Non-Hodgkin Lymphoma in Children
Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Non-Hodgkin Lymphoma in Children Be Found Early?
- Signs and Symptoms of Non-Hodgkin Lymphoma in Children
- Tests for Non-Hodgkin Lymphoma in Children

Stages for Non-Hodgkin Lymphoma in Children

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- Stages of Non-Hodgkin Lymphoma in Children

Outlook (Prognosis)

Doctors often use survival rates as a standard way of discussing someone’s outlook (prognosis). Some people want to know about survival statistics, while others might not find the numbers helpful, or might even not want to know them.

- Survival Rates for Childhood Non-Hodgkin Lymphoma

Questions to Ask About Non-Hodgkin Lymphoma in Children

Here are some questions you can ask the cancer care team to help you better understand your child’s diagnosis and treatment options.
What Should You Ask Your Child's Doctor About Non-Hodgkin Lymphoma?

Can Non-Hodgkin Lymphoma in Children Be Found Early?

Non-Hodgkin lymphoma (NHL) in children is uncommon, and there are no widely recommended screening tests for this cancer. (Screening is testing for cancer in people who don't have any symptoms.) Still, sometimes NHL can be found early.

The best way to find this cancer early is to be aware of its possible signs and symptoms and to take your child to the doctor if something concerns you.

Careful, regular medical checkups are important for children, especially those with known risk factors for NHL, such as:

- Certain inherited immune deficiencies
- Prior cancer treatment or organ transplant
- HIV infection

These children do not usually develop NHL, but it's important for parents and doctors to know the possible symptoms and signs of lymphoma.

References


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Signs and Symptoms of Non-Hodgkin Lymphoma in Children

Childhood non-Hodgkin lymphoma (NHL) can cause many different signs and symptoms, depending on where it is in the body. Common symptoms include:

- Enlarged lymph nodes (seen or felt as lumps under the skin)
- Swollen abdomen (belly)
- Feeling full after only a small amount of food
- Shortness of breath or cough
- Fever
- Weight loss
- Night sweats
- Fatigue (feeling very tired)

**Enlarged lymph nodes**

Non-Hodgkin lymphoma may grow in lymph nodes under the skin (on the sides of the neck, in the underarm area, above the collar bone, or in the groin area). The enlarged nodes are often seen or felt as lumps under the skin and are not usually painful. They are often first noticed by the child, parent, or a health care provider.

Enlarged lymph nodes in children are more often caused by infections than by NHL. Lymph nodes that grow in reaction to infection are called *reactive nodes* or *hyperplastic nodes* and are often tender to the touch.

**Lymphoma in the abdomen (belly)**

Lymphoma growing inside the abdomen can make it swollen and painful. There may also be a buildup of fluid that causes even more swelling.

Lymphoma can sometimes enlarge the spleen and make it press on the stomach. This can make a child feel full after eating only a small amount of food.
When lymphoma causes swelling near the intestines, bowel movements may be blocked, which may lead to belly pain, nausea, and vomiting.

Lymphoma can also block urine from leaving the kidneys. This can lead to low urine output, tiredness, loss of appetite, nausea, or swelling in the hands or feet.

**Lymphoma in the chest**

When lymphoma starts in the thymus (a small organ in the middle of the chest) or lymph nodes in the chest, it can press on the nearby trachea (windpipe). This can lead to coughing, shortness of breath, and trouble breathing.

The superior vena cava (SVC) is a large vein that carries blood from the head and arms back to the heart. It passes next to the thymus and lymph nodes inside the chest. Lymphomas in this area may press on the SVC, which can make the blood back up in the veins. This can lead to swelling in the face, neck, arms, and upper chest (sometimes with a bluish-red skin color). It can also cause trouble breathing, as well as headaches, dizziness, and a change in consciousness if it affects the brain. This condition, known as *SVC syndrome*, can be life-threatening, so it needs to be treated right away.

**Lymphoma in the brain and spinal cord**

Some types of lymphoma can spread to the area around the brain and spinal cord. This can cause problems such as headache, nausea, vision changes, facial numbness, and trouble talking.

**Lymphoma in the skin**

Some lymphomas can affect the skin itself. They can cause itchy, red or purple lumps or nodules under the skin.

**General lymphoma symptoms (B symptoms)**

Along with causing symptoms in the part of the body where it starts, NHL can also cause general symptoms such as:

- Fever and chills
- Sweating (particularly at night)
- Unexplained weight loss
When talking about lymphoma, doctors sometimes call these B symptoms. B symptoms are often found in more rapidly growing lymphomas.

Other symptoms can be caused by low blood cell counts. Blood counts can become low if lymphoma spreads to the bone marrow and crowds out the normal, healthy cells that make new blood cells. This can lead to problems like:

- Severe or frequent infections (from low white blood cell counts)
- Easy bruising or bleeding (from low blood platelet counts)
- Fatigue and pale skin (from low red blood cell counts; anemia)

Many of the signs and symptoms above are more likely to be caused by something other than a lymphoma, such as an infection. Still, if your child has any of these symptoms, check with the doctor so that the cause can be found and treated, if needed.

- **References**


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**Tests for Non-Hodgkin Lymphoma in Children**
Non-Hodgkin lymphoma (NHL) is usually found when a child is brought to a doctor because of signs or symptoms he or she is having. This might lead the doctor to suspect the child could have a lymphoma, but tests are needed to confirm this. The exams and tests below are used to diagnose lymphoma, to find out what type it is, and to learn how advanced it is.

**Medical history and physical exam**

If any signs and symptoms suggest a child might have lymphoma, the doctor will ask about the symptoms and how long they have been present. The doctor might also ask if there is any history of possible risk factors, such as immune system problems.

During the physical exam, the doctor will probably focus on any enlarged lymph nodes or other areas of concern. For example, the abdomen (belly) may be felt for signs of an enlarged spleen or liver.

The most common cause of enlarged lymph nodes in a child is an infection, so this is often what doctors think of first. Because of this, the diagnosis of NHL in a child can sometimes be delayed. There is usually little cause for concern in children with swollen lymph nodes unless they are very large (more than 1 inch across). Even in these instances, the child is usually watched closely for a time or given a course of antibiotics first to see if the nodes will shrink. If they don't, more tests are done, such as a biopsy to remove part or all of a swollen node (see next section). But if the lymph nodes seem to be growing quickly or the child's health seems to be getting worse, a biopsy may be needed right away.

**Biopsy**

A doctor can't diagnose NHL in a child based only on symptoms or a physical exam. Most of the symptoms NHL can cause are more often caused by other problems, like infections. They may also be caused by other kinds of cancers. If a child does have NHL, it's important to know which type it is, because each type is treated slightly differently.

The only way to diagnose these things for sure is to remove some or all of an abnormal lymph node (or tumor) for viewing under a microscope and other lab tests. This is called a biopsy.

**Types of biopsies used to diagnose non-Hodgkin lymphoma**
There are several types of biopsies. Doctors choose which one to use based on the situation. The goal is to get a sample large enough to make an accurate diagnosis as quickly as possible, with as few side effects as possible.

**Surgical (excisional or incisional) biopsy:** These are the most common types of biopsies done if lymphoma is suspected. An exception might be large chest tumors, for which a needle biopsy (described below) might be used instead.

In these procedures, a surgeon cuts through the skin to remove either an entire lymph node (excisional biopsy) or a small part of a large tumor (incisional biopsy).

If the node is near the skin surface, this is an operation that might be done with either local anesthesia (numbing medicine at the biopsy site) and sedation, or with general anesthesia (where the child is in a deep sleep). If the node is inside the chest or abdomen, then general anesthesia is typically needed.

This method almost always provides enough of a sample to diagnose the exact type of NHL.

**Needle biopsy:** These biopsies use hollow needles to remove small pieces of tissue. There are 2 main types:

- In an **fine needle aspiration (FNA) biopsy**, the doctor uses a very thin, hollow needle attached to a syringe to withdraw (aspirate) a small amount of tissue from an enlarged lymph node or a tumor mass.
- For a **core needle biopsy**, the doctor uses a larger needle to remove a slightly larger piece of tissue.

If an enlarged lymph node is just below the skin, the doctor can aim the needle while feeling the node. If the enlarged node or tumor is deep in the body (such as in the chest or abdomen), the doctor can guide the needle while watching it on a CT scan or ultrasound (see discussion of imaging tests later in this section).

The main advantage of a needle biopsy is that it does not require surgery. This can be especially important for children with tumors in the chest, because general anesthesia (where the child is in a deep sleep) can sometimes be dangerous for these children. A needle biopsy is also useful when the lymphoma is in places other than the lymph nodes, such as the bones.

In children, needle biopsies can often be done using local anesthesia to numb the area, along with sedation to make the child sleepy. General anesthesia is needed less often.
The main drawback of needle biopsies (especially FNA) is that sometimes the needle might not remove enough of a sample to make a definite diagnosis. Most doctors don’t use needle biopsies if they strongly suspect lymphoma (unless other types of biopsies can’t be done for some reason). But if the doctor suspects that lymph node swelling is caused by an infection (even after antibiotics), a needle biopsy may be the first type of biopsy done. If a biopsy is needed, doctors typically prefer to do a core biopsy instead of FNA. An excisional biopsy might still be needed to diagnose and classify lymphoma, even after a needle biopsy has been done.

Once lymphoma has been diagnosed, needle biopsies are sometimes used to check areas in other parts of the body that might be lymphoma spreading or coming back after treatment.

**Other types of biopsies**

These other types of biopsies are not normally used to diagnose lymphoma, but they might be done if a lymphoma has already been diagnosed to help show how far it has spread.

**Bone marrow aspiration and biopsy:** These tests can show if a lymphoma has reached the bone marrow. The 2 tests are usually done at the same time. The biopsy samples are usually taken from the back of the pelvic (hip) bones, although sometimes they may be taken from the front of the hip bones or from other bones.

For a **bone marrow aspiration**, the skin over the hip and the surface of the bone is numbed with local anesthetic. In most cases, children will be given other medicines to make them drowsy or asleep during the biopsy. A thin, hollow needle is then inserted into the bone, and a syringe is used to suck out a small amount of liquid bone marrow.

A **bone marrow biopsy** is usually done just after the aspiration. A small piece of bone and marrow is removed with a slightly larger needle that is put into the bone. Once the biopsy is done, pressure will be applied to the site to help stop any bleeding.

**Lumbar puncture (spinal tap):** This test is used to look for lymphoma cells in the cerebrospinal fluid (CSF), which is the fluid that surrounds the brain and spinal cord.

For this test, the doctor first numbs an area in the lower part of the back near the spine. The doctor usually also gives the child medicine to make him or her sleep during the procedure. A small, hollow needle is then placed between the bones of the spine to withdraw some of the fluid.
In children already diagnosed with lymphoma, a lumbar puncture can also be used to put chemotherapy drugs into the CSF to try to prevent or treat the spread of lymphoma to the spinal cord and brain.

**Pleural or peritoneal fluid sampling:** If lymphoma spreads to the thin membranes that line the inside of the chest and abdomen it can cause fluid to build up. Pleural fluid (inside the chest) or peritoneal fluid (inside the belly) can be removed by putting a hollow needle through the skin into the chest or abdomen.

- When this procedure is used to remove fluid from the chest, it’s called a **thoracentesis**.
- When it's used to collect fluid from inside the belly, it’s known as a **paracentesis**.

Before the procedure, the doctor uses a local anesthetic to numb the skin and may give the child other medicines so they are drowsy or asleep during the procedure. The fluid is then drawn out and looked at with a microscope to check for lymphoma cells.

**Lab tests on biopsy samples**

All biopsy samples and fluids are looked at by a pathologist (a doctor with special training in using lab tests to identify cancer cells). The doctor uses a microscope to look at the size and shape of the cells and how they are arranged. This can show if a child has lymphoma, and sometimes what type of lymphoma it is, as well. But usually other types of lab tests will be needed, too.

**Flow cytometry and immunohistochemistry**

For flow cytometry and immunohistochemistry, samples of cells are treated with antibodies, which are proteins that stick only to certain other proteins on cells. For immunohistochemistry, the cells are then looked at with a microscope to see if the antibodies stuck to them (meaning they have these proteins), while for flow cytometry a special machine is used.

These tests can help determine if a lymph node is swollen because of lymphoma, some other cancer, or a non-cancerous disease. The tests can also be used for **immunophenotyping** – determining which type of lymphoma a child has, based on certain proteins in or on the cells. Different types of lymphocytes have different proteins on their surface, which correspond to the type of lymphocyte and how mature it is.

**Chromosome tests**
Doctors use these tests to evaluate the chromosomes (long strands of DNA) in the lymphoma cells. In some types of lymphoma, the cells have changes in their chromosomes, such as having too many, too few, or abnormal chromosomes. These changes can often help identify the type of lymphoma.

**Cytogenetics:** In this type of lab test, the cells are looked at under a microscope to see if the chromosomes have any abnormalities. A drawback of this test is that it usually takes about 2 to 3 weeks because the lymphoma cells must grow in lab dishes for a couple of weeks before their chromosomes are ready to be seen with a microscope.

**Fluorescent in situ hybridization (FISH):** This test looks more closely at lymphoma cell DNA using fluorescent dyes that only attach to specific gene or chromosome changes. FISH can find most chromosome changes (such as translocations) that can be seen under a microscope on standard cytogenetic tests, as well as some changes too small to be seen with usual cytogenetic testing. FISH is very accurate and results are usually ready within a couple of days, which is why this test is now used in many medical centers.

**Polymerase chain reaction (PCR):** This is a very sensitive DNA test that can also find some chromosome changes too small to be seen with a microscope, even if there are very few lymphoma cells in a sample.

**Blood tests**

Blood tests measure the amounts of certain types of cells and chemicals in the blood. They are not used to diagnose lymphoma, but they might be one of the first types of tests done in children with symptoms to help the doctor determine what is going on. If a child has been diagnosed with lymphoma, these tests can also sometimes help tell how advanced the lymphoma is.

- The **complete blood count (CBC)** is a test that measures the levels of different cells in the blood, such as the red blood cells, the white blood cells, and the platelets. In children already known to have lymphoma, low blood cell counts might mean that the lymphoma is growing in the bone marrow and damaging new blood cell production.
- Blood levels of **lactate dehydrogenase (LDH)** may be checked. LDH will often be abnormally high in patients with fast-growing lymphomas.
- **Blood chemistry tests** can help detect liver or kidney problems caused by the spread of lymphoma cells or certain chemotherapy drugs. These tests can also help determine if treatment is needed to correct low or high blood levels of certain
minerals.
- Tests may also be done to make sure the blood is clotting properly.
- For some types of lymphoma, the doctor might also want to order other blood tests to see if the child has been infected with certain viruses, such as the Epstein-Barr virus (EBV), hepatitis B virus (HBV), or human immunodeficiency virus (HIV). Infections with some of these viruses can affect your child’s treatment.

**Imaging tests**

Imaging tests use x-rays, sound waves, magnetic fields, or radioactive substances to create pictures of the inside of the body. These tests might be done for a number of reasons, including:

- To look for possible causes of certain symptoms (such as trouble breathing)
- To help determine the stage (extent) of the lymphoma
- To help show if treatment is working
- To look for possible signs of lymphoma coming back after treatment

A child with a known or suspected lymphoma might need one or more of these tests.

**Chest x-ray**

A chest x-ray may be done to look for enlarged lymph nodes inside the chest.

**Computed tomography (CT or CAT) scan**

The CT scan combines many x-rays to make detailed, cross-sectional images of the body. CT scans can be used to look for enlarged lymph nodes or other masses in the chest, abdomen, pelvis, head, and neck.

During the test, your child will need to lie still on a table that slides in and out of the ring-shaped scanner. Some younger children may be given medicine to help keep them calm or even asleep during the test to help make sure the pictures come out well.

**CT-guided needle biopsy:** A CT scan can also be used to guide a biopsy needle precisely into a suspected tumor or enlarged lymph node. For this procedure, the child remains asleep on the CT scanning table, while the doctor advances a biopsy needle through the skin and toward the area. CT scans are repeated until the needle is in the right place. A biopsy sample is then removed and looked at under a microscope.
**Ultrasound (sonogram)**

Ultrasound uses sound waves and their echoes to create pictures of internal organs or masses.

Ultrasound can be used to look at lymph nodes near the surface of the body or to look inside the abdomen (belly) for enlarged lymph nodes or organs such as the liver, spleen, and kidneys. (It can’t be used to look inside the chest because the ribs block the sound waves.) It is also sometimes used to help guide a biopsy needle into an enlarged lymph node.

**Magnetic resonance imaging (MRI) scan**

An MRI scan, like a CT scan, shows detailed images of soft tissues in the body. This test is not used as often as CT scans for lymphoma, but MRI is very useful for looking at the brain and spinal cord if a child has symptoms that might be caused by problems in the nervous system.

MRI scans take longer than CT scans, often up to an hour. Your child may have to lie inside a narrow tube, which can be distressing, so sedation is sometimes needed. Newer, more open MRI machines may be another option, although your child will still have to lie still.

**Positron emission tomography (PET) scan**

For a PET scan, a slightly radioactive sugar is injected into the blood. (The amount of radioactivity used is very low and will pass out of the body within a day or so.) Because lymphoma cells grow quickly, they absorb more of the sugar. After about an hour, your child will be moved onto a table in the PET scanner. He or she will lie on the table for about 30 minutes while a special camera creates a picture of areas of radioactivity in the body. Younger children may be given medicine to help keep them calm or even asleep during the test.

The picture from a PET scan is not detailed like a CT or MRI scan, but it provides helpful information about the whole body.

PET scans can be used for many reasons in a child with lymphoma:

- They can help tell if an enlarged lymph node contains lymphoma.
- They can help spot small areas in the body that might be lymphoma, even if the
area looks normal on a CT scan.

- They can help tell if a lymphoma is responding to treatment. Some doctors will repeat the PET scan after 1 or 2 courses of chemotherapy. If the chemotherapy is working, the lymphoma will no longer show up as well on the scan.
- They can be used after treatment to help decide if an enlarged lymph node still contains lymphoma or is just scar tissue.

**PET/CT or PET/MRI scan:** Some newer machines can do both a PET as well as a CT or MRI scan at the same time. This lets the doctor compare areas of higher radioactivity on the PET scan with the more detailed appearance of that area on the CT or MRI scan.

**Bone scan**

A bone scan is not usually needed unless a child is having bone pain or has lab test results that suggest the lymphoma might have reached the bones.

For this test, a radioactive substance called technetium is injected into the blood. (The amount of radioactivity used is very low and will pass out of the body within a day or so. Technetium travels to damaged areas of the bone over a couple of hours. Your child then lies on a table for about 30 minutes while a special camera detects the radioactivity and creates a picture of the skeleton. Younger children may be given medicine to help keep them calm or even asleep during the test.

A bone scan can detect bone damage from lymphoma. But a bone scan may also show other things that are not cancer, so other tests might be needed to be sure.

- **References**


Stages of Non-Hodgkin Lymphoma in Children

What is the stage of a lymphoma?

A lymphoma's stage is the extent of the disease at the time of diagnosis. The treatment and prognosis (outlook) for a child with non-Hodgkin lymphoma (NHL) depend, to a large extent, on the lymphoma’s stage.

The stage is based on the results of physical exams, biopsies, and imaging tests (CT scan, PET scan, etc.), which are described in Tests for Non-Hodgkin Lymphoma in Children.

A staging system is a standard way for the cancer care team to describe how far a cancer has spread. The staging system most often used to describe the spread of NHL in children is called the St. Jude staging system. This is different from the staging system used for lymphomas in adults.

St. Jude staging system

The St. Jude system divides NHL in children into 4 stages:
• Stage I and II lymphomas are usually considered **limited-stage** disease and are treated the same way.
• Stage III and IV lymphomas are usually thought of as **advanced-stage** disease and are also treated alike.

**Stage I**

The lymphoma is in only one place, either as a single tumor *not* in lymph nodes, or in lymph nodes in one part of the body (the neck, groin, underarm, etc.). The lymphoma is not in the chest or abdomen (belly).

**Stage II**

Stage II lymphomas are not in the chest, and one of the following applies:

• The lymphoma is a single tumor and is also in nearby lymph nodes in only one part of the body (the neck, groin, underarm, etc.).
• The lymphoma is more than one tumor and/or in more than one set of lymph nodes, all of which are either above or below the diaphragm (the thin breathing muscle that separates the chest and abdomen). For example, this might mean nodes in the underarm and neck area are affected but not the combination of underarm and groin nodes.
• The lymphoma started in the digestive tract (usually at the end of the small intestine) and can be removed by surgery. It might or might not have reached nearby lymph nodes.

**Stage III**

For stage III lymphomas, one of the following applies:

• The lymphoma started in the chest (usually in the thymus or lymph nodes in the center of the chest or the lining of the lung).
• The lymphoma started in the abdomen and has spread too widely within the abdomen to be removed completely by surgery.
• The lymphoma is located next to the spine (and may be elsewhere as well).
• The lymphoma is more than one tumor or in more than one set of lymph nodes that are both above and below the diaphragm. For example, the lymphoma is in both underarm and groin lymph nodes.
Stage IV

The lymphoma is in the central nervous system (brain or spinal cord) and/or the bone marrow when it is first found. (If more than 25% of the bone marrow is made up of cancer cells, called blasts, the cancer is classified as acute lymphoblastic leukemia [ALL] instead of lymphoma.)

- References


Survival Rates for Childhood Non-Hodgkin Lymphoma

Survival rates tell you what percentage of people with the same type and stage of cancer are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can’t tell exactly what will happen with any person, but they may help give you a better understanding about how likely it is that treatment will be successful. Some parents might want to know the survival rates for their child’s cancer, and some might not. If you don’t want to know, you don’t have to.

What is a survival rate?

Statistics on the outlook for a certain type of cancer are often given as survival rates. For example, the 5-year survival rate is the percentage of people who live at least 5 years after being diagnosed with cancer. A 5-year survival rate of 80% means that an estimated 80 out of 100 people who have that cancer are still alive 5 years after being
diagnosed. Keep in mind, however, that many of these people live much longer than 5 years.

Many cancer doctors prefer not to use the word “cure” when discussing cancer treatment and prognosis (outlook), because it can be hard to know for sure that all of the cancer is gone after treatment. But when it comes to children with non-Hodgkin lymphoma (NHL), those who are still alive and free of lymphoma after 5 years are very likely to have been cured, as it’s rare for these cancers to return after this much time.

Cancer survival rates don’t tell the whole story

Survival rates are often based on previous outcomes of large numbers of children who had the disease, but they can’t predict for sure what will happen in any particular child’s case. There are some limitations to keep in mind:

- The outlook for children with NHL varies by the type and stage (extent) of the lymphoma. But other factors can also affect a child’s outlook, such as the location and size of the tumor(s), and how well the lymphoma responds to treatment. The outlook for each child is specific to their circumstances.
- The numbers below are among the most current available. But to get these survival rates, doctors have to look at children were treated at least several years ago. As treatments are improving over time, children who are now being diagnosed with NHL may have a better outlook than these statistics show.

Your child’s doctor can tell you how these numbers might apply to your child’s particular situation.

Survival rates for non-Hodgkin lymphoma

Advances in treatment have increased the overall survival rates for children with NHL dramatically in recent decades.

The ranges of numbers given below are based on the results of several studies that have used different treatment regimens or included slightly different groups of patients.

Lymphoblastic lymphoma

With intensive treatment, the long-term survival rate for children with limited stage (stage I or II) lymphoblastic lymphoma is higher than 90%.
The long-term survival rate for more advanced (stage III or IV) lymphoblastic lymphomas is generally higher than 80%.

**Burkitt and Burkitt-like lymphoma**

Treatment of limited stage (stage I and II) Burkitt lymphomas is usually very successful, with a long-term survival rate of over 90%.

The long-term survival rate for children with more advanced (stage III or IV) Burkitt lymphoma ranges from about 80% to 90%.

**Large cell lymphomas**

The long-term survival rate is over 90% for limited stage (stage I and II) diffuse large B-cell lymphomas and is slightly lower for anaplastic large cell lymphomas.

The long-term survival rate for children with advanced (stage III or IV) diffuse large B-cell lymphoma ranges from about 80% to 90%.

For advanced anaplastic large cell lymphoma, the long-term survival rate is about 60% to 75%.

Remember, all of these survival rates are only estimates – they can’t predict what will happen with any child. We understand that these statistics can be confusing and may lead you to have more questions. Talk to your child’s doctor to better understand your child's specific situation.

- **References**


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What Should You Ask Your Child’s Doctor About Non-Hodgkin Lymphoma?

It is important to have open, honest discussions with your child’s cancer care team. You should ask any question, no matter how minor it might seem. For instance, consider asking these questions:

When you’re told your child has non-Hodgkin lymphoma

- What type of non-Hodgkin lymphoma does my child have?
- What is the stage (extent) of the lymphoma, and what does that mean?
- What tests need to be done before we can decide on treatment?
- Do we need to see any other types of doctors?

When deciding on a treatment plan

- How much experience do you have treating this type of lymphoma?
- What are our treatment options?
- What treatment do you recommend and why?
- Should we get a second opinion before starting treatment? Can you suggest someone?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How much of the treatment will need to be done in the hospital?
- How will treatment affect our daily activities?
- What are the risks and side effects of the treatments you suggest?
- Which side effects start shortly after treatment and which ones might develop later on?
- Will treatment affect my child’s ability to learn, grow, and develop?
What are the chances of curing the lymphoma?
What would our options be if the treatment doesn’t work or if the lymphoma comes back?
What type of follow-up will my child need after treatment?

You should also talk with your child’s doctor before treatment to find out about the possible long-term side effects. For example, you may want to ask about how it may affect your child’s fertility later on. Here are some questions you might want to ask about the risk of infertility with treatment:

- Will this treatment affect my child’s ability to have children someday?
- Is there anything that can be done to prevent or lower the risk of infertility? Would this interfere with my child’s cancer treatment?
- If my child becomes infertile, what are their options for having a family?
- Should we talk to a fertility specialist?
- Once my child finishes treatment, how will we know if they might have fertility problems?

**During treatment**

Once treatment begins, you’ll need to know what to expect and what to look for. Not all of these questions may apply, but getting answers to the ones that do could be helpful.

- How will we know if the treatment is working?
- Is there anything we can do to help manage side effects?
- What symptoms or side effects should we tell you about right away?
- How can we reach you on nights, holidays, or weekends?
- Are there any limits on what my child can do?

**After treatment**

- What type of follow-up will my child need after treatment?
- Are there any limits on what they can do?
- What symptoms should we watch for?
- How will we know if the lymphoma has come back? What would our options be if that happens?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about recovery times so that you can plan
work and school schedules. Or you may want to ask about clinical trials for which your child may qualify.

Keep in mind that doctors aren’t the only ones who can give you information. Other health care professionals, such as nurses and social workers, can answer some of your questions. To find out more about communicating with your health care team, see The Doctor-Patient Relationship.

- References

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