

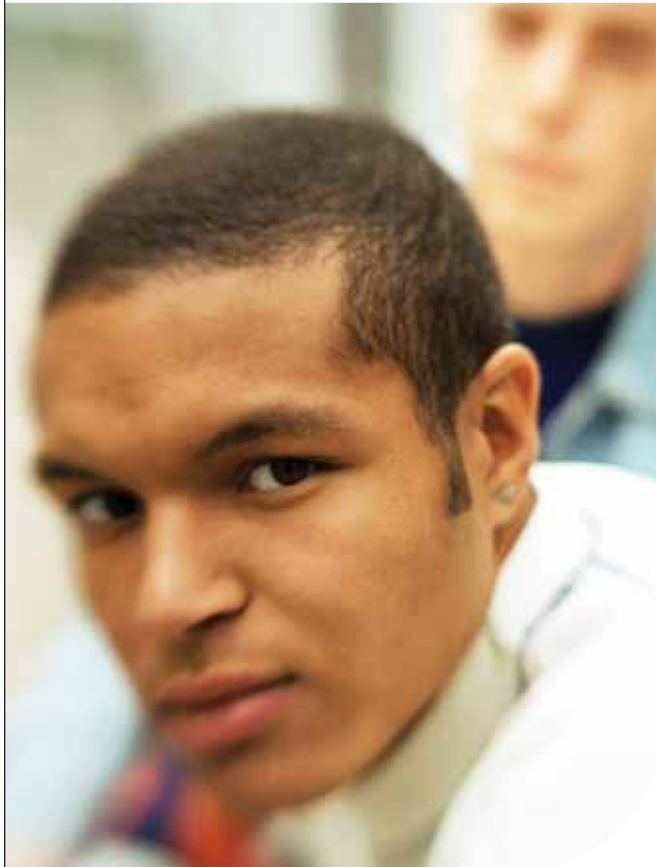


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Hodgkin Lymphoma

Understanding your diagnosis



Let's Make Cancer History

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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 Hodgkin lymphoma (also called *Hodgkin's disease*).* 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.

* This brochure is about Hodgkin lymphoma in adults. For information about Hodgkin lymphoma in children, please contact our *Cancer Information Service* at 1 888 939-3333.

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 do not always form solid tumours. These abnormal cells circulate in the blood, bone marrow and lymphatic system.

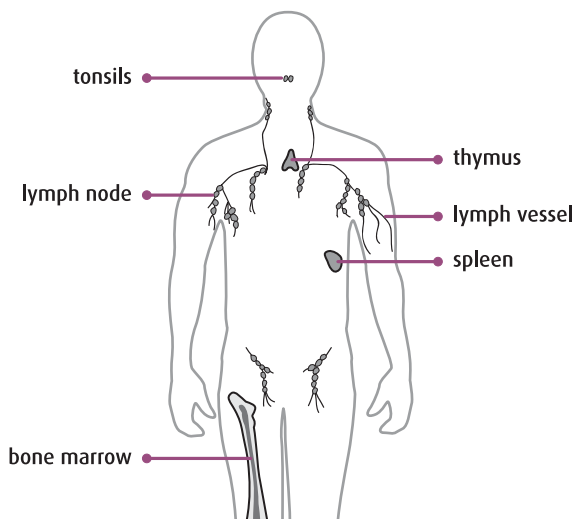
What is Hodgkin lymphoma?

Hodgkin lymphoma is cancer that starts in the lymphocytes, the cells of the lymphatic system. The lymphatic system works with 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. *Lymph nodes* are small bean-shaped glands. Clusters of lymph nodes are found in your neck,

underarms, chest, abdomen and groin. The 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.

Hodgkin lymphoma can begin in almost any part of the body. It usually starts in a group of lymph nodes in one part of the body – most often the neck – and grows in a predictable, orderly way from one lymph node group to the next. Eventually, it can spread to almost any tissue or organ in the body through the lymphatic system or the bloodstream.



Other cancers of the lymphatic system are called non-Hodgkin lymphomas.* The cells of Hodgkin lymphoma and non-Hodgkin lymphoma look different, behave differently and are treated differently.

Causes of Hodgkin lymphoma

Most people with Hodgkin lymphoma are between 15 and 35, or older than 55. It affects more men than women. There is no single cause of Hodgkin lymphoma, but some factors increase the risk of developing it:

- Epstein-Barr virus
- family history of Hodgkin lymphoma (especially in a parent, sister or brother)

Some people develop Hodgkin lymphoma without any of these risk factors.

Symptoms of Hodgkin lymphoma

The most common symptom of Hodgkin lymphoma is swelling of the lymph nodes in the neck, underarm or chest. This swelling is usually painless. 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

* For information about non-Hodgkin lymphoma, please contact our *Cancer Information Service* at 1 888 939-3333.

Often, these signs or symptoms are not caused by 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 Hodgkin lymphoma

After taking your medical history and completing a physical examination, your doctor may suspect you have Hodgkin lymphoma. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to “stage” 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 show how well organs are working, in particular those organs that make blood cells, like the spleen and bone marrow. Abnormal test results may suggest whether or not you have cancer.

Imaging studies: Imaging studies allow tissues, organs and bones to be looked at in more detail. Using x-rays, ultrasounds, CT scans, 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.

Biopsy: A biopsy is usually necessary to make a definite diagnosis of cancer. To confirm a diagnosis of Hodgkin lymphoma, all or part

of a lymph node will be removed. The tissue sample is checked under a microscope for Reed-Sternberg cells. Reed-Sternberg cells are large, abnormal cells usually found with Hodgkin lymphoma. If the cells are cancerous, they may be studied further to see how fast they are growing.

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

- A *surgical biopsy* is the most common type of biopsy for Hodgkin lymphoma. 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 (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 a sample of tissue from the lymph node. A local anesthetic will be used to numb the area.
- For a *laparoscopy*, a thin, flexible tube with a light and camera at the end is inserted through a small cut in the abdomen. Your doctor will look around the abdomen and may take several small biopsy samples from the lymph nodes or from the liver. This may be done with a local anesthetic or general anesthetic. A laparoscopy may be used if the signs of lymphoma are in your abdomen or pelvis.

Further testing: If the initial diagnostic tests show that you have Hodgkin lymphoma, your doctor may order more blood tests, imaging studies and possibly more biopsies of lymph nodes, the liver or bone marrow to find out if the cancer has spread.

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 in a clinic or hospital on an outpatient basis (you will not stay overnight).

Staging

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.

The cancer stage for Hodgkin lymphoma describes where the cancer is and tells whether it has spread beyond the place where it started to grow. The Ann Arbor system is the most common staging system for Hodgkin 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 help 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.

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

Treatments for Hodgkin lymphoma

Your healthcare team will consider your age, general health and the type and stage of the lymphoma, as well as which symptoms you have, 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 Hodgkin lymphoma, you might receive one or more of the following treatments.

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 can be combined with chemotherapy to treat Hodgkin lymphoma. Radiation may be given either before or after chemotherapy.

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.

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. Chemotherapy for Hodgkin lymphoma may be given alone or with radiation therapy.

Stem cell transplant: Sometimes high doses of chemotherapy are used to treat Hodgkin lymphoma, usually if the cancer comes back after treatment. High-dose chemotherapy destroys the bone marrow 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.

A stem cell transplant is a very 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 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.

For many people, treatment will completely cure Hodgkin lymphoma. Occasionally, it 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.

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, our services or to make a donation.



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