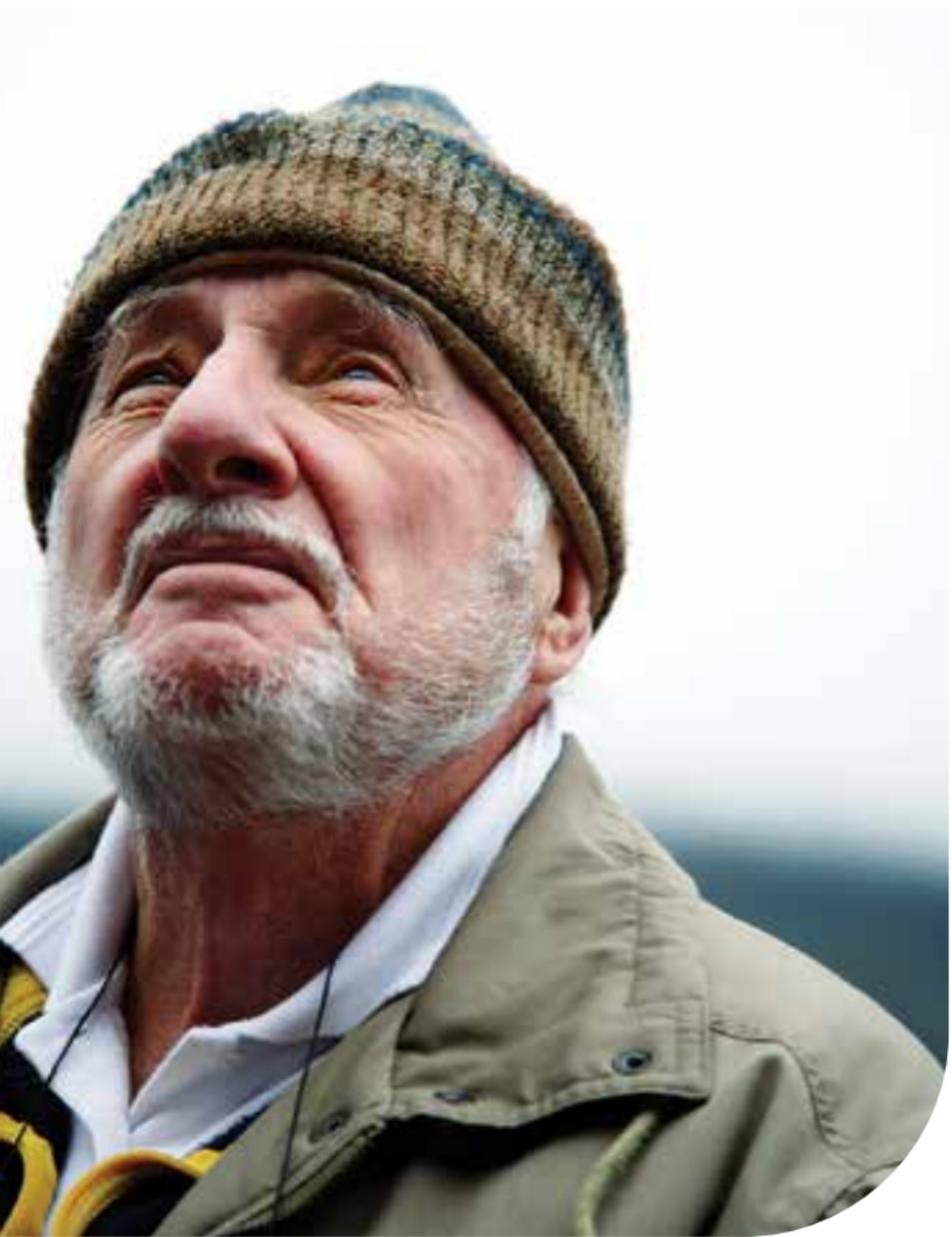




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# Non-Hodgkin Lymphoma

*Understanding your diagnosis*



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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 have to take in and the decisions you need to make.

“ *All I could hear was ‘cancer.’ I heard my doctor say something like, ‘We’re going to start your treatment as soon as possible.’ I didn’t hear one word after that.* ”

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

### **For more information**

The information in this brochure provides an introduction to non-Hodgkin lymphoma. More in-depth information is available on [cancer.ca](http://cancer.ca). You can also call our Cancer Information Service at 1-888-939-3333 to learn more about cancer, diagnosis, treatment, support and the services we offer.

Check out our video series on common cancer topics. These short, simple videos cover subjects like *What is cancer?* and *Coping when you’re first diagnosed*.

**Find the series at [cancer.ca/cancerbasics](http://cancer.ca/cancerbasics).**

## What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of trillions 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. But abnormal cells from the immune system or the blood do not always form solid tumours. These abnormal 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. Lymphocytes are cells of the lymphatic system. The lymphatic system works with other parts of your immune system to help your body fight infection and disease. It is made up of a network of lymph vessels, lymph nodes and the lymphatic organs (such as the spleen, thymus, tonsils and bone marrow).

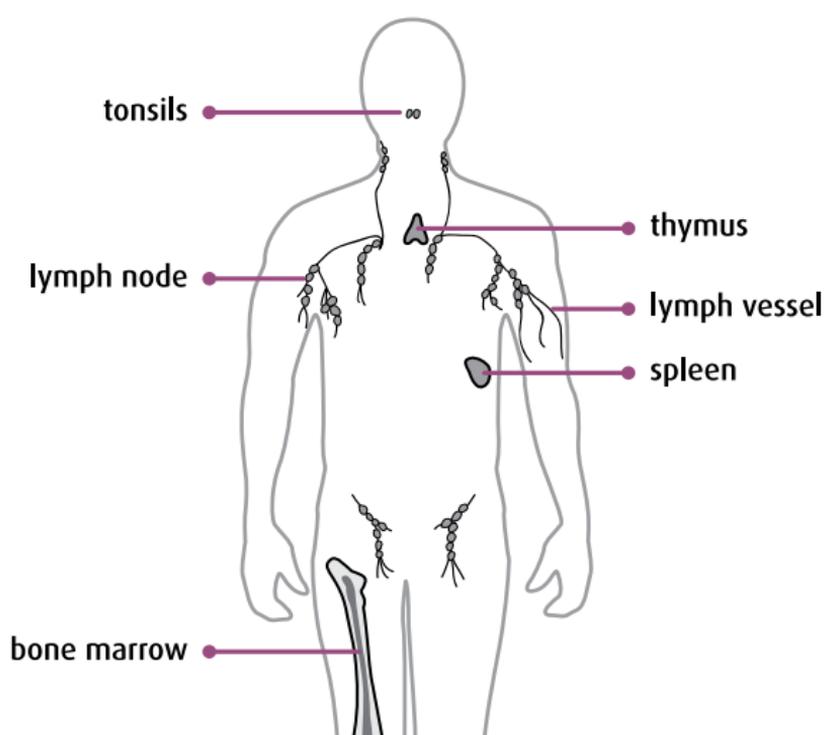
Lymph vessels carry lymph fluid, which is clear, yellowish fluid that contains lymphocytes. Lymphocytes are special white blood cells that help fight infection. They develop in the bone marrow from basic cells (called stem cells).

There are 2 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. You have clusters of lymph nodes in your neck, underarms, chest, abdomen and groin. Lymph nodes filter out waste, bacteria and unwanted cells, including cancer cells, as the lymph fluid passes through them. Lymph vessels collect lymph fluid from different tissues throughout the body, filter it through the lymph nodes and return it to the bloodstream.

## The Lymphatic System



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 called lymphomas. Non-Hodgkin lymphoma 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 30 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 to find out if the non-Hodgkin lymphoma developed from T cells or B cells so you get the treatment that works best for that type.

Another cancer that starts in the lymphatic system is Hodgkin lymphoma. The cells of Hodgkin lymphoma and non-Hodgkin lymphoma look different, behave differently and are treated differently.

## Diagnosing non-Hodgkin lymphoma

Your doctor may suspect you have non-Hodgkin lymphoma after taking your medical history and doing a physical exam. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to “stage” and “grade” the cancer and help plan the treatment.

**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 this swelling does not cause any pain, especially in the early stages. You may find 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:

- skin rash or itchy skin
- fatigue
- unexplained fever
- drenching night sweats
- unexplained weight loss

Other health problems can cause some of the same symptoms. The process of diagnosis may seem long and frustrating, but it is important for the doctor to make sure there are no other possible reasons for a health problem.

Your doctor will do one or more of the following tests to make a diagnosis.

**Lymph node biopsy:** A biopsy is usually needed to make a definite diagnosis of cancer. Cells are taken from the body and checked under a microscope. If the cells are cancerous, they are studied further to find out the 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.

- A surgical biopsy is an operation that is used if the enlarged lymph node cannot be easily reached with a needle. There are 2 types of surgical biopsies. An excisional biopsy removes the entire lymph node. An incisional biopsy removes only part of the lymph node. A surgical biopsy may be done with a local anesthetic (freezing) or under a general anesthetic (you will be unconscious).
- For a core needle biopsy, your doctor inserts a needle through a small cut in the skin to remove part of the lymph node. A local anesthetic is used to numb the area.

**Bone marrow aspiration and biopsy:** A bone marrow aspiration and biopsy may be done to see if the lymphoma has spread to the bone marrow. Bone marrow is the soft, spongy material in the centre of most bones (where blood cells are made). There are 2 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.

Aspirations and biopsies use a local anesthetic to freeze the area. It can be painful when cells are pulled into the syringe, but this lasts only a few seconds. Usually you will be an outpatient (you won't stay overnight) in a clinic or hospital where bone marrow aspirations and biopsies are done. Often an aspiration and biopsy will be done at the same time.

**Blood tests:** Blood is taken and studied to see if the different types of blood cells are normal in number and how they look. The results show how well your organs are working, in particular, the 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 for certain substances, such as lactate dehydrogenase (LDH). LDH is released into the blood by organs and tissues in the body. Some types of lymphoma can cause a higher level of LDH in the blood.

**Imaging studies:** Imaging studies let your healthcare team look at your tissues, organs and bones in more detail. Using x-rays, ultrasounds, CT scans, MRIs, bone scans or PET scans, they can get a picture of where the cancer is and see if it has spread. These tests are usually painless, and you don't need an anesthetic.

**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 cerebrospinal fluid to check for cancer cells. A needle is inserted between 2 vertebrae in the backbone, and a small amount of the fluid from around the spine 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 reduce the chance of getting a headache.

**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 and help plan your treatment.

### **Will I be OK?**

Most people with cancer want to know what to expect. Can they be cured?

A prognosis is your doctor's best estimate of how cancer will affect you and how it will respond to treatment. A prognosis looks at many factors including:

- the type, stage and grade of cancer
- the treatments chosen and how you respond to treatment
- your age, sex and overall health

Even with all this information, it can still be very hard for your doctor to say exactly what will happen. Each person's situation is different.

Your doctor is the only person who can give a prognosis. Ask your doctor about the factors that affect your prognosis and what they mean for you.

## Staging and grading

Once a definite diagnosis of cancer has been made, the cancer is given a stage and a grade. This information helps you and your healthcare team choose the best treatment for you.

The cancer stage describes the tumour size and tells whether it has spread.

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.

For non-Hodgkin lymphoma, there are 4 stages.\*

| Stage | Description   |
|-------|---|
| 1     | Cancer is found in only 1 group of lymph nodes or 1 nearby organ or area.   |
| 2     | Cancer is found in 2 or more groups of lymph nodes on the same side of the diaphragm (either above or below, but not both). The diaphragm is the muscle separating your chest and abdomen. Cancer may also be found in a nearby organ or area.  |
| 3     | Cancer is found in groups of lymph nodes both above and below the diaphragm. Cancer may also be found in a nearby organ or area.  |
| 4     | Cancer has spread to 1 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.<br><b>OR</b> cancer is found in only 1 organ outside of the lymphatic system, and it has spread to distant lymph nodes. |

\* The Ann Arbor system with Cotswolds revisions is the most common staging system for non-Hodgkin lymphoma.

As well as giving each stage a number, doctors may add a letter code to 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.
- **X** means the cancer is bulky. It is larger than one-third the width of the chest or at least 10 cm (4 in) across.
- **A** means you have no fever, night sweats or unexplained weight loss.
- **B** means you have fever, night sweats and unexplained weight loss.

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

There are 2 grades for non-Hodgkin lymphoma.

| Grade                | Description  |
|----------------------|--|
| indolent lymphomas   | Indolent lymphomas 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.   |

## Treatments for non-Hodgkin lymphoma

Your healthcare team considers your general health and the type, stage and grade of the cancer to recommend the best treatments for you. You'll work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

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

Some treatments may affect your ability to have children. Loss of fertility may be temporary or permanent, depending on your age and whether your testicles or ovaries receive radiation. Stem cell transplants and some of the chemotherapy drugs used to treat non-Hodgkin lymphoma may also cause fertility problems.

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 treatment right away. Instead, your doctor may suggest watchful waiting. This means your healthcare team will watch the cancer closely. You will visit your doctor regularly, usually every 3 months, for a physical exam. 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 uses drugs to treat cancer. Chemotherapy drugs may be given as pills or by injection (with a needle). They 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 a sore mouth, nausea, vomiting, loss of appetite, fatigue, hair loss or an increased risk of infection. Some drugs used for non-Hodgkin lymphoma may cause your skin to become darker.

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

**Biological therapy:** Biological therapy (sometimes called immunotherapy) uses your immune system to fight cancer or to help control side effects of cancer treatments. Natural body substances or drugs made from natural body substances 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, nausea and fatigue. More serious side effects are rare. Some people may have a severe skin rash, breathing problems, increased risk of infection 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 depend on what part of the body receives the radiation. You may feel more tired than usual, have some diarrhea or bladder problems, or notice changes to the skin (it may be red or tender) where the treatment was given.

**For more information on treatment**, you may want to read our booklets *Chemotherapy and Other Drug Therapies* and *Radiation Therapy*.

**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 needs 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 are 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 start to make blood cells.

A stem cell transplant can be 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 and effective for participants. Ask your doctor if any clinical trials are available as a suitable treatment option for you. You may benefit and so may future cancer patients.

**Our brochure** *Clinical Trials* has more information, including how to find a clinical trial.

**Complementary therapies:** Complementary therapies - for example, massage therapy or acupuncture - are used *together with* conventional cancer treatments, often to help ease tension and stress as well as other side effects of treatment. They don't treat the cancer itself. 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 enough for safety or effectiveness. Using alternative treatments alone for cancer may have serious health effects.

If you're thinking about using a complementary or alternative therapy, learn 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 other treatments.

### ***Side effects of treatments***

Some cancer treatments cause side effects, such as fatigue, hair loss or nausea. Because treatments affect everyone differently, it's hard to predict which side effects - if any - you may have.

Side effects can often be well managed and even prevented. If you're worried about side effects, tell your healthcare team about your concerns and ask questions. They can tell you which side effects you should report right away and which ones can wait until your next appointment.

If you notice any side effects or symptoms that you didn't expect, talk to a member of your healthcare team as soon as possible. They'll help you get the care and information you need.

## 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 after treatment, and less often after that. After treatment has ended, 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.

**Self-image and sexuality:** It's natural to be concerned about the effects of non-Hodgkin lymphoma and its treatment on your sexuality. You may be worried about how your body looks after treatment, about having sex with a partner or that you may be rejected. It may help to talk about these feelings with someone you trust. Your doctor can also refer you to specialists and counsellors who can help you with the emotional side effects of non-Hodgkin lymphoma treatment.

**Our booklet** *Sex, Intimacy and Cancer* has more detailed information.

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're worried about your treatment ending, talk to your healthcare team. They're there to help you through this transition period.

## Living with cancer

**Our booklet** *Coping When You Have Cancer* has more detailed information and resources.

Many sources of help are 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:** People 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 drive you to your doctor's office.

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

**Yourself:** Coping well with cancer doesn't mean that you have to be happy or cheerful all the time. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically. Take some time to find coping strategies to help you through this experience. You may also want to talk to a counsellor for more help.

### **Talking to someone who's been there**

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at [match.cancer.ca](http://match.cancer.ca) or call us at 1-888-939-3333.

### **Want to connect with people online?**

If you'd like to join our online community, visit [CancerConnection.ca](http://CancerConnection.ca). You can read news, join discussion groups, get support and help others at the same time. You'll find caring, supportive people there.

## What causes non-Hodgkin lymphoma?

There is no single cause of non-Hodgkin lymphoma, but some factors increase the risk of developing it. Some people can develop non-Hodgkin lymphoma without any risk factors, while others who have these factors do not get it. The risk increases with age, and it is more common in men than women.

Risk factors for non-Hodgkin lymphoma include:

- having a weakened immune system due to:
  - > taking immunosuppressant drugs after an organ transplant
  - > HIV/AIDS
  - > immunodeficiency disorders such as ataxia-telangiectasia or Wiskott-Aldrich syndrome
  - > autoimmune diseases such as Sjogren's syndrome or rheumatoid arthritis
- infections such as human T-cell leukemia/lymphoma virus (HTLV-1), Epstein-Barr virus or *Helicobacter pylori* (a bacteria)
- previous treatment with radiation or chemotherapy

## Canadian Cancer Society

*We're here for you.*

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

**Call our toll-free number 1 888 939-3333.**



**Ask** a trained cancer information specialist your questions about cancer. Call us or email [info@cis.cancer.ca](mailto:info@cis.cancer.ca).



**Connect** with people online to join discussions, get support and help others. Visit [CancerConnection.ca](http://CancerConnection.ca).



**Browse** Canada's most trusted online source of information on all types of cancer. Visit [cancer.ca](http://cancer.ca).

Our services are free and confidential. Many are available in other languages through interpreters.

### **Tell us what you think**

Email [cancerinfo@cancer.ca](mailto:cancerinfo@cancer.ca) and tell us how we can make this publication better.





## What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

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



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