
EASY READING

If You Have Non-Hodgkin Lymphoma

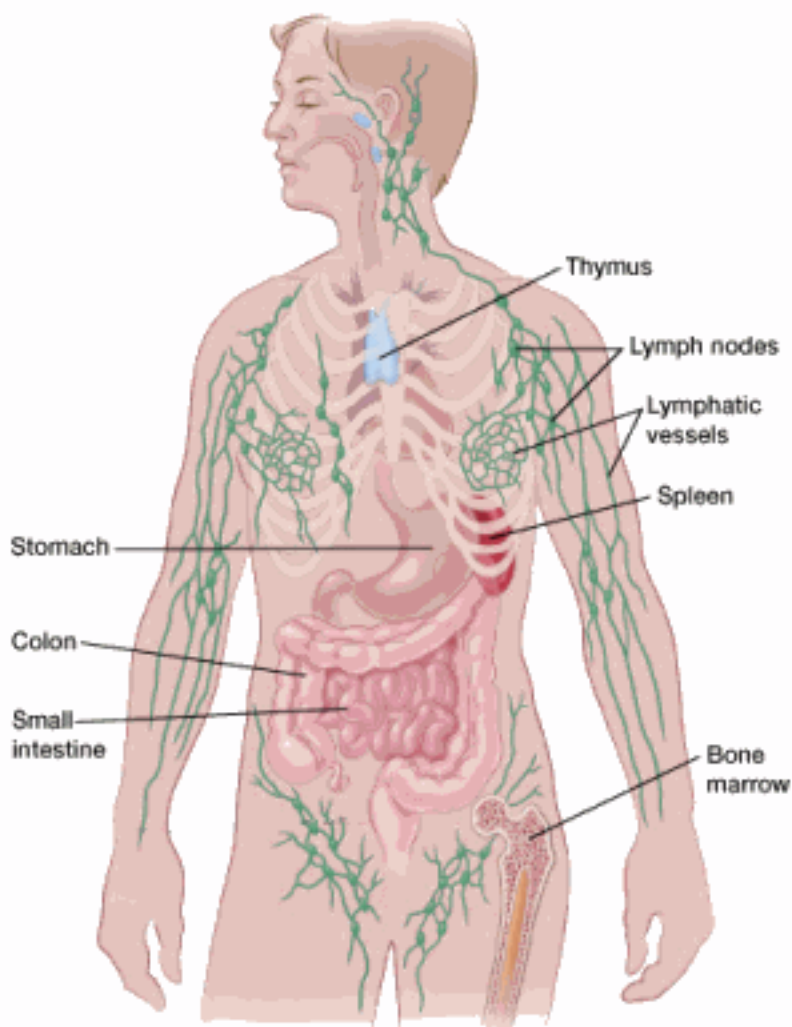
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What is non-Hodgkin lymphoma?

Non-Hodgkin lymphoma (NHL) is a cancer that affects the body's lymph system (also known as the *lymphatic system*). The lymph system is part of the immune system, which helps fight infections and some other diseases. It also helps fluids move through the body.

NHL can start any place in the body where lymph tissue is found, including the lymph nodes (small bean-shaped sacs that help filter germs) and tonsils, and inside bones and certain organs.



The lymphatic system Ask your doctor to use this picture to show you where the lymphoma is

Types of non-Hodgkin lymphoma

NHL is a term that's used for [many different types of lymphoma](#)¹ that have certain things in common. (There is another kind of cancer that affects the lymph system called [Hodgkin lymphoma](#)², but it needs different kinds of treatment.)

Types of NHL are named based on the type of cell they start in. The most common types start in B cells (also called B lymphocytes), which are a type of white blood cell that make antibodies to help fight infections. Other types of NHL start in T cells (also called T lymphocytes) which are white blood cells that destroy germs and help other

immune system cells.

There are many types of NHL, and some are very rare, so talk to your doctor to learn about the type you have. The two most common types in the US are:

- Diffuse large B-cell lymphoma
- Follicular lymphoma

Questions to ask the doctor

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

How does the doctor know I have non-Hodgkin lymphoma?

The first sign of NHL is often a lump under the skin that doesn't go away. Or you might just not feel well and go in for a check-up.

The doctor will ask you questions about your health and do a physical exam. The doctor will feel the lymph nodes and other organs that may be affected. Swollen or hard lymph nodes are a common sign of non-Hodgkin lymphoma.

Tests that may be done

If signs are pointing to non-Hodgkin lymphoma, more tests will be done. Here are some of the [tests you may need](#)³:

Biopsy: A biopsy is the only way to tell for sure if you have non-Hodgkin lymphoma. In this test, the doctor takes out a lymph node or a small piece of tissue to check it for cancer cells. There are many different ways to do a biopsy, so talk to your doctor about the type you will need. 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.

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

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

CT scan: This is also called a “CAT scan.” It’s a special kind of x-ray that takes detailed pictures to look for swollen lymph nodes or other organs.

MRI scan: MRIs use radio waves and strong magnets instead of x-rays to take detailed pictures. An MRI might be done to look at the spinal cord and brain if your doctor thinks the lymphoma might have spread there.

Ultrasound: A small wand is moved around on your skin. It gives off sound waves and picks up the echoes as they bounce off tissues. The echoes are made into a picture on a computer screen. Ultrasound can be used to look for swollen lymph nodes in places like your belly.

PET scan: In this test, a special type of sugar is put into your blood that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as “hot spots” where the cancer is found. This test can help show where 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?
- Who can explain them to me?
- 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 cancer?

If you have NHL, the doctor will want to find out [how far it has spread](#)⁴. This is called *staging*. Your doctor will want to find out the stage of your lymphoma to help decide what type of treatment is best for you.

NHL can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread outside the lymphatic system. Be sure to ask the doctor about the cancer stage and what it means for you.

Questions to ask the doctor

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

What kind of treatment will I need?

Not all types of NHL need to be treated right away, but when treatment is needed, doctors often use [several different types](#)⁵, including certain kinds of drugs (like chemotherapy), and radiation. The treatment plan that's best for you will depend on:

- The type of non-Hodgkin lymphoma you have
- The stage of your lymphoma
- The chance that a type of treatment will cure your lymphoma or help in some way
- Your age
- Other health problems you have
- 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 treat cancer. The drugs may be given as an IV (into a vein) or taken as pills. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break or rest period. Most of the time, 2 or more chemo drugs are given. Treatment often lasts for many months.

Side effects of chemo

Chemo can make you feel tired, sick to your stomach, and may cause your hair to fall out. These problems often 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.

Immunotherapy

Immunotherapy is treatment that either boosts your own immune system or uses man-made versions of parts of the immune system that attack the lymphoma cells. These drugs can be given into a vein or taken as pills.

Side effects of immunotherapy

Immunotherapy can cause many different side effects depending on which drug is used. These drugs often make you feel tired, sick to your stomach, and may cause fever, chills, and rashes. Most of these problems go away after treatment ends.

There are ways to treat most of the side effects caused by immunotherapy. If you have side effects, talk to your cancer care team so they can help.

Targeted therapy

Targeted therapy drugs attack cancer by targeting the changes in cells that cause cancer. These drugs don't work the same as chemo drugs and often cause different side effects. They can be given as an IV (into a vein), as a shot, or as pills.

Side effects of targeted therapy

Targeted therapy can cause many different side effects depending on which drug is used. These drugs often cause skin changes, rash, high blood pressure, bleeding problems, or blood clotting problems. These side effects usually go away after treatment ends.

There are ways to treat most of the side effects caused by targeted therapy. If you have side effects, talk to your cancer care team so they can help.

Radiation therapy

Radiation uses high-energy rays (like x-rays) to kill cancer cells. This treatment may be used as the main treatment for some stage 1 or 2 lymphomas. In some cases, it's given along with chemo.

There are 2 main ways radiation can be given. It can be aimed at the cancer from a machine outside the body. This is called *external beam radiation*. Or, the radiation can be attached to an immunotherapy drug which takes it right to the lymphoma cells.

Side effects of radiation treatments

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

- Skin changes where the radiation is given
- Feeling very tired (fatigue)

Most side effects get better after treatment ends. Some might last longer. Talk to your cancer care team about what you can expect.

Surgery

Surgery is often used to do a biopsy to find out if a person has non-Hodgkin lymphoma and, if so, the type. But it's rarely used as a form of treatment.

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.

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.

If you would 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. See [Clinical Trials](#)⁶ to learn more.

What about other treatments 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](#)⁷.

Questions to ask the doctor

- Do I need to start 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's the goal of these treatments?
- 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?

You'll be glad [when treatment is over](#)⁸. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of these follow-up visits. You will have exams, blood tests, and scans to see if the cancer has come back. At first, your visits may be every few months. 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 improve 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 \(CSN\)](#)⁹, a

safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)¹⁰, 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/cancer/non-hodgkin-lymphoma/about/what-is-non-hodgkin-lymphoma.html
2. www.cancer.org/cancer/hodgkin-lymphoma/if-you-have-hodgkin-lymphoma.html
3. www.cancer.org/cancer/non-hodgkin-lymphoma/detection-diagnosis-staging/how-diagnosed.html
4. www.cancer.org/cancer/non-hodgkin-lymphoma/detection-diagnosis-staging/staging.html
5. www.cancer.org/cancer/non-hodgkin-lymphoma/treating.html
6. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
7. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine/complementary-and-alternative-methods-and-cancer.html
8. www.cancer.org/cancer/non-hodgkin-lymphoma/after-treatment/follow-up.html
9. csn.cancer.org/
10. www.caringbridge.org/
11. 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

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

Spleen: an immune system organ found in the upper left side of the belly; it helps make white blood cells like lymphocytes

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (www.cancer.org)¹¹. 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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