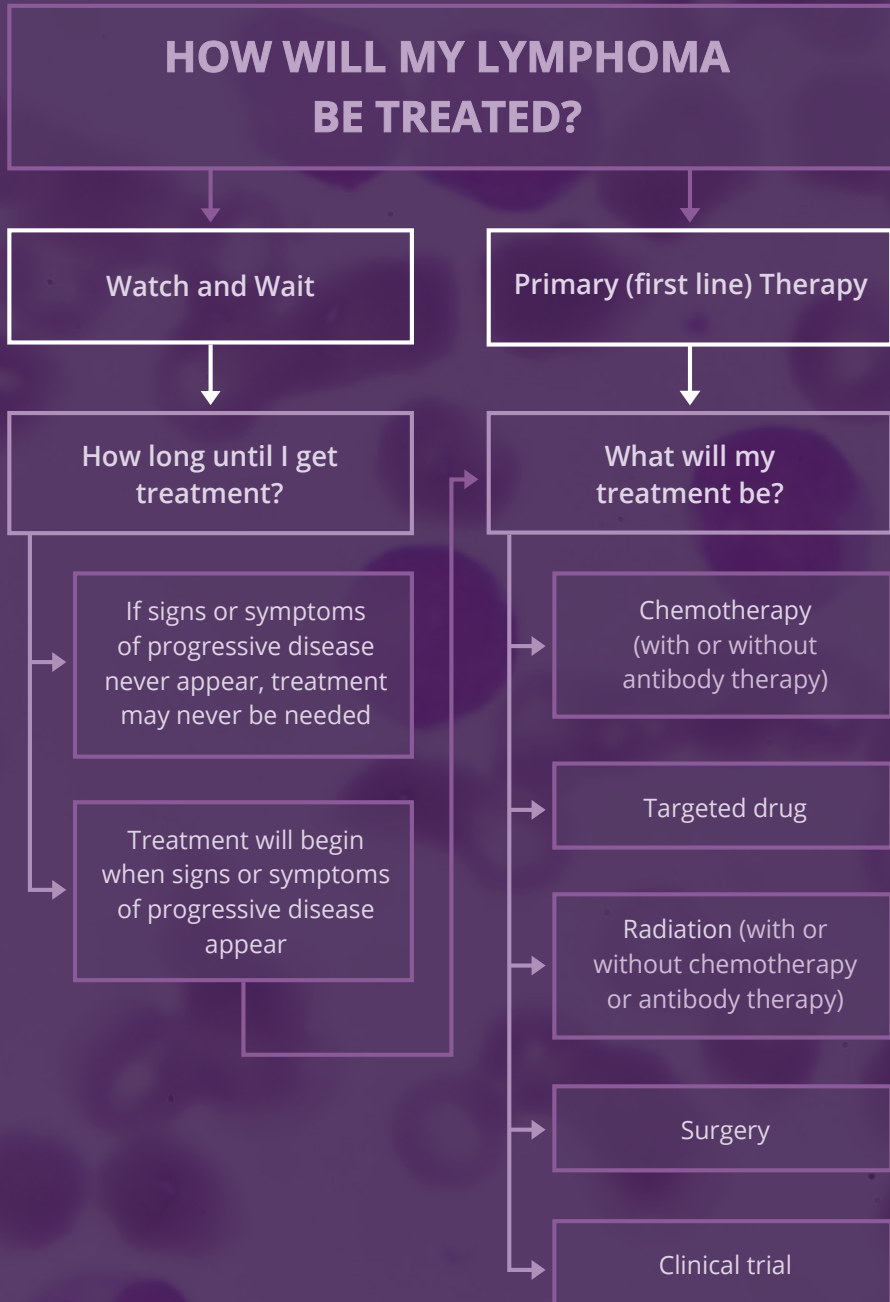
Chemotherapy (with or without antibody therapy)

Targeted drug

Radiation (with or without chemotherapy or antibody therapy)

Surgery

Clinical trial



WHAT HAPPENS AFTER TREATMENT?

Response to treatment

No response to treatment

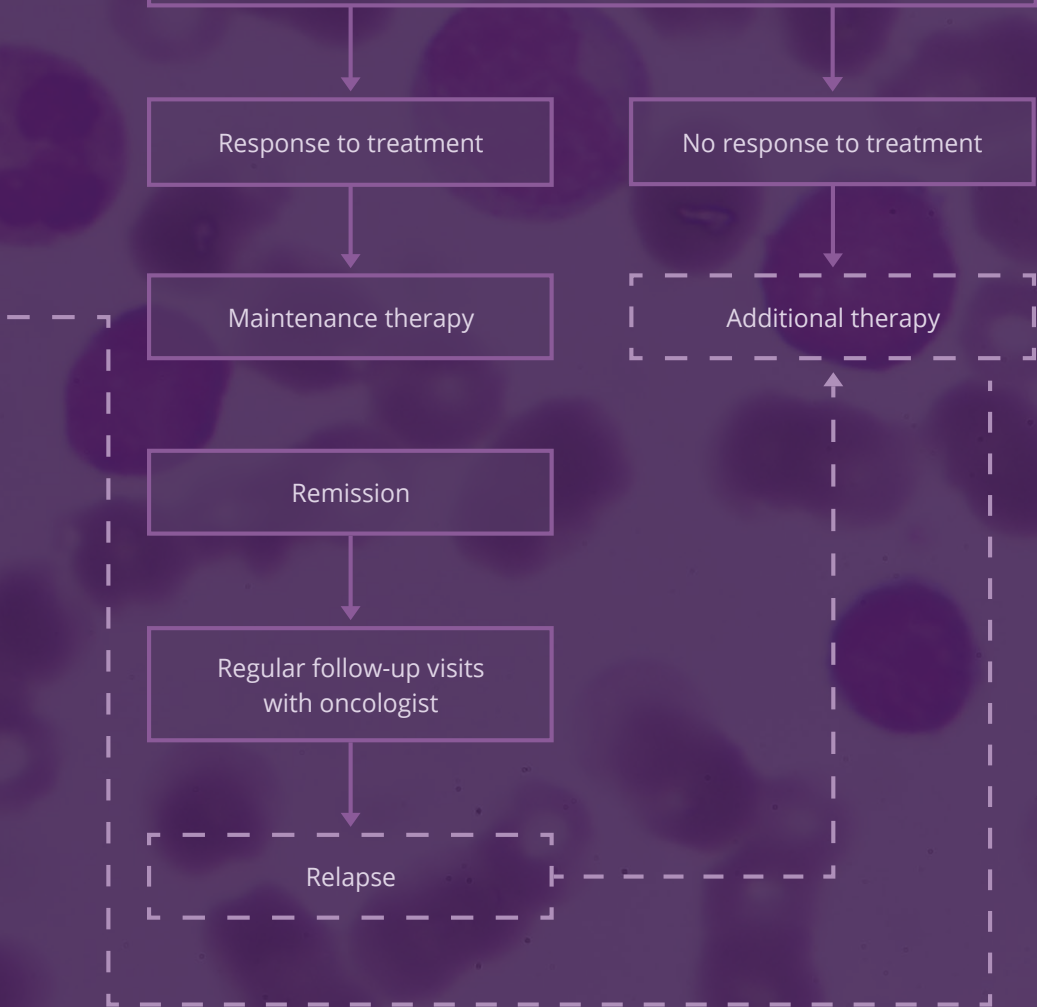
Maintenance therapy

Additional therapy

Remission

Regular follow-up visits
with oncologist

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;

- + **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. NHL 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 NHL. 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 transplantation
- + Maintenance therapy
- + Supportive therapy

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.



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.

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 number of cycles you receive will depend on the type and stage of your NHL 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 drugs, your doctor might 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.

TYPE OF VENOUS CATHETER	DESCRIPTION
Tunneled catheter Central line Hickman® line	A tube inserted by a surgeon into a vein in the neck, chest or groin. The line is “tunneled” under the skin to an exit site a short distance away from the vein. This helps minimize the risk of infection.
Peripherally-inserted central catheter (PICC)	A peripherally-inserted central catheter (PICC) is a catheter inserted into a vein in the arm. The catheter is pushed up the vein until the end reaches the major vein leading to the heart. It can be used to deliver drugs or withdraw blood samples.
Implanted chemotherapy port (port-a-cath)	This device is a small round chamber with a catheter placed under the skin, usually in the chest. The catheter is connected to the major vein leading to the heart.

Chemotherapy does not usually cross the blood/brain barrier. In rare cases, when there is lymphoma in the central nervous system (CNS), you may need to have intrathecal chemotherapy. This means chemotherapy drugs are delivered directly into the cerebrospinal fluid surrounding the brain and spinal cord, through a lumbar puncture or a device under the scalp.

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	Feeling tired and weak. Shortness of breath. Lightheadedness.	Injections may be given to help boost the bone marrow production of red blood cells. Red blood cell transfusions might be required for severe anemia.
Neutropenia – decrease in the number of neutrophils, a type of white blood cell that fights infections	More frequent and/or serious infections or the recurrence of old viruses, like shingles. Fever; sore throat; rash; diarrhea; redness, pain or swelling around a wound.	Chemotherapy might be delayed or the dose reduced. Antibiotics may be prescribed. Injections might be given to boost the bone marrow production of neutrophils (G-CSF).

Thrombocytopenia – decrease in the number of platelets	Increased bruising. Excessive bleeding from cuts, nosebleeds and bleeding gums.	Avoiding blood-thinning medications, such as aspirin, might be recommended. Platelet transfusion might be necessary in severe cases.
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- + **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.

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’. Several antibody therapies are available for the treatment of NHL and many more are under clinical investigation.

Antibody therapy is most often given in combination with chemotherapy drugs, which is called chemoimmunotherapy. Like some chemotherapy drugs, 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 the side effects 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.

OTHER TARGETED THERAPIES

Scientists are learning more about the cell signals (the communication of information within the cell and between cells) that contribute to the growth and survival of lymphoma cells. Drugs are being developed to specifically block or disrupt these signals and stop the growth and spread of lymphoma cells, while limiting damage to healthy cells.

Currently, there are many new targeted therapies undergoing investigation in clinical trials and some have recently been approved to treat lymphomas.

Many of these targeted therapies are available in pill form, making it possible for patients to take their medication at home.

Most targeted therapies affect the bone marrow so there is a risk of infection and bleeding. Many patients experience fatigue and the drugs can cause nausea or bowel upset. Some of these drugs can also cause peripheral neuropathy (see description under chemotherapy side effects).

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.

SPLENECTOMY

The spleen is an organ on the left side of the body, near the stomach. A splenectomy is an operation to remove the spleen. It can be helpful if the spleen becomes very large as a result of the disease. Cancer cells can enlarge the spleen and cause discomfort in some patients. Also, an enlarged spleen may lower your blood cell counts to dangerous levels.

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.

MAINTENANCE THERAPY

Maintenance therapy is treatment that is given to patients who go into remission after they finish their course of therapy. The goal of maintenance therapy is to help prevent a relapse and improve overall survival. It includes treatment with drugs or antibodies that kill cancer cells, and it may be given for a long period of time.

SUPPORTIVE THERAPY

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

Supportive care for NHL can include:

- + Antibiotics to treat infections caused by bacteria or fungi.
- + Antivirals to treat infections caused by viruses.
- + Vaccinations.
- + Blood transfusions or growth factors to increase red blood cell counts.
- + IVIG treatments may be used to help boost your immune system.
- + Growth factors to increase white blood cell counts (G-CSF).

RELAPSED OR REFRACTORY NON-HODGKIN LYMPHOMA

Relapsed NHL means that the disease has returned after responding to treatment. This is sometimes also called a recurrence. Refractory NHL means that your disease does not respond to a specific treatment or that the response to the treatment does not last very long.

If your cancer should come back (relapse), you may require more treatments. In some cases, the treatment options available depend on what your initial therapy was. For this reason it is important to discuss options early on with your doctor and consider your personal treatment goals so the best treatment plan can be selected for you.

INDOLENT NHL

The majority of patients with indolent NHL experience relapses of their disease, despite having had treatment. The duration between treatment and relapse can vary, but it is typically between 18 months and four years.

There are many treatment options for people with relapsed or refractory indolent NHL. The type of treatment that you will receive if you need additional treatment depends on factors such as age, extent and location of the disease, overall health, types of previous therapies you received, and the length of response to previous therapies.

Possible treatments include:

- + The watch and wait approach, which may be the best option for patients who have no symptoms that are troubling them;
- + Chemotherapy, which is the most common treatment for relapsed disease;
- + Antibody therapy is often used for certain types of relapsed NHL, usually in combination with chemotherapy, to increase the effectiveness of chemotherapy.

Many of the new therapies most recently approved by Health Canada and those being tested in clinical trials are used specifically for patients with relapsed or refractory disease. Lymphoma research is evolving quickly as doctors and scientists discover new treatments and more effective ways of giving existing therapies.

Transformation

It is possible for low-grade, slow-growing lymphoma to become more aggressive. This is known as a transformation. This can happen because the cells in low-grade lymphomas are surviving beyond their natural lifetime and may become damaged over time. They become

less responsive to treatment and the damage causes the cells to start to grow rapidly, similar to high-grade lymphomas.

Treating patients with transformed NHL can be difficult. You may be treated with high-dose chemotherapy with or without a stem cell transplant. This can also be combined with antibody therapy in order to destroy any residual lymphoma cells in the bone marrow.

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.

AGGRESSIVE NHL

A small number of patients with aggressive NHL do not respond to treatment and some patients who do respond to treatment experience a relapse after a remission. Although treatment is difficult, cure or remission can still be achieved in some patients with a second line of treatment, called salvage treatment. Salvage treatment for aggressive NHL usually consists of combination chemotherapy (chemotherapy with combination drugs). High-dose chemotherapy and autologous stem cell transplant may also be performed if necessary.

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.

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?



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/clinicaltrials**



FOLLOW-UP

CARE

Follow-up care after treatment is an important part of cancer care. Follow-up for NHL 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 _____ **90**

Secondary Cancers _____ **92**

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 the rest of your life. 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 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.lifebeyondlymphoma.ca**

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, likely as a result of treatment received for lymphoma. This increased risk continues for up to 20 years after treatment. Some indolent lymphoma patients, regardless of whether or not they have received treatment, are at a higher risk of developing other kinds of cancer.

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 resting on a white surface. The stethoscope's chest piece is in the foreground, and its tubing loops around in the background. A white, heart-shaped object is also visible. In the lower foreground, the curved edges of several books are visible. The overall scene is brightly lit, creating soft shadows.

MEDICAL

TERMS

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

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.

Aggressive lymphoma: Lymphoma that grows at a fast rate. They are also referred to as intermediate or high-grade lymphomas.

Allogeneic stem cell transplant: A procedure where a patient receives stem cells from the bone marrow or peripheral blood of a compatible donor. For additional information, see page 78.

Alopecia: Loss of hair, either from the head or elsewhere on the body. Alopecia during cancer treatment most commonly occurs as a side effect of chemotherapy and is almost always temporary. Hair will re-grow once 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 33.

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 69.

Antibody therapy: Laboratory-made antibodies attach to the target protein on the cancer cell, marking the cell so that the immune system will kill it. Antibody therapy is sometimes known as ‘immunotherapy’ or ‘biologic therapy’. For additional information, see page 69.

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 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 cell that helps the body fight disease and infection.

B cell lymphoma: A type of NHL where the cancer affects B cells.

B symptom: Symptoms that some people may experience with B cell 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.

Binet staging system: Describes the extent to which a cancer has spread within the body. There are three stages in the Binet staging system typically used with CLL in Europe: stage A; stage B; stage C (more widespread).

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

Biomarkers: Any substance found in an increased amount in the blood, other body fluids or tissues that can be used to indicate the presence of some diseases or predict the outcome of a disease.

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-brain barrier: A selective, semi-permeable barrier which prevents certain materials from the blood from entering the brain. This protects the brain from harmful substances, such as toxins and bacteria, and maintains a constant environment for the brain.

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 on patients with NHL as part of staging their cancer and 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 28.

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 commonly 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: 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.

CD5 antigen: A protein on the surface of some B cells. This protein can be found during the biopsy procedure and, if present, is used to confirm the diagnosis of certain types of NHL.

CD20 antigen: A protein found on the surface of B cells. The CD20 antigen is used as a target for monoclonal antibody therapy in certain types of NHL.

CD30 antigen: A protein found on the surface of some T cells. This protein can be found during the biopsy procedure and, if present, is used to confirm the diagnosis of a certain type of T cell NHL: anaplastic large cell lymphoma, primary cutaneous-type.

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

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.

Cerebrospinal fluid: Watery fluid that surrounds the brain and spinal cord. In NHL, it may be examined to determine if the cancer has spread to these areas.

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

Chemosensitive: A term used to describe cancer that responds 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 63.

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

Chemotherapy course: The total number of required chemotherapy cycles.

Chronic: A disease that lasts for a long period of time or is recurring.

Classification (of NHL): Determining the exact type of NHL a patient has. There are many different types of NHL and it is important to know what type the patient has to make sure they get the most appropriate treatment.

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.

Deletion: Chromosome abnormality where part of the chromosome is missing.

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.

Erythrocyte: Red blood cell.

Etiology: The cause(s) of disease. The cause of NHL 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.

First-line or front-line therapy: See *primary therapy*.

Flow cytometry: A procedure that examines the cancer cells and their DNA.

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. Errors in genes can increase the risk of cancer.

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

Grade (clinical grade): NHL can be classified as low, intermediate or high-grade depending on how fast the cancer is growing. The term indolent is often used to describe low-grade NHL, whereas aggressive is a higher grade NHL.

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) attacks 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.

Hemaphagocytic syndrome: A serious condition in which there is uncontrolled activation of certain parts of the immune system. It can occur in a certain types of NHL: subcutaneous panniculitis-like T cell lymphoma and extranodal T cell lymphoma of nasal type.

Hematologist: Doctors specializing in diseases of the blood.

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.

Hepatosplenomegaly: Abnormal enlargement of both the liver and spleen.

High-grade NHL: An aggressive, fast-growing form of NHL.

Hodgkin lymphoma: One of the two main types of lymphoma, Hodgkin lymphoma is 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.

HTLV-1 infection: HTLV stands for human T-lymphotropic virus. It is a family of viruses that infects T cells and can make people more likely to develop a certain type of NHL: adult T cell lymphoma. This virus is rare in North America and is more common in countries such as Japan and China.

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.

Indolent lymphoma: A slow-growing form of lymphoma. Indolent lymphoma and low-grade lymphoma are terms often used interchangeably.

Induction therapy: Cancer treatment used as the first step towards shrinking the cancer. If necessary, induction therapy is followed by additional therapy to treat the remaining cancer.

Intermediate-grade NHL: A form of NHL that is growing at a moderate rate. It is often considered an aggressive form of NHL that usually requires prompt treatment.

Intrathecal chemotherapy: The chemotherapy drugs are delivered directly into the cerebrospinal fluid surrounding the brain and spinal cord, through a lumbar puncture or a device under the scalp.

Intravenous (IV): Administered into a vein.

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

Lactate dehydrogenase (LDH): An enzyme found in the blood that indicates damage to cells. If elevated, it may indicate a more aggressive form of NHL.

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

Leukemia: A cancer of white blood cells. In leukemia, the cancerous cells are in the blood, whereas in lymphoma the cancerous cells (lymphocytes) are primarily found in the lymphatic system.

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.

Low-grade lymphoma: Also referred to as indolent lymphoma, low-grade indicates a slow-growing lymphoma.

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 9.

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.

Lymphocytosis: An increase in the number of lymphocytes in the blood.

Lymphoma: Cancer of the lymphocytes.

Lymphomatoid papulosis: A non-cancerous skin disorder that can progress into some forms of NHL, including anaplastic large cell lymphoma, primary cutaneous-type.

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 local tissue and spread to other areas of the body. Benign tumours are not invasive and do not spread.

MALT: Mucosa-associated lymphatic tissue. Extranodal marginal zone B cell lymphoma of MALT-type is a certain type of NHL that can affect the lymphatic tissues of the gastrointestinal tract, eye, thyroid, salivary glands, bladder, kidney, lungs, neurological system or skin. Mucosa-associated tissue means tissue that is lined with a moist, mucous-producing layer of cells.

Mediastinum: The central area 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 a minute number of cancer cells remain either during or after treatment.

Molecular genetic testing: Tests to find out what chromosome abnormalities and genetic changes are present in your lymphoma cells. See Genetic mutation.

Monoclonal: Derived from one cell.

Monoclonal antibody therapy: A type of biologic therapy (or immunotherapy) used for cancer treatment. A synthetic antibody is created to target a specific protein on the surface of cells. This marks the cell so that the immune system will kill it.

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.

Non-bulky tumour: A tumour that is small in size.

Non-Hodgkin lymphoma (NHL): A group of related cancers that affect the lymphatic system. 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.

Null: A cell of unknown type.

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 response: Also called partial remission. The term used when the 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.

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 a 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.

PICC line: A peripherally-inserted central catheter (PICC) is a catheter inserted into a vein in the arm. It can be used to deliver drugs or withdraw blood samples.

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

Plasma cell: The main function of plasma cells is antibody production. Thus, 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.

Prognostic factors: Along with the stage, there are other factors that help predict a person's outlook. These factors are sometimes taken into account when looking at possible treatment options. Factors that tend to be linked with shorter survival time are called adverse prognostic factors. Those that predict longer survival are favourable prognostic factors.

Psoralen: A drug that is part of a therapy called PUVA, used for a type of NHL called cutaneous T cell lymphoma. Also called photochemotherapy, PUVA consists of psoralen plus ultraviolet A (UVA) light. Psoralen makes the skin more sensitive to the healing effects of the UVA light.

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 73.

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.

Rai staging system: Describes the extent to which a cancer has spread within the body. Classic Rai is staged between 0 and 4. The Modified Rai gives a risk level of low, intermediate or high. Commonly used in Canada to stage CLL.

Randomized controlled trial: A clinical trial that involves testing an experimental drug treatment in comparison with a control treatment.

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. NHL 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.

Richter's Syndrome (RS), also known as Richter's Transformation: A rare complication of lymphoma characterized by the sudden transformation of the lymphoma into a significantly more aggressive form of large cell lymphoma.

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 32.

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). For additional information, see page 77.

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 77.

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 recognize and destroy abnormal cells (such as virus-infected cells and cancer cells) and play 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.

Transformed NHL: Indolent NHL that has changed or transformed into a more aggressive form of lymphoma.

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

Trisomy: Chromosome abnormality that includes the presence of an extra copy of a chromosome.

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.

Tumour lysis syndrome (TLS): Tumour lysis syndrome (TLS) is a potential complication during cancer treatment, caused by an anticancer drug triggering the quick death of a large number of cancer cells, making them break apart and enter the bloodstream. The kidneys can't properly filter the cellular contents of the dying cells from the blood. TLS is a group of problems involving the blood – high blood potassium, high blood phosphorus, low blood calcium and high blood uric acid. This is a potentially fatal complication, and patients at increased risk for TLS should be closely monitored before, during, and after their course of treatment.

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.

Watch and wait: An approach to cancer where patients have no serious symptoms so no immediate treatment is given after diagnosis. Patients are closely monitored through regular visits with their doctor to ensure the cancer is not progressing. This strategy is often appropriate for patients with indolent (slow-growing) NHL.

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).

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