If You Have Hodgkin Lymphoma

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What is Hodgkin lymphoma?

Hodgkin lymphoma, sometimes called Hodgkin disease, is a cancer that starts in the lymph system in white blood cells called lymphocytes. This cancer can start almost any place in the body.
The lymph system

Ask your doctor to use this picture to show you where the Hodgkin lymphoma is located

Types of lymphoma

The 2 kinds of lymphoma are:

- Hodgkin lymphoma (named after Dr. Thomas Hodgkin, who first found it)
- Non-Hodgkin lymphoma
These types of lymphomas are not treated the same way. Be sure to ask your doctor what kind of lymphoma you have.

The lymph system and lymphocytes

The lymph system, also known as the lymphatic system, is part of the immune system. (The immune system is how the body fights germs and some diseases.) The lymph system is a network of lymph nodes and certain body parts, such as the spleen, tonsils, and thymus. The parts of the lymph system are connected by tube-like lymph vessels.

Lymph nodes are small, bean-shaped sacs all over the body that help clean germs and cell waste out of the body. Hodgkin lymphoma often starts in lymph nodes, which can be nearly anywhere in the body.

Lymph nodes are made up mainly of lymphocytes, which are a kind of white blood cell. The main types of lymphocytes are B lymphocytes (B cells) and T lymphocytes (T cells). Hodgkin lymphoma almost always starts in B lymphocytes.

Types of Hodgkin lymphoma

There are a few types of Hodgkin lymphoma. The type can affect which treatments are likely to work best. Your doctor can tell you about the kind of Hodgkin lymphoma you have.

Questions to ask the doctor

• Why do you think I have Hodgkin lymphoma?
• Is there a chance I don’t have Hodgkin lymphoma?
• Would you please write down the kind of Hodgkin lymphoma you think I have?
• What will happen next?

How does the doctor know I have Hodgkin lymphoma?

Hodgkin lymphoma might cause symptoms like:

• Lumps or bumps under the skin (swollen lymph nodes) that don’t go away
• Fever
• Sweating a lot at night
Losing weight when you're not trying to
Itching a lot

Be sure to go for a check-up if you have any of these symptoms.

The doctor will ask you questions about your health and do an exam. The doctor will feel the lymph nodes and other body parts that may be affected. If signs are pointing to Hodgkin lymphoma, more tests will be done. Here are some of the tests you may need:

Tests that may be done

Biopsy: In this test, the doctor takes out a lymph node or a little bit of tissue to check it for cancer cells. This is often done in a hospital under local anesthesia. This means you’re awake but it’s numb around the lymph node. You may also be given medicine to make you sleepy.

A biopsy is the only way to tell for sure if you have Hodgkin lymphoma. There are many types of biopsies. Ask your doctor what kind you will need. Each type has pros and cons. The choice of which type to use depends on your own case.

Blood tests: Certain blood tests can tell the doctor more about the levels of different types of cells and chemicals in your blood.

Bone marrow aspiration and biopsy: If Hodgkin lymphoma has been found, these tests are done sometimes to tell if it has reached the bone marrow (the soft, inner part of some bones). A doctor uses thin, hollow needles to take out a little bit of bone marrow, most often from the hip bone. The area around the bone is numbed, and you may be given a drug to make you sleep during the test. The samples are sent to a lab to see if there are Hodgkin cells in the bone marrow.

Chest x-rays: X-rays may be done to look for swollen lymph nodes in the chest.

CT scan: This is also called a CAT scan. It’s a kind of x-ray that takes clear pictures to look for swollen lymph nodes or other body parts.

MRI scan: MRIs use radio waves and strong magnets instead of x-rays to take clear pictures. MRIs may be used to look at the spinal cord and brain if the doctor thinks the Hodgkin lymphoma may have spread there.

PET scan: In this test, you are given a type of sugar that can be seen inside your body with a type of camera. If there is cancer, this sugar shows up as “hot spots” where the
cancer is found. This test can help show where Hodgkin lymphoma has spread.

**Questions to ask the doctor**

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

**How serious is my lymphoma?**

If you have Hodgkin lymphoma, the doctor will want to find out how far it has spread. This is called staging. You may have heard someone say that their cancer was stage 1 or stage 2. Your doctor will want to find out the stage of your Hodgkin lymphoma to help decide what type of treatment is best for you.

The stage describes where and how much the Hodgkin lymphoma has spread in your body.

Hodgkin lymphoma can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number means a worse lymphoma that has spread farther. Be sure to ask the doctor about the stage of your lymphoma and what it means for you.

**Questions to ask the doctor**

- Do you know the stage of my Hodgkin lymphoma?
- If not, how and when will you find out the stage?
- Would you explain to me what the stage means in my case?
- Based on the stage of my lymphoma, how long do you think I'll live?
- What will happen next?

**What kind of treatment will I need?**

Most people with Hodgkin lymphoma will get chemotherapy often along with radiation. The treatment plan that is best for you will depend on:
• The type and stage of Hodgkin lymphoma
• The chance that a type of treatment will cure the lymphoma or help in some other way
• Your age and overall health
• Your feelings about the treatment and the side effects that come with it

Chemo

Chemo is the short word for chemotherapy — the use of drugs to fight cancer. The drugs may be given into a vein or taken as pills. These drugs go into the blood and spread all over the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 4 or more chemo drugs are given. Treatment often lasts for many months.

Side effects of chemo

Chemo can have many side effects, like:

• Hair loss
• Mouth sores
• Not feeling like eating
• Diarrhea
• Feeling sick to your stomach and throwing up
• Getting a lot of infections
• Getting black and blue marks and bleeding easily
• Feeling very tired

These problems tend to go away after treatment ends. There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

Radiation treatments

Radiation uses high-energy rays (like x-rays) to kill cancer cells. In some cases, it’s given along with chemo.

For Hodgkin lymphoma, radiation is aimed at the cancer from a machine outside the body. This is called external beam radiation. Radiation therapy works better when the
lymphoma is only in one part of the body. Ask your doctor if radiation is part of your treatment plan.

**Side effects of radiation treatments**

If your doctor says you should have radiation, talk about what side effects might happen. Side effects depend on the part of the body that’s treated. The most common side effects of radiation are:

- Skin changes where the radiation is given, such as redness or getting blisters
- Feeling very tired

Most side effects get better after treatment ends. But some side effects might last longer, or might not show up until years later. Talk to your cancer care team about what you can expect.

**Stem cell transplant**

A stem cell transplant (SCT) lets doctors use very high doses of chemo to kill the Hodgkin cells. The high doses of these drugs destroy the bone marrow, which is where new blood cells are made. Although the drugs destroy the bone marrow, stem cells given after chemo can bring back the blood cell-making bone marrow stem cells. There are different kinds of SCT, each of which can have bad side effects. Ask your doctor which type you will have and what to expect.

**Monoclonal antibodies**

Monoclonal antibodies are man-made types of immune system proteins (antibodies) that are given into a vein (IV). Once in the blood, they can attach to a certain place on Hodgkin cells. This can help kill the cells or tell them to die.

These drugs can be given alone or along with chemo. There are different kinds of monoclonal antibodies. Each one can cause different side effects, so ask your doctor what you can expect.

**Clinical trials**

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.
If you'd like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that’s studying the kind of cancer you have, it’s up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

What about other treatments that I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you’re thinking about using, whether it’s a vitamin, a diet, or anything else.

Questions to ask the doctor

- Do I need treatment right away?
- What treatment do you think is best for me?
- What’s the goal of this treatment? Do you think it could cure the lymphoma?
- Will I need other types of treatment, too?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What’s the next step?

What will happen after treatment?

Even if you have completed treatment, your doctors will still want to watch you closely. It’s very important to go to all your follow-up visits. Follow-up care will be needed for
many years after treatment for Hodgkin lymphoma.

During these visits, the doctor will ask about symptoms, do physical exams, and may order blood tests or tests that take pictures inside your body such as CT or PET scans. Most people need doctor visits and tests every few months for the first few years after treatment. Then the longer you’re cancer-free, the less often the visits are needed.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to better your health. Call us at 1-800-227-2345 or talk to your cancer care team to find out what you can do to feel better.

You can’t change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

**For connecting and sharing during a cancer journey**

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN)\(^3\), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge\(^4\), a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

**Hyperlinks**

1. [www.cancer.org/treatment/understanding-your-diagnosis/tests.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests.html)
4. [www.caringbridge.org/](http://www.caringbridge.org/)
5. [www.cancer.org](http://www.cancer.org)

**Words to know**

**Biopsy** (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells in it.

**Immune system**: The body system that fights infection.

**Lymph (limf) nodes**: Small, bean-shaped collections of immune system tissue found all
over the body and connected by lymph vessels; also called lymph glands.

**Lymph system:** The tissues and organs (including lymph nodes, spleen, thymus, and bone marrow) that make and store **lymphocytes** (white blood cells that fight infection) and the channels or vessels that carry the lymph fluid; also known as the **lymphatic system**.

**Lymphocyte** (LIM-fo-site): A type of white blood cell that helps fight infection; also the cell in which Hodgkin lymphoma starts.

**Lymphoma** (lim-FOAM-uh): A cancer that starts in the **lymph system**, a network of thin vessels and nodes throughout the body that helps to fight infection. The 2 main types of lymphoma are **Hodgkin lymphoma (Hodgkin disease)** and **non-Hodgkin lymphoma**.

**How can I learn more?**

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org)⁵. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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