
EASY READING

If Your Child Has Non-Hodgkin Lymphoma

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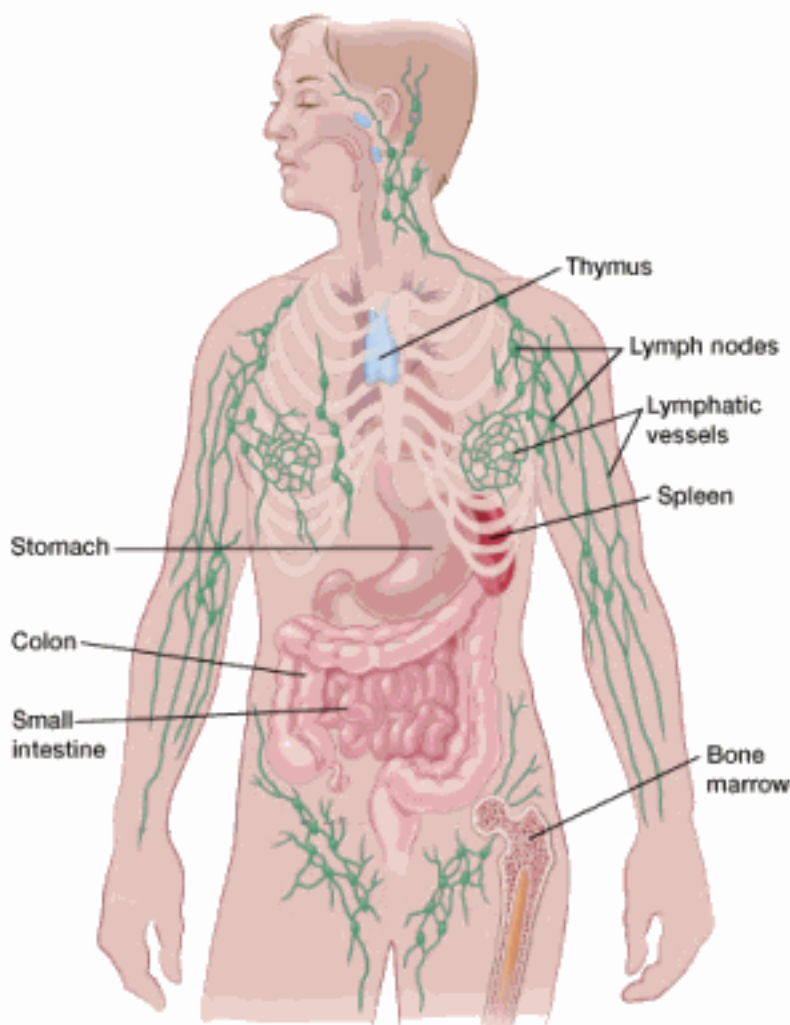
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What is childhood non-Hodgkin lymphoma?

[Cancer](#)¹ can start any place in the body. Non-Hodgkin lymphoma (NHL) is a cancer that affects the body's lymph system (also known as the [lymphatic system](#)²). 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 starts in early forms of cells called **lymphocytes**, which are a type of white blood cell.

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 child's doctor to use this picture to show you where the lymphoma is

Types of non-Hodgkin lymphoma (NHL)

NHL is a term that's used for [different types of lymphoma](#)³ that have certain things in common. (There is another kind of cancer that affects the lymph system called [Hodgkin lymphoma](#)⁴, but it needs different kinds of treatment.)

The types of NHL seen most often in children and teens are largely different from the ones seen most often in adults. The most common types of NHL in children and teens in the US are:

- Lymphoblastic lymphoma
- Burkitt lymphoma
- Diffuse large B-cell lymphoma (DLBCL)
- Anaplastic large cell lymphoma (ALCL)

Children and teens can have other types of NHL, but these are much less common. Talk to your child's doctor to learn more about the type your child has.

Questions to ask the doctor

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

How does the doctor know my child has non-Hodgkin lymphoma?

Childhood NHL can cause different [signs and symptoms](#),⁵ depending on the type of NHL and where it is in the body. Many of these symptoms are common in children and most likely have other causes. But a parent might bring a child to see a doctor if the symptoms don't go away or if they start to get worse.

The doctor will ask questions about your child's health and will examine your child. The doctor will feel the lymph nodes and other organs that may be affected.

Tests that may be done

If signs are pointing to lymphoma, more tests will be done. Here are some of the [tests your child may need](#)⁶:

Biopsy: A biopsy is the only way to tell for sure if your child has NHL. In this test, the doctor takes out a lymph node or a small piece of tissue to check it for cancer cells. There are different ways to do a biopsy, so talk to your doctor about the type your child will need. The biopsy is often done in a hospital or surgery center. It might be done with numbing medicine, but in many cases your child might be put into a deep sleep before the biopsy.

If lymphoma is found, biopsies of other parts of the body might be done as well to help

tell how far the lymphoma has spread. Biopsy samples might be taken from the bone marrow, from the fluid that surrounds the brain and spinal cord, and/or from the fluid inside the chest or belly.

All biopsy samples are sent to a lab, where they are tested for lymphoma cells.

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 test 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: For this test, a small wand-like instrument is moved around on your child's skin. It gives off sound waves and picks up the echoes as they bounce off organs inside the body. 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 child's belly.

PET scan: In this test, a special type of sugar is put into your child’s blood that can be seen inside the 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. It might be combined with an MRI (PET/MRI) or with a CT scan (PET/CT).

Questions to ask the doctor

- What tests will my child need?
- Who will do these tests?
- Where will they be done?
- How and when will we get the results?
- Who will explain the results to us?
- What do we need to do next?

How serious is my child's cancer?

If your child has NHL, the doctor will want to find out how far it has spread. This is called the [stage of the lymphoma](#)⁷. The stage can help decide what type of treatment is likely to be best.

NHL can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 3 or 4, means the cancer has spread farther and might need more intense treatment.

The type and stage of the NHL are important when trying to determine the best treatment and how likely it is to work. But other factors can be important, too, such as your child's age and where the lymphoma is in the body.

To learn more, ask your child's doctor about what the stage of the NHL and other factors might mean for your child.

Questions to ask the doctor

- Do you know the stage of my child's lymphoma?
- If not, how and when will you find out the stage of the lymphoma?
- Would you explain what the stage means?
- Are there any other factors that might affect my child's outlook?
- Based on the stage and other factors, how likely is it that we can cure the lymphoma?
- What will happen next?

What kind of treatment will my child need?

Several types of treatment can be used for NHL, including different kinds of drugs (like chemotherapy), surgery, and radiation. The treatment plan that's thought to be best for your child will depend on:

- The type of NHL
- The stage of the lymphoma
- The chance that a type of treatment will cure your child's lymphoma or help in some way
- Your child's age and overall health
- Your feelings about the treatment and the side effects that might come with it

Chemo

[Chemotherapy](#)⁸ (chemo) is the use of certain kinds 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. Sometimes chemo might also be given into the spinal fluid to treat (or prevent) the spread of NHL to the brain or spinal cord.

Chemo for childhood NHL needs to be intense. Most of the time, many chemo drugs are given. Some chemo might need to be given in the hospital, especially at the start of treatment. Chemo is given in cycles or rounds. Each round of chemo is followed by a break or rest period. Treatment often lasts for many months.

Side effects

Chemo can make your child feel tired or sick to their stomach, and it might cause their hair to fall out. These problems often go away after treatment ends.

There are ways to treat most chemo side effects. If your child is having side effects, talk to your cancer care team so they can help.

Other drug treatments

[Other types of drugs](#)⁹ might also be used to treat childhood NHL. These drugs work in different ways from chemo. Some attack different parts of cancer cells, while others help the body's immune system attack the cancer cells. These drugs might be used along with chemo or by themselves to treat some types of NHL. These drugs can be given into a vein or taken as pills.

Side effects

These drugs can cause many different side effects depending on which one is used. Talk to your child's health care team to find out more about what you can expect. There are ways to treat most of the side effects.

High-dose chemo and stem cell transplant

[A stem cell transplant](#)¹⁰ (SCT) lets doctors use very high doses of chemo. These high doses can destroy the child's bone marrow, which can keep new blood cells from being made. This could be threatening to the child's life, but after chemo is finished, the child will get blood-forming stem cells to replace the bone marrow.

A stem cell transplant might be an option to treat childhood NHL, especially if the lymphoma comes back after treatment.

This is a complex treatment that often requires a long hospital stay. There are different kinds of SCT, each of which can have serious side effects. If your child's doctor suggests a SCT as an option, ask which type your child would have and what to expect.

Radiation treatments

[Radiation](#)¹¹ uses high-energy rays (like x-rays) to kill cancer cells. This treatment is not often needed to treat childhood NHL, but it might be used in some situations.

The treatment itself is much like getting an x-ray, but the radiation is stronger. It is painless, but some younger children might need to be sedated to help make sure they don't move during the treatment.

Side effects

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
- Feeling very tired (fatigue)

These effects usually go away once treatment ends.

Radiation might also cause some long-term side effects, or effects that don't show up until many years after treatment. Because of this, the use of radiation in children is limited as much as possible. Talk to your child's cancer care team about what to expect.

Surgery

[Surgery](#)¹² is often used to do a biopsy to find out if a child or teen has non-Hodgkin lymphoma and, if so, what type it is. Surgery might be used to treat some early-stage lymphomas before chemo is given. Surgery might also be used to put a small plastic tube (called a [catheter or port](#)¹³) into a large blood vessel, which can stay in place for months. This can be used to give chemo or draw blood samples.

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 child's doctor can find one that's studying the kind of cancer your child has, it's up to you whether to take part. And you can always stop at any time.

If you would like to learn more about clinical trials that might be right for your child, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)¹⁴ to learn more.

What about other treatments we hear about?

You might hear about other ways to treat your child's cancer or to treat their symptoms. These may not always be standard medical treatments. They might include 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 child's doctor about anything you're thinking about using, whether it's a [vitamin, a diet, or anything else](#)¹⁵.

Questions to ask the doctor

- Do e need to start treatment right away?
- What treatment do you think is best for my child?
- What's the goal of this treatment? Do you think it could cure the lymphoma?
- Will my child need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could my child have from these treatments?
- What can we do about side effects?
- Is there a clinical trial that might be right for my child?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- What should we do to be ready for treatment?
- Is there anything we 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](#)¹⁶. But it's hard not to worry about cancer coming back. Even if it never comes back, people still worry about it. For years after treatment ends, your child will still need to see their cancer doctor. Be sure they go to all of these follow-up visits. Your child will have exams, blood tests, and maybe other tests to see if lymphoma has come back. At first, the visits may be about once a month. Then, the longer your child is cancer-free, the less often the visits will be needed.

With support from family, friends, other survivors, mental health professionals, and others, many children who survive lymphoma can thrive in spite of the challenges they've had to face.

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 \(CSN\)](#)¹⁷, a safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)¹⁸, 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/what-is-cancer.html
2. www.cancer.org/treatment/understanding-your-diagnosis/lymph-nodes-and-cancer.html
3. www.cancer.org/cancer/non-hodgkin-lymphoma/about/what-is-non-hodgkin-lymphoma.html
4. www.cancer.org/cancer/hodgkin-lymphoma/if-you-have-hodgkin-lymphoma.html
5. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/detection-diagnosis-staging/signs-symptoms.html
6. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/detection-diagnosis-staging/how-diagnosed.html
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8. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/treating/chemotherapy.html
9. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/treating/monoclonal-antibodies.html

10. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/treating/bone-marrow-stem-cell-transplant.html
11. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/treating/radiation-therapy.html
12. www.cancer.org/cancer/childhood-non-hodgkin-lymphoma/treating/surgery.html
13. www.cancer.org/treatment/treatments-and-side-effects/planning-managing/tubes-lines-ports-catheters.html
14. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
15. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine/complementary-and-alternative-methods-and-cancer.html
16. www.cancer.org/cancer/non-hodgkin-lymphoma/after-treatment/follow-up.html
17. csn.cancer.org/
18. www.caringbridge.org/

Words to know

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

Bone marrow: the soft, spongy tissue in the hollow middle of certain bones of the body. This is where new blood cells are made.

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

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

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

Thymus: a small immune system organ located behind the breast bone in the chest

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