

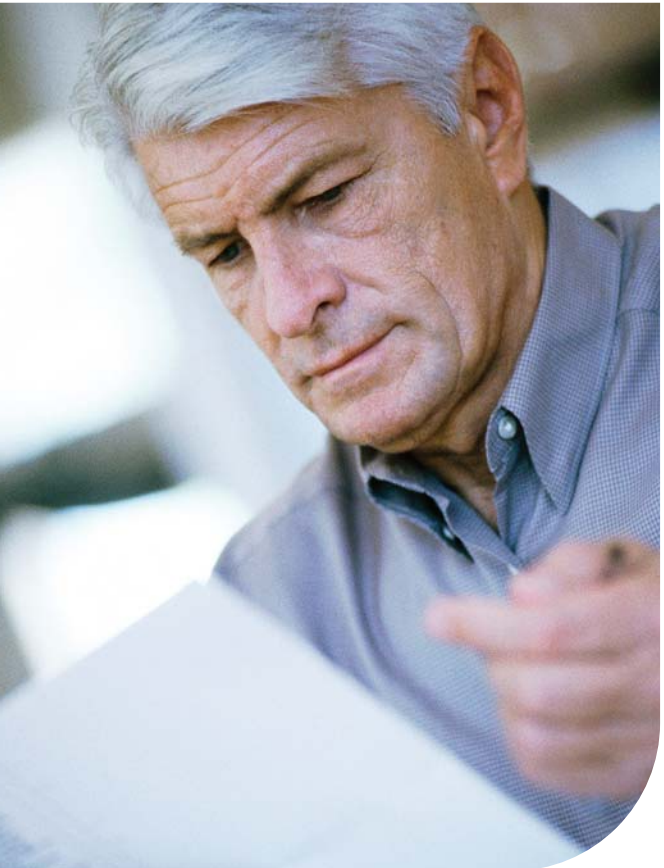


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# Non-Hodgkin Lymphoma

*Understanding your diagnosis*



Let's Make Cancer History

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# Non-Hodgkin Lymphoma

## *Understanding your diagnosis*

When you first hear that you have cancer you may feel alone and afraid. You may be overwhelmed by the large amount of information you will have to take in and the decisions you will need to make.

The introductory information in this brochure can help you and your family take the first step in learning about non-Hodgkin lymphoma. A better understanding may give you a sense of control and help you work with your healthcare team to choose the best care for you.

## What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

But sometimes the instructions in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably.

Abnormal cells from most organs form solid lumps, or tumours. Abnormal cells from the immune system or the blood, however, do not form tumours. Instead, these cancer cells circulate in the blood, bone marrow and lymphatic system.

## What is non-Hodgkin lymphoma?

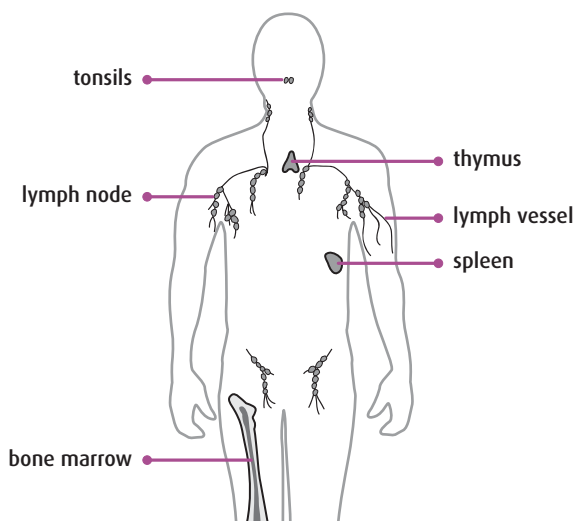
Non-Hodgkin lymphoma is a cancer that starts in the lymphocytes, the cells of the lymphatic system. The lymphatic system works with other parts of your immune system to help your body fight infection and disease. The lymphatic system is made up of a network of lymph vessels (which are a little like veins), lymph nodes and the lymphatic organs (such as the spleen, thymus, tonsils and bone marrow).

*Lymph* is a clear, yellowish fluid that contains *lymphocytes*. Lymphocytes are special white blood cells that help fight infection. They develop in the bone marrow from immature

cells (called *stem cells*). There are two kinds of lymphocytes:

- *B-cells* stay in the bone marrow or lymphatic organs until they mature.
- *T-cells* move to the thymus gland to mature.

*Lymph nodes* are small bean-shaped glands. Clusters of lymph nodes are found in your neck, underarms, chest, abdomen and groin. Lymph nodes filter out waste, bacteria and unwanted cells, including cancer cells, as the lymph passes through them. *Lymphatic vessels* collect lymph from different tissues throughout the body, filter it through the lymph nodes and return it to the bloodstream.



Non-Hodgkin lymphoma develops when a lymphocyte, either a B-cell or T-cell, becomes abnormal. It can begin in almost any part of the body and can form tumours. It usually starts in a group of lymph nodes in one part

of the body, most often the neck. Eventually, it can spread to almost any tissue or organ in the body through the lymphatic system or the bloodstream.

There are over 20 types of non-Hodgkin lymphoma. The cells of the different types look different under a microscope, and they develop and spread differently (for example, slowly or aggressively). The way the abnormal cells develop and spread depends on the type of lymphocyte the lymphoma started in. Most types of non-Hodgkin lymphoma develop from B-cells. It is important for your doctor to find out which type of non-Hodgkin lymphoma you have so you can get the treatment that works best for that type.

## Causes of non-Hodgkin lymphoma

There is no single cause of non-Hodgkin lymphoma, but some factors increase the risk of developing it:

- being older and male
- having a weakened immune system due to:
  - > taking immunosuppressant drugs after an organ transplant
  - > HIV/AIDS
  - > autoimmune diseases, such as rheumatoid arthritis or Sjögren syndrome
  - > inherited disorders such as ataxia-telangiectasia or Wiskott-Aldrich syndrome
- infections such as human T-cell leukemia/lymphoma virus (HTLV-1), Epstein-Barr virus or *Helicobacter pylori* (a bacteria)

- exposure to pesticides
- previous treatment with radiation or chemotherapy

Most people develop non-Hodgkin lymphoma without any of these risk factors.

## Symptoms of non-Hodgkin lymphoma

The most common symptom of non-Hodgkin lymphoma is swelling of the lymph nodes in the neck, underarm or groin. Usually, especially in the early stages, this swelling does not cause any pain. You may discover the enlarged (swollen) lymph node, or your doctor may find it during a routine physical exam or x-ray of the chest.

Other symptoms include:

- unexplained weight loss
- unexplained fevers
- drenching night sweats
- lack of energy, fatigue
- itchy skin

Often, these symptoms are not caused by non-Hodgkin lymphoma. Swollen lymph nodes are very common. Other health problems can cause them, such as the flu or an infection. Testing is needed to make a diagnosis.

## Diagnosing non-Hodgkin lymphoma

After taking your medical history and completing a physical examination, your doctor may suspect you have non-Hodgkin lymphoma. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to “stage” and “grade” the cancer. You may have one or more of the following tests.

**Blood tests:** Blood is taken and studied to see if the different types of blood cells are normal in number and appearance. The results also show how well organs are working, in particular those organs that make blood cells, like the bone marrow. Abnormal test results may suggest whether or not you have cancer. The blood sample may also be checked to measure the amounts of certain substances, such as lactate dehydrogenase (LDH), released into the blood by organs and tissues in the body. Some types of lymphoma can cause a higher than normal level of LDH in the blood.

**Imaging studies:** Imaging studies allow tissues, organs and bones to be looked at in more detail. Using x-rays, ultrasounds, CT scans, MRIs, bone scans or PET scans, your healthcare team can get a picture of where the cancer is and see if it has spread. These tests are usually painless and do not require an anesthetic.

**Lymph node biopsy:** A biopsy is usually necessary to make a definite diagnosis of cancer. Cells are removed from the body and checked under a microscope. If the cells are cancerous, they will be studied further to find out the exact type of non-Hodgkin lymphoma you have.

There are many ways to do a biopsy. The type you have depends on where the enlarged lymph nodes are.

- For a *core needle biopsy*, your doctor inserts a needle through a small cut in the skin to remove a sample of tissue from the lymph node. A local anesthetic (freezing) will be used to numb the area.
- A *surgical biopsy* is an operation that is used if the enlarged lymph node cannot be easily reached with a needle. There are two types of surgical biopsies. An *incisional* biopsy takes a tissue sample from the lymph node. An *excisional* biopsy takes out the entire lymph node. This may be done with a local anesthetic or under a general anesthetic (you will be unconscious).

**Further testing:** If the initial tests show that you have non-Hodgkin lymphoma, your doctor may order more tests to find out if the cancer has spread. They may include blood tests, imaging studies, more biopsies of lymph nodes or the liver, bone marrow or cerebrospinal fluid (the fluid around the spinal cord and brain).

**Bone marrow aspiration and biopsy:** A bone marrow aspiration or biopsy may be done to see if the lymphoma has spread to the bone marrow. Bone marrow is the soft, spongy material that fills the centre of most bones (those where blood cells are made). There are two ways to get a bone marrow sample:

- For a *bone marrow aspiration*, the doctor uses a thin needle to remove samples of bone marrow.
- A *bone marrow biopsy* uses a thicker needle to remove a sample of bone marrow and a small piece of bone.

Both types of biopsies use a local anesthetic to numb the area. It can be painful when cells are pulled into the syringe, but this lasts only a few seconds. Usually, bone marrow aspirations and biopsies are done at the same time in a clinic or hospital on an outpatient basis (you will not stay overnight).

**Lumbar puncture:** A lumbar puncture (also called a *spinal tap*) may be done to see if the lymphoma has spread to the nervous system. A lumbar puncture is a biopsy that removes a small amount of cerebrospinal fluid to check for cancer cells. A needle is inserted between two vertebrae in the backbone and a small amount of the fluid that surrounds the spinal cord is removed. A local anesthetic is used. A lumbar puncture takes about 30 minutes. You must lie flat for 1 to 2 hours afterward to lessen the chances of getting a headache.

## Staging and grading

Once a definite diagnosis of cancer has been made and your healthcare team has the information it needs, the cancer will be given a stage and a grade.

The cancer stage for non-Hodgkin lymphoma describes where the cancer is (in the lymph nodes or other organs or tissues). It also tells how many lymph nodes are affected and whether cancer has spread beyond the place where it started to grow. The *Ann Arbor* system is the most common staging system for lymphoma. There are four stages.

Stage	Description
1	Cancer is found in only one group of lymph nodes.
2	Cancer is found in two or more groups of lymph nodes on the same side of the diaphragm (either above or below, but not both). The diaphragm is a sheet of muscle separating your chest and abdomen.
3	Cancer is found in groups of lymph nodes both above and below the diaphragm.
4	Cancer has spread to one or more organs outside the lymphatic system, such as the liver, bones, lungs or bone marrow. Cancer cells may or may not be found in lymph nodes near the affected organs.

As well as giving each stage a number, doctors may add a letter code to further describe the lymphoma. One or more of the following letters may be used:

- **E** (extranodal) means the cancer is found in an area or organ other than the lymph

nodes or has spread to tissues outside the lymphatic system.

- **S** (spleen) means the cancer is also found in the spleen.
- **A** means you have no fever, night sweats or unexplained weight loss.
- **B** means you have fever, night sweats and unexplained weight loss.

To find out the grade of the lymphoma, the biopsy sample is examined under a microscope. A grade is given based on how the cancer cells grow and develop compared with normal cells. This can give your healthcare team an idea of how quickly the cancer may be growing. There are two grades.

Grade	Description
Indolent lymphomas	Indolent lymphomas tend to grow very slowly. They may need little or no treatment for months or even years. They are usually treated only when symptoms appear. Indolent lymphomas can shrink or sometimes seem to disappear with treatment, but they tend to come back.
Aggressive lymphomas	Aggressive lymphomas grow quickly. They usually cause symptoms and need treatment right away. Aggressive lymphomas can sometimes be cured with intensive chemotherapy.

It is important to know the stage and grade of the cancer. This information helps you and your healthcare team choose the best treatment for you.

## Treatments for non-Hodgkin lymphoma

Your healthcare team will consider your general health, symptoms and the type, stage and grade of the lymphoma to recommend what treatments will be best for you. You will work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

Treatments affect everyone in different ways. It's hard to predict which side effects you will have. Your healthcare team will tell you what to expect with each treatment. They will also let you know what side effects you should report right away and which ones you can wait to tell them about at your next appointment. If you notice any side effects or symptoms that you did not expect, talk to a member of your healthcare team as soon as possible.

Patients often worry about the side effects of cancer treatment. However, side effects can often be well managed and even prevented. Be open with your healthcare team. Tell them your concerns and ask questions. They will help you get the care and information you need.

### Talk to your doctor about your fertility options before starting treatment

Some treatments can affect your ability to have children. Loss of fertility may be temporary or permanent, depending on your age and whether the testicles or ovaries receive radiation.

For non-Hodgkin lymphoma, you might receive one or more of the following treatments.

**Watchful waiting:** If you have indolent non-Hodgkin lymphoma without any symptoms, you may not need active treatment right away. Instead, your doctor may offer you a program called *watchful waiting*. Watchful waiting means your healthcare team will watch the cancer closely. You will visit your doctor regularly, usually every 3 months, for a physical examination. Other tests may be done from time to time. Active treatment, such as chemotherapy or radiation, may be considered only if signs of cancer appear or change. Indolent non-Hodgkin lymphoma may not cause any problems for a very long time.

**Chemotherapy:** Chemotherapy may be given as pills or by injection. Chemotherapy drugs interfere with the ability of cancer cells to grow and spread, but they also damage healthy cells. Although healthy cells can recover over time, you may experience side effects from your treatment like nausea, vomiting, loss of appetite, fatigue, hair loss and an increased risk of infection. Some drugs used for non-Hodgkin lymphoma may cause your skin to become darker.

If the lymphoma has spread to the nervous system, the chemotherapy drugs may be injected directly into the cerebrospinal fluid. This is called *intrathecal chemotherapy*. It is given with a local anesthetic.

Chemotherapy for non-Hodgkin lymphoma may be given alone or with other therapies, such as biological therapy or radiation therapy.

**Biological therapy:** Biological therapy is a treatment that uses your immune system to fight cancer or to help control side effects of other cancer treatments. Natural body substances or drugs made from natural body substances are used to boost the body's own defences against illness.

*Monoclonal antibodies* are a type of biological therapy used to treat some types of non-Hodgkin lymphoma, either alone or together with chemotherapy. They are given by injection. These drugs may cause flu-like symptoms, such as chills, fever, muscle aches, weakness and nausea. More serious side effects are rare. Some people may have a severe skin rash, breathing problems or low blood pressure. The side effects usually disappear once treatment is finished.

**Radiation therapy:** In *external beam radiation therapy*, a large machine is used to carefully aim a beam of radiation at the tumour. The radiation damages the cells in the path of the beam - normal cells as well as cancer cells.

Radiation side effects will be different depending on what part of the body receives the radiation. You may feel more tired than usual, have some diarrhea, or notice changes to the skin (it may be red or tender) where the treatment was given.

**Stem cell transplant:** Sometimes high doses of chemotherapy, radiation therapy or both are used to treat non-Hodgkin lymphoma that has come back. High-dose chemotherapy and radiation therapy destroy the bone marrow cells as well as the cancer cells, so the bone marrow will need to be replaced with a transplant of stem cells. All blood cells develop from stem cells found in the bone marrow and in the bloodstream.

Before high-dose chemotherapy is given, stem cells will be taken from you or from a donor whose bone marrow is a close match to your own. Soon after the chemotherapy treatment, the stem cells are put back into your blood. Within a few weeks, the new stem cells will start to make blood cells.

A stem cell transplant is a risky and complex procedure. For this reason, stem cell transplants are done in specialized transplant centres or hospitals by a team of highly trained healthcare professionals. Side effects can be very serious and may even be life-threatening. You will be watched very closely after a stem cell transplant and carefully followed up for a period of time after leaving the hospital. It may take several months to fully recover after a stem cell transplant.

**Clinical treatment trials:** Clinical treatment trials investigate new approaches to treating cancer, such as new drugs, new types of treatments or combinations of existing treatments. They are closely monitored to make sure that they are safe for the participants.

Ask your doctor if there is a clinical trial suitable as a treatment option for you. You may benefit and so may future cancer patients.

**Complementary therapies:** Complementary therapies are used *together with* conventional treatments. More research is needed to understand if these therapies are effective and how they work.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested for safety or effectiveness. It is still unknown whether they will harm you or be effective in the treatment of cancer.

If you are thinking about using a complementary or alternative therapy, it is important to find out as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might interfere with test results or regular treatments.

## After treatment

Follow-up care helps you and your healthcare team monitor your progress and your recovery from treatment. At first, your follow-up care may be managed by one of the specialists from your healthcare team. Later on it may be managed by your family doctor.

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year or two after treatment, especially if you had a stem cell transplant. It can take the immune system a year or longer to recover from a stem cell transplant. The time between follow-up appointments may become longer as time goes on. You should report new symptoms and symptoms that don't go away to your doctor without waiting for your next scheduled appointment.

Non-Hodgkin lymphoma can come back (recur). If this happens, it can often be treated successfully. You and your healthcare team will discuss treatment options, such as chemotherapy with different drugs than you had before, radiation therapy, or a combination of both, or high-dose treatment with a stem cell transplant.

The end of cancer treatment may bring mixed emotions. You may be glad the treatments are over and look forward to returning to your normal activities. But you could feel anxious as well. If you are worried about your treatment ending, talk to your healthcare team. They are there to help you through this transition period.

## Living with cancer

There are many sources of help available for people with cancer and for their caregivers.

**Your healthcare team:** If you need practical help or emotional support, members of your healthcare team may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

**Family and friends:** Those closest to you can be very supportive. Accept offers of help. When someone says “Let me know how I can help,” tell them what they can do. Maybe they can run errands, cook a meal or give you a ride to your doctor’s office.

**People who have had a similar experience:** Consider visiting a support group or talking with a cancer survivor in person, over the telephone or online. Talking with and learning from others who have had similar experiences can be helpful. Try more than one option to see which one suits you best.

**Yourself:** Try to stay positive. Staying positive is about figuring out how to deal with cancer in the best way that you can – and everyone will do this their own way. It doesn’t mean that you must seem happy or cheerful all the time or avoid talking or thinking about the difficulties of having cancer. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically.

## The Canadian Cancer Society *Helping you understand cancer*

Now that you have been introduced to the basics of non-Hodgkin lymphoma, you may want to learn more. Please contact the Canadian Cancer Society for more detailed information on non-Hodgkin lymphoma. Our services are free and confidential.

If you would like to talk to someone who has had a similar cancer experience, we can help you connect with a trained volunteer – in person, over the phone or in a group setting.

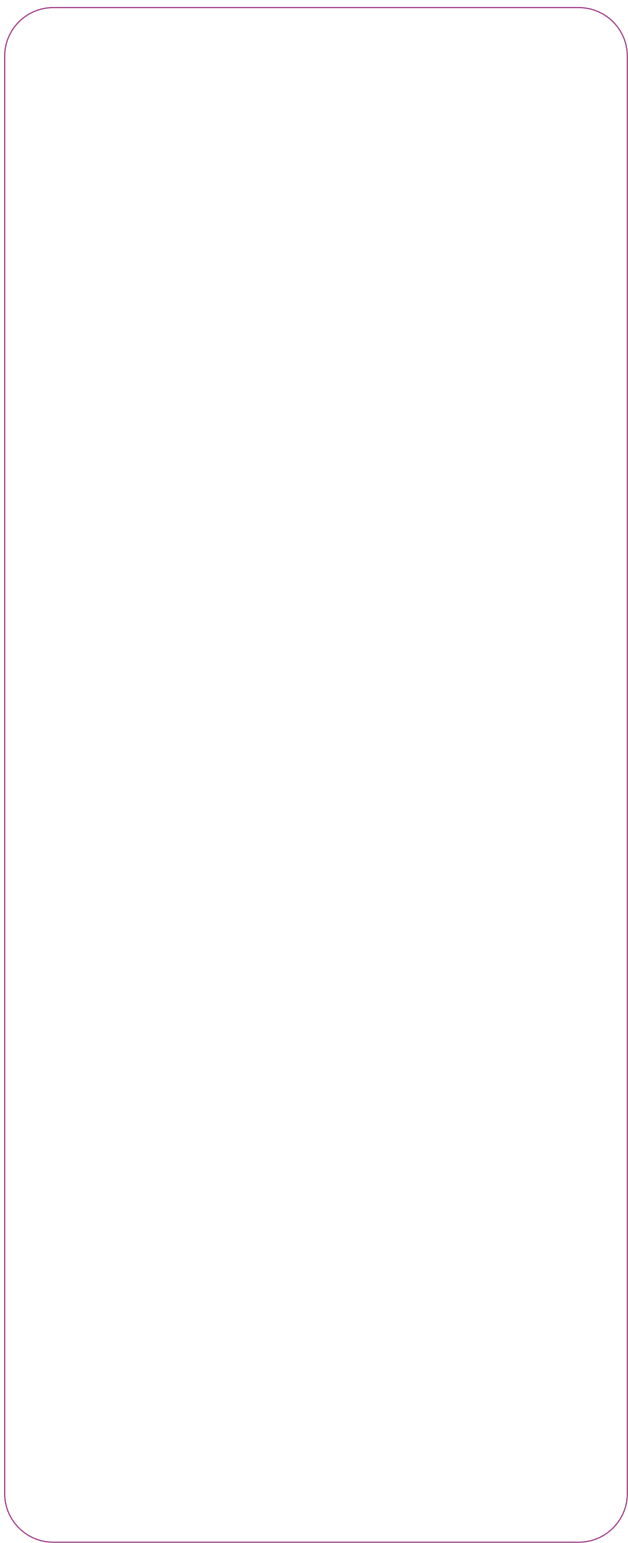
To contact the Canadian Cancer Society:

- Call an information specialist toll-free at **1 888 939-3333** Monday to Friday 9 a.m. to 6 p.m.
- E-mail us at [info@cis.cancer.ca](mailto:info@cis.cancer.ca).
- Visit our website at [www.cancer.ca](http://www.cancer.ca).
- Contact your local Canadian Cancer Society office.









## What we do

Thanks to the work of our volunteers and staff, and the generosity of our donors, the Canadian Cancer Society is leading the way in the fight against cancer. The Canadian Cancer Society:

- funds excellent research for all types of cancer
- advocates for healthy public policy
- promotes healthy lifestyles to help reduce cancer risk
- provides information about cancer
- supports people living with cancer

Contact us for up-to-date information about cancer, our services, or to make a donation.



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