What You Need <u>To Know About</u> Hodgkin Lymphoma

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health

How Can We Help?

You may want information about cancer for yourself, your family, and your friends.

- Call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237)
- Visit us at http://www.cancer.gov or http://m.cancer.gov/ (mobile)
- Chat using LiveHelp, NCI's instant messaging service, at http://www.cancer.gov/livehelp
- Email us at cancergovstaff@mail.nih.gov
- Order publications at http://www.cancer.gov/publications or by calling 1-800-4-CANCER (1-800-422-6237)
- Get help with quitting smoking at 1-877-44U-QUIT (1-877-448-7848)
- Follow us on Facebook f Twitter YouTube a RSS

About This Booklet

This National Cancer Institute (NCI) booklet is for you someone who has just been diagnosed with **Hodgkin lymphoma**. This type of **cancer** starts in the **lymph system**. Another name for this cancer is Hodgkin disease.

Words that may be new to you are shown in **bold**. See the **Words To Know** on page 25 to learn what a new word means and how to pronounce it.

This booklet is about medical care for people with Hodgkin lymphoma. Learning about medical care for this disease can help you take an active part in making choices about your care.

You can read this booklet from front to back. Or, you can read only the sections you need right now.

This booklet has lists of questions that you may want to ask your doctor. Many people find it helpful to take a list of questions to a doctor visit. To help remember what your doctor says, you can take notes. You may also want to have a family member or friend go with you when you talk with the doctor—to take notes, ask questions, or just listen.

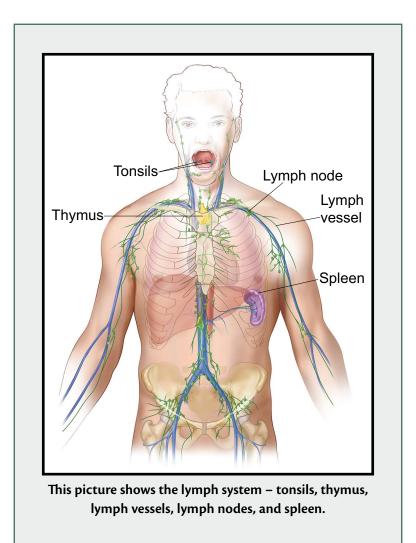
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The Lymph System

The lymph (lymphatic) system helps the body fight infections and other diseases. It's made up of **tissue** and **organs**:

- Lymph vessels: The lymph system has a network of lymph vessels. Lymph vessels branch into all the tissues of the body.
- Lymph: Lymph vessels carry clear fluid (lymph).
 Lymph contains white blood cells, especially lymphocytes such as B cells and T cells.
- Lymph nodes: Lymph vessels are connected to small, round organs called lymph nodes. Groups of lymph nodes are found in the neck, armpits, chest, abdomen, and groin. Lymph nodes store white blood cells. They trap and remove harmful substances that may be in lymph.
- Other parts of the lymph system: Other parts of the lymph system include the tonsils, thymus, and spleen. Lymph tissue is also found in other parts of the body including the stomach, skin, and small intestine.



Hodgkin Lymphoma

Hodgkin lymphoma starts in the lymph system, usually in a lymph node. The disease may be found because of a swollen lymph node in the neck, chest, or other areas.

The disease begins when a lymphocyte (almost always a B cell) becomes abnormal. The abnormal cell divides to make copies of itself. The copies keep dividing, making more abnormal cells that build up.

When white blood cells collect around the abnormal cells, the lymph node that contains abnormal cells becomes swollen. Abnormal cells may spread through the lymph vessels or blood vessels to other parts of the body.

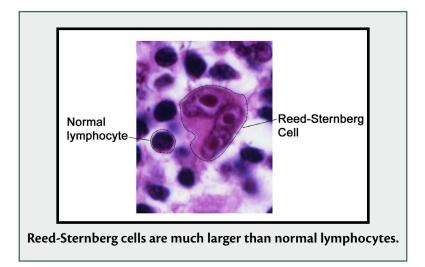
Although normal cells die when they get old or damaged, abnormal cells don't die. Also unlike normal cells, abnormal cells can't help the body fight infections.

Types of Hodgkin Lymphoma

In 2013, more than 9,000 Americans will be diagnosed with Hodgkin lymphoma. About 4,000 of these people will be children, teens, and adults younger than 35 years old.

Classical type

Most people diagnosed with Hodgkin lymphoma have the classical type. In 2013, about 8,550 Americans will be diagnosed with this type. In classical Hodgkin lymphoma, the abnormal cell is called a **Reed-Sternberg cell**. See photo of the large cell below.



Other abnormal cells may also be found in people with classical Hodgkin lymphoma. These cells are called Hodgkin cells. They are larger than normal lymphocytes but smaller than Reed-Sternberg cells.

Rare type

In 2013, about 450 Americans will be diagnosed with **lymphocyte-predominant Hodgkin lymphoma**. In this rare type of Hodgkin lymphoma, the abnormal cell is called a lymphocyte-predominant cell, and the treatment options are different.

Staging Tests

After you learn that you have Hodgkin lymphoma, you may need other tests to help with making decisions about treatment. Staging tests can show the stage (extent) of disease, such as whether lymphoma cells are found in more than one group of lymph nodes.

Lymphoma cells usually spread from one group of lymph nodes to the next. For example, Hodgkin lymphoma that starts in lymph nodes in the neck may spread first to lymph nodes above the collarbones, and then to lymph nodes under the arms and within the chest.

In time, lymphoma cells can invade blood vessels and spread to almost any other part of the body. For example, they can spread to the liver, lungs, bone, and **bone marrow**.

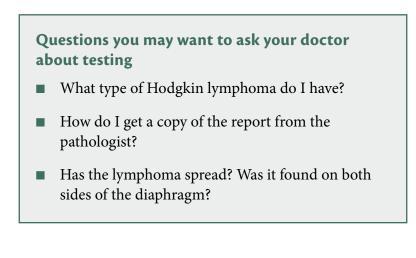
Staging tests may include:

- CT scan: Your doctor may order a CT scan of your neck, chest, abdomen, and pelvis. An x-ray machine linked to a computer will take a series of detailed pictures of these areas. You'll receive contrast material by mouth and by injection into a blood vessel in your arm or hand. The contrast material makes swollen lymph nodes and other abnormal areas easier to see. The pictures can show whether Hodgkin lymphoma has spread.
- PET scan: Your doctor may use a PET scan to find Hodgkin lymphoma that has spread. You'll receive an injection of a small amount of radioactive sugar. A machine makes computerized pictures of cells in your body that have taken up the radioactive sugar.

Because lymphoma cells take up sugar faster than do normal cells, areas with lymphoma cells look brighter on the pictures.

Bone marrow biopsy: To check for lymphoma cells in the bone marrow, your doctor will use a thick needle to remove a small sample of bone and bone marrow from your hipbone or another large bone. Local anesthesia can help control pain.

Other staging tests may include biopsies of lymph nodes or other tissue.



Stages

The stage of Hodgkin lymphoma depends mainly on:

- The number and location of lymph nodes that have Hodgkin lymphoma cells
- Whether the disease has spread to the spleen, liver, bone marrow, lung, or bone

Stages of Hodgkin lymphoma

Doctors describe the stages of Hodgkin lymphoma using the Roman numerals I, II, III, and IV. Stage I is **early-stage cancer**, and Stage IV is **advanced cancer**, such as Hodgkin lymphoma that has spread to the liver.

Stage I

Lymphoma cells are in one lymph node group (such as the lymph nodes in the neck or armpit). Very rarely, Hodgkin lymphoma may start somewhere in the body other than a lymph node and lymphoma cells are found in only that one part.

Stage II

Lymphoma cells are in at least two lymph node groups, but both groups are on the same side of the **diaphragm**. Or, lymphoma cells are in one part of a tissue or an organ and the lymph nodes near that organ on the same side of the diaphragm. Lymphoma cells may be in other lymph node groups on the same side of the diaphragm.

Stage III

Lymphoma cells are in lymph nodes on both sides of the diaphragm. Lymphoma cells may also be found in one part of a tissue or an organ near these lymph node groups or in the spleen.

Stage IV

Lymphoma cells are found in several parts of at least one organ or tissue. Or, lymphoma cells are in an organ (such as the liver, lung, or bone) and in lymph nodes on the other side of the diaphragm.

A, B, E, and S

In addition to using the Roman numerals I, II, III, and IV, doctors describe the stages of Hodgkin lymphoma with the letters A, B, E, and S.

A and B

Your doctor may describe the stage as A or B:

- A (without symptoms): You have not had symptoms, such as weight loss, drenching night sweats, or fevers.
- **B (with symptoms)**: You have had symptoms, such as weight loss, drenching night sweats, or fevers.

E and S

Your doctor may describe the stage with an E, S, or both letters:

- E (outside the lymph system): Lymphoma is found in tissues outside the lymph system, such as in liver or lung tissue. Other less common places to find lymphoma include the bone, bone marrow, skin, digestive tract, kidneys, ovaries, or testicles. For example, the stage may be IIE.
- **S (in the spleen)**: Lymphoma is found in the spleen. For example, the stage may be IIIS.



You and your doctor will develop a treatment plan.

Treatment

People with Hodgkin lymphoma have many treatment options. Treatment options include:

- Chemotherapy
- Targeted Therapy
- Radiation Therapy
- Stem Cell Transplant

The treatment that's right for you depends mainly on the type of Hodgkin lymphoma (most people have classical Hodgkin lymphoma), where the lymphoma was found in your body (its stage), and whether you've had weight loss, drenching night sweats, or fevers. It also may depend on whether you have a tumor that is bigger than 10 centimeters (4 inches). You may receive more than one type of treatment, such as chemotherapy and radiation therapy.

At any time, care is available to prevent infections, control pain, relieve the **side effects** of treatment, and ease emotional concerns. You can get information about coping on NCI's website at **http://www.cancer.gov/cancertopics/coping**.

Also, you can get information about coping from NCI's Cancer Information Service at **1–800–4–CANCER** (**1–800–422–6237**). Or, chat using NCI's instant messaging service, LiveHelp (https://livehelp.cancer.gov).

Doctors Who Treat Hodgkin Lymphoma

Whenever possible, people should be treated at a medical center that has doctors experienced in treating Hodgkin lymphoma. If this isn't possible, your doctor may discuss the treatment plan with a specialist at such a center.

Resources are available to help you find doctors who treat Hodgkin lymphoma:

- Your doctor may be able to refer you to specialists.
- You can ask a hospital, medical school, or medical society for names of specialists near you.

- NCI's Cancer Information Service can give you information about treatment centers near you. Call 1-800-4-CANCER (1-800-422-6237). Or, chat using LiveHelp (https://livehelp.cancer.gov), NCI's instant messaging service.
- Other sources can be found in the NCI fact sheet *How To Find a Doctor or Treatment Facility If You Have Cancer.*

Your health care team may include the following specialists:

- Medical oncologist: A medical oncologist is a doctor who specializes in treating Hodgkin lymphoma and other cancers with chemotherapy, targeted therapy, and stem cell transplants.
- Radiation oncologist: A radiation oncologist is a doctor who specializes in treating Hodgkin lymphoma and other cancers with radiation therapy.

Your health care team may also include an **oncology nurse**, a **social worker**, and a **registered dietitian**.

Ask your health care team about your treatment options, the expected results of each option, and possible side effects. Because cancer treatments often damage healthy cells and tissues, side effects are common. These side effects depend on many factors, including the type of treatment. The specific side effects may not be the same for everyone, and they may even change from one treatment session to the next.

You may want to talk with your doctor about taking part in a research study (**clinical trial**) of new treatment methods. Research studies are an important option for people with Hodgkin lymphoma. See the **Treatment Clinical Trials** section on page 14.

Questions you may want to ask your doctor about treatment options What are my treatment options? Which do you recommend for me? Why? What are the expected benefits of each kind of treatment? What are the risks and possible side effects of each treatment? How can side effects be managed? What can I do to prepare for treatment? What is the treatment likely to cost? Will my insurance cover it? How will treatment affect my normal activities? Would a treatment research study be right for me?

Second Opinion

Before starting treatment, you might want a second opinion about your diagnosis and treatment options. Some people worry that the doctor will be offended if they ask for a second opinion. Usually the opposite is true. Most doctors welcome a second opinion. And many health insurance companies will pay for a second opinion if you or your doctor requests it. Some insurance companies actually require a second opinion.



You may want to get a second opinion before starting treatment.

If you get a second opinion, the second doctor may agree with your first doctor's diagnosis and treatment recommendation. Or, the second doctor may suggest another approach. Either way, you have more information and perhaps a greater sense of control. You can feel more confident about the decisions you make, knowing that you've looked at all of your options.

It may take some time and effort to gather your medical records and see another doctor. In most cases, it's not a problem to take several weeks to get a second opinion. The delay in starting treatment usually will not make treatment less effective. To make sure, you should discuss this delay with your doctor. Some people with Hodgkin lymphoma need treatment right away.

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