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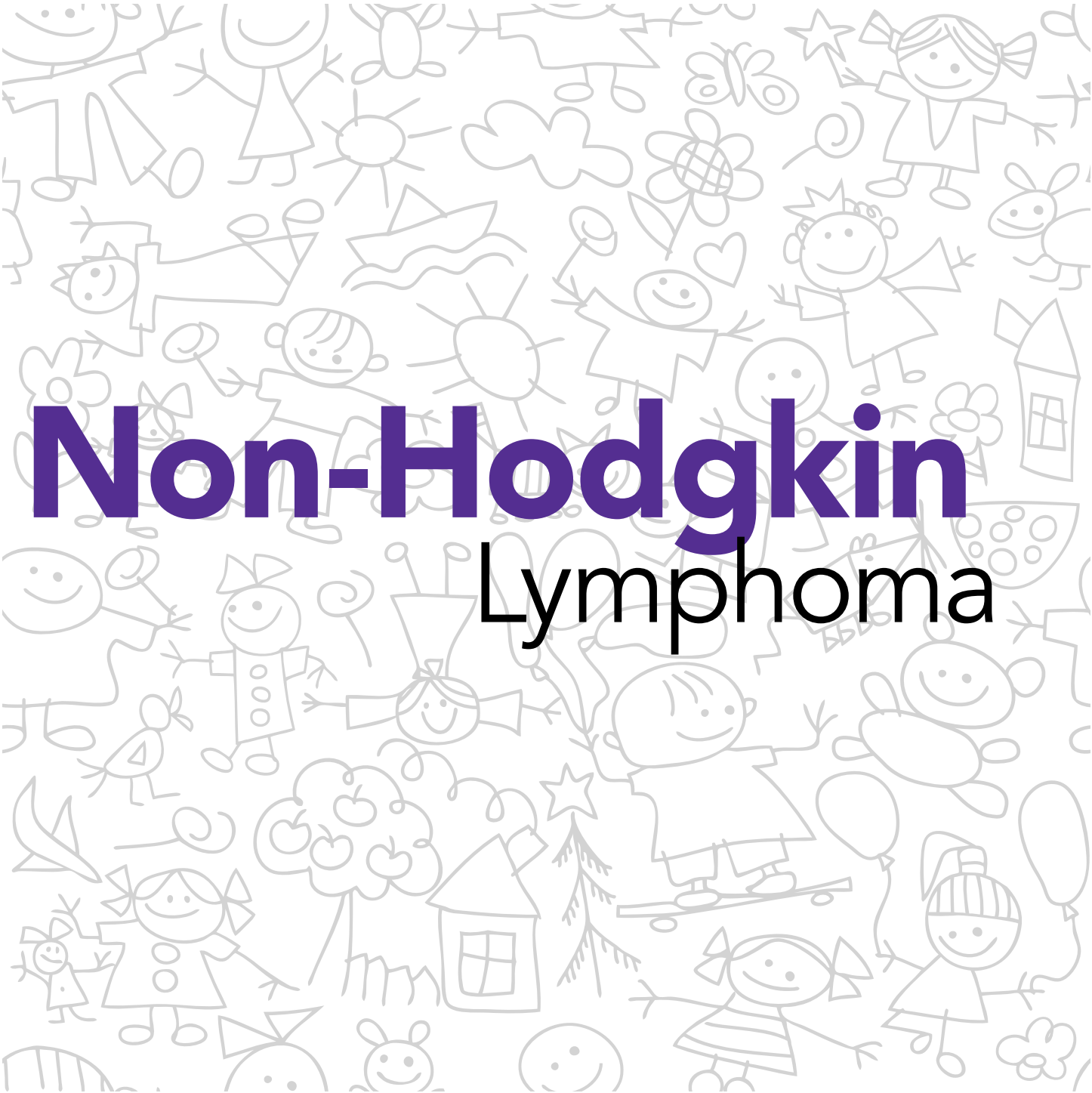
A Handbook for Families



Non-Hodgkin Lymphoma

ONCOLOGY SERIES

NON-HODGKIN LYMPHOMA
A HANDBOOK FOR FAMILIES

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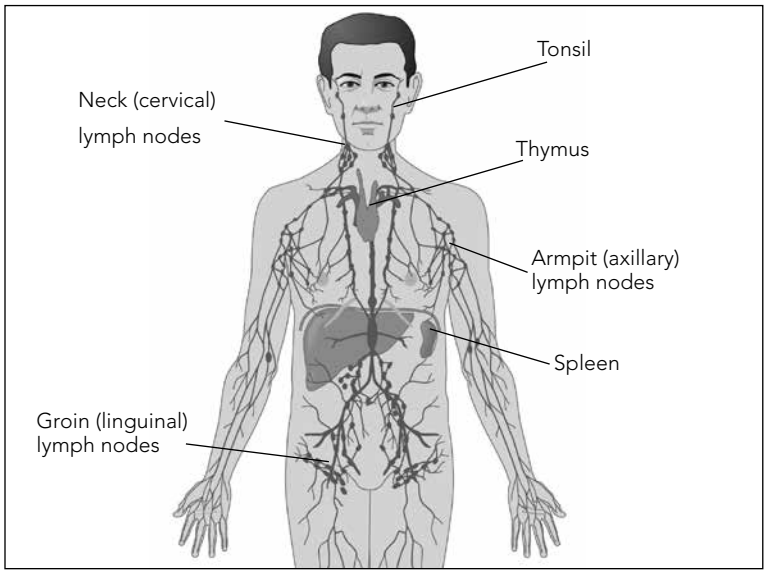
WHAT IS NON-HODGKIN LYMPHOMA?

Non-Hodgkin lymphoma is a cancer that develops from cells that make up the lymph system. The lymph system includes specialized cells and organs, such as lymph nodes, the spleen, tonsils, and bone marrow. These are located in various places around the body and are responsible for helping to protect the body from infection.

Non-Hodgkin lymphoma can start anywhere in the body but is most often located in the head/neck, chest, or abdomen (belly).

The Lymph System



WHAT TYPES OF NON-HODGKIN LYMPHOMA OCCUR IN CHILDREN?

There are three main types of non-Hodgkin lymphoma that occur in children. Small B-cell non-Hodgkin lymphoma is one type; it is also known as "Burkitt's lymphoma." This type accounts for 30%–40% of non-Hodgkin lymphoma cases and usually starts in the abdomen, or belly. Lymphoblastic lymphoma (sometimes called T-cell lymphoma) accounts for approximately 30% of non-Hodgkin lymphoma and is most often found in the chest. It can also be found in lymph nodes. Large cell lymphoma, the third type, accounts for approximately 30%–35% of non-Hodgkin lymphoma and can be found in the lungs, bones, and skin as well as lymph nodes.

WHAT ARE SOME SYMPTOMS OF NON-HODGKIN LYMPHOMA?

Symptoms of non-Hodgkin lymphoma depend on its location in the body. For example, if the main tumor is located in the chest, the child may have a cough, shortness of breath, difficulty breathing, or chest pain. If there is a tumor in the belly, the child may have pain, bloating, nausea, vomiting, constipation, or diarrhea. Some children may have swollen necks or bumps around the collarbones.

WHAT CAUSES NON-HODGKIN LYMPHOMA?

We do not know what causes non-Hodgkin lymphoma. There is some association between the Epstein-Barr virus (EBV) and the African type of non-Hodgkin lymphoma; however, this association does not typically occur in the United States. Non-Hodgkin lymphoma is not contagious.

WHO GETS NON-HODGKIN LYMPHOMA?

Non-Hodgkin lymphoma accounts for approximately 4%–5% of cancer occurring in children with about 800 cases diagnosed each year in the United States. Non-Hodgkin lymphoma is rare in children younger than 2 years of age. Burkitt's lymphoma occurs more in children 5–14 years old, while large cell lymphoma occurs more in teenagers 15–19 years old. Lymphoblastic lymphoma occurs at a similar rate for children and teenagers. There is an increased incidence in boys compared to girls in all the types (3:1). Non-Hodgkin lymphoma is more often diagnosed in White children compared to other racial groups. Also, children who have weakened immune systems or diseases that affect the immune system, or those who have had an organ transplant are at higher risk of developing non-Hodgkin lymphoma.

IS NON-HODGKIN LYMPHOMA INHERITED?

Non-Hodgkin lymphoma does not appear to be inherited. However, children who already have an inherited medical condition may have an increased chance of developing non-Hodgkin lymphoma.

WHAT IS METASTASIS?

Metastasis refers to tumor cells that have spread from the original tumor location (primary site) to other parts of the body. Non-Hodgkin lymphoma cells can spread to the lungs, other lymph nodes, the bones and the bone marrow (area inside the bones where blood cells are made), and the spinal fluid. It is important to evaluate if any metastases are present to help determine the type of treatment your child will receive.

WHAT IS STAGING?

Staging is the process of determining the location and amount of the disease at the time of diagnosis. This helps to determine the best treatment. The staging system usually used for children with non-Hodgkin lymphoma is called the "St. Jude Staging System" and is divided into four stages.

STAGE I

There is only one tumor or involved lymph node in one part of the body (such as the neck or underarm). The tumor is not in the chest or the belly. There is no metastasis, and it has not spread to other areas.

STAGE II

There is one tumor that has spread to nearby lymph nodes. Another possibility is two or more lymph nodes or tumors located on the same side of the diaphragm (the breathing muscle that separates the chest and belly areas). For example, there might be a lymph node in the neck and one in the underarm but not one in the neck and one in the groin (opposite sides of the diaphragm). Another area of involvement may be the intestine.

STAGE III

There is tumor in the chest or belly that cannot be completely removed by surgery, or there are two or more lymph nodes on both sides of the diaphragm that are affected. Sometimes the tumor may be located near the spine. For example, a lymph node may be located in the neck and groin area.

STAGE IV

The tumor has spread from its original location to the bone marrow or central nervous system (brain or spinal fluid).

WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

In order to diagnose non-Hodgkin lymphoma and determine the extent of your child's disease, a number of tests and procedures are necessary. The first step will be a complete history of the illness and a physical examination. Any previous illnesses or organ transplants, as well as immune system problems, should be discussed with the healthcare team. The following tests may be needed.

CHEST X RAY

A chest X ray is taken to look for enlarged lymph nodes inside the chest or lungs. Efforts will be made to minimize your child's exposure to X rays.

CT SCAN

The *computed tomography* (CT) scan is a computer-assisted X ray that shows detailed pictures of internal organs and tumors. It is a very important and useful test for looking at non-Hodgkin lymphoma in the chest, belly, and pelvis. It is a painless test, but your child must be able to lie still during the scan. Some children require sedation to help them lie still. If your child is having a CT scan of the belly, he or she will be asked to drink a special dye that makes the pictures clearer. Some children may require a small amount

of dye to be injected through an intravenous (IV) line as well. Generally, there are no side effects from either type of dye; however, allergic reactions are possible.

MRI

Magnetic resonance imaging (MRI) is a test that is helpful in examining the brain and spinal cord for non-Hodgkin lymphoma. MRI uses radio waves instead of X rays. A computer helps translate the pattern of radio waves into very detailed pictures of parts of the body. The test is painless, but the machine makes quite a bit of noise. Your child must be able to lie still; some children may require sedation.

PET SCAN

A *positron emission tomography* (PET) scan can be a very useful test because it is sensitive in determining if enlarged lymph nodes contain non-Hodgkin lymphoma cells or are benign (not cancerous). A glucose solution (type of sugar solution) that contains a slightly radioactive substance is injected through an IV line and travels around the body; pictures are then taken with a special camera. Non-Hodgkin lymphoma cells can absorb the glucose solution and "light up" on the pictures. The test is painless, but the test may take a while and your child must be able to lie still. Some children require sedation. The substance is naturally excreted from the body and no special precautions are needed.

GALLIUM SCAN

A *gallium scan* is very similar to a PET scan and can also detect areas of non-Hodgkin lymphoma. Instead of a glucose solution, a tiny amount of radioactive gallium is injected through an IV line and travels around the body. Pictures are taken a few days later with a special camera. The test is painless, but some children may require sedation to help them lie still.

BONE SCAN

A *bone scan* may be done to see if the non-Hodgkin lymphoma cells are present in or have spread to any of the bones. A small amount of dye is injected through an IV line and travels around the body. Pictures are taken about 2–3 hours later. The test is painless, but your child needs to lie still for the pictures and may require sedation.

ULTRASOUND

An ultrasound uses the echoes from sound waves to produce a picture of internal organs or tumors. It can help find tumors in the belly and can also see if the kidneys have tumors in them or have become swollen from being blocked by enlarged lymph nodes. An ultrasound is a painless test and uses no radiation. Your child lies on a table for a short time. If the ultrasound is of the belly, your child may not be able to eat or drink for several hours before the test.

BLOOD TESTS

Blood tests are done to monitor your child's blood cells and body chemistries. The complete blood cell (CBC) count is used to detect anemia (low hemoglobin) and can also detect changes in the white blood cells (infection-fighting cells) and platelets (cells that help the blood to clot properly). Chemistries monitor changes in kidney and liver function. Other blood tests look for substances such as lactate dehydrogenase (LDH) and erythrocyte sedimentation rate (ESR), which can be indicators or markers of disease in children with non-Hodgkin lymphoma.

BONE MARROW ASPIRATION AND BIOPSY

Bone marrow aspiration and biopsy are done to help determine if the non-Hodgkin lymphoma cells have spread to the bone marrow, the blood-producing factory in the body. Aspiration involves inserting a special needle into one of the bones (usually the back of the hip bone) and drawing a small amount of bone marrow (liquid part) out into a syringe. The biopsy is done after the aspiration is completed and includes taking a very small piece of bone (bone chip) and sending it to the laboratory for review. This test helps determine the stage of the disease. The procedure is uncomfortable; most children are given pain medicine or sedated during the test.

LUMBAR PUNCTURE

This test is done to determine if any non-Hodgkin lymphoma cells have spread to the brain or spinal cord. A needle is inserted between the spaces of the spinal bones in order to obtain a sample of cerebrospinal fluid (CSF). This test can be slightly uncomfortable. Some children are given sedation to help them lie still.

PLEURAL OR PERITONEAL FLUID ASSESSMENT

Sometimes non-Hodgkin lymphoma cells can spread to the thin membranes inside the pleural (chest) or peritoneal (belly) cavities, causing fluid to accumulate. Testing of the fluid can be done by inserting a needle through the skin into the chest or belly and withdrawing a small sample of the fluid. Your child's skin is numbed with a local anesthetic. Most children will be sedated for the procedure. This procedure may be done in place of a tumor biopsy in certain situations.

TUMOR BIOPSY

In order to obtain an accurate diagnosis and determine the type of non-Hodgkin lymphoma, a biopsy is needed. A biopsy is routinely done by removing one of the enlarged lymph nodes or removing a small part of the tumor. The biopsy is usually performed in the operating room by a surgeon. Some medical centers perform the biopsy in the radiology department. In some cases, the biopsy sample is obtained through a needle that is guided into the lymph node or tumor (fine-needle aspiration biopsy). In other cases, an incision is made. Your child's comfort and anxiety level will always be considered in planning procedures that involve needles.

VENOUS ACCESS DEVICE

A *venous access device* (VAD), sometimes called a "central line," is a permanent IV tube that can be used for the duration of your child's therapy. A VAD can be used to administer medications, chemotherapy, blood products, and nutritional support when needed, as well as to draw blood for testing. It is inserted when your child is under heavy sedation or anesthesia. A VAD is used in some but not all children.

HOW IS NON-HODGKIN LYMPHOMA TREATED?

Non-Hodgkin lymphoma is primarily treated with chemotherapy. Surgery is performed to obtain a biopsy to make a diagnosis. Surgical removal of the tumor may be done for children with Burkitt's-type non-Hodgkin lymphoma. Radiation is not usually used to treat non-Hodgkin lymphoma, except in certain emergency situations, such as breathing problems.

CHEMOTHERAPY

Chemotherapy refers to treatment using medications that help kill cancer cells. Multiple types of chemotherapy medications are used in the treatment of non-Hodgkin lymphoma. Chemotherapy is given in a specific sequenced combination. It is mostly given by IV; however, some drugs are administered by mouth, as a shot, or during a lumbar puncture. Your healthcare team will explain in detail the possible side effects of the types of chemotherapy your child will receive.

MONOCLONAL ANTIBODIES

Monoclonal antibodies are medications that are made in a laboratory and used for some types of cancer. They are usually given along with chemotherapy. These antibodies are made to "attach" to specific markers on the tumor cells. Once this happens, the cells become more visible to the body's immune system. The immune system can then help attack those cells. Your healthcare team will inform you if a monoclonal antibody will be part of your child's treatment regimen.

SURGERY

Surgery is sometimes performed to remove the primary tumor in children with Burkitt's-type non-Hodgkin lymphoma. The timing of the surgery depends on the site and extent of the tumor; it is often done after several rounds of chemotherapy have been given to help shrink the tumor. Surgery may also depend on whether any nerves or blood vessels are located near or around the tumor. If surgery is necessary, the surgeon and healthcare team will explain what to expect during the recovery period.

HOW LONG WILL MY CHILD'S THERAPY LAST?

The length of therapy depends on the type and stage of non-Hodgkin lymphoma and the treatment plan. Chemotherapy can last from several weeks to 2 years, depending on the type and stage of non-Hodgkin lymphoma. Your child's doctor and healthcare team will review the treatment plan with you in detail.

WHAT IS MY CHILD'S PROGNOSIS?

Non-Hodgkin lymphoma has a very good prognosis. Overall survival of children with non-Hodgkin lymphoma is now more than 80%, and the majority of children are cured.

WHAT IF THE NON-HODGKIN LYMPHOMA COMES BACK AFTER TREATMENT?

It is possible for the cancer to come back, or recur. If this happens, treatment with additional chemotherapy, monoclonal anitbodies, or stem cell transplant may be offered. A stem cell transplant involves the administration of very high-dose chemotherapy followed by infusion of previously collected stem cells. The stem cells hep the bone marrow to make new blood cells and provide immune function.

WHAT NEW METHODS OF THERAPY ARE AVAILABLE?

Most advances made in the treatment of non-Hodgkin lymphoma have been gained through a process known as "clinical trials." *Clinical trials* use research to develop better ways to treat patients with non-

Hodgkin lymphoma. In clinical trials, the best known (standard) treatment is compared with a new (experimental) treatment that is believed to be as good as, and possibly better than, the standard treatment. Clinical trials allow doctors to determine whether promising new treatments are safe and effective. Participation in clinical trials is voluntary. Before you are asked to make a decision about your child's participation in a clinical trial, the healthcare team will discuss it with you in detail, including the risks and benefits.

HOW CAN I WORK WITH THE HEALTHCARE TEAM?

The care of your child requires a team approach. You are a key player on your child's healthcare team. You know your child better than anyone else, and your input is important. Other members of your child's healthcare team include doctors, nurses, and social workers.

Always communicate openly with the other members of your child's healthcare team. Ask questions when you are unsure about anything. It may help to write down your questions as you think of them. This will help you remember all of your questions when you must meet with the healthcare team.

Important questions you may want to ask

- What stage is the cancer, and what does that mean?
- What treatment choices are available?
- What treatment do you recommend and why?
- What are the risks or side effects during the treatment?
- What are the risks and side effects after the treatment?
- What are my child's chances for survival?
- What are the chances for recurrence?

ARE MY FEELINGS NORMAL?

Hearing that your child has cancer is often shocking and overwhelming. Many parents say, "I didn't remember anything after the words 'your child has cancer.' " Parents often feel numb and have a hard time believing the diagnosis. It is important to know this is normal and expected. Most families have difficulty processing all of the information the healthcare team is providing them in the beginning. However, with time, information will be absorbed.

Many families feel responsible somehow for their child's disease. Feelings of guilt because they could not protect their child from illness or about the amount of time it took to diagnose the child are also common. This disease was not caused by anything that you did or did not do. The cause of childhood cancer is not known. Symptoms are often the same as many childhood illnesses, and it may have taken a while for the diagnosis of non-Hodgkin lymphoma to be made.

Feelings of sadness, anger, and helplessness about your child's diagnosis are also common. These feelings are normal. Each member of your family may express these emotions in different ways and at different times. Talking honestly with each other about these feelings, emotions, and reactions will help everyone in your family. Keep in mind there is no right or wrong way to feel. Each family member needs the chance to express his or her feelings when they are ready and in their own way.

Talking to friends, family, and members of the healthcare team can be difficult at times, but expressing your feelings can help you cope. Your child will benefit from family and friends showing their care through communication and support.

HOW CAN I HELP MY CHILD?

Children often think that something they did caused their cancer; reinforce that this is not the case. Make sure your child understands that your feelings of anger and sadness are directed at the cancer and not at him or her. This will help you maintain closeness and keep your relationship honest. Your child will need to share his or her feelings with someone trusted. Sometimes, children choose to share feelings with someone other than a parent because they are afraid they might upset the parent. Don't be afraid to ask your child about his or her feelings—it may be what your child is waiting for. Also, don't be afraid to share information about what is happening and why with your child. The things children sometimes imagine on their own are often more frightening than what is actually happening.

In spite of your child's disease, keep in mind that he or she is still a child first. All children need love, attention, the opportunity to learn and try new skills, and limits. As your child goes through cancer treatment, keep in mind that he or she still has all the needs of a growing child. Do not avoid talking to your child about therapy; instead, use direct terms and explanations your child will understand. Children tolerate treatment better if they understand it and are allowed to help make decisions about their care when appropriate.

As a parent, it may be difficult to watch your child undergo cancer therapy. Your child may sometimes seem sicker than before the therapy began. Your feelings about what your child is going through during treatment must be balanced with the knowledge that treatment provides the chance of curing the disease and having your child live a full and meaningful life. Accepting the changes in your child that the non-Hodgkin lymphoma and the treatment may cause is often difficult, but keep in mind that many of them, such as hair loss, are often temporary. Always remember that, despite outward changes, your child is still the same person on the inside.

IS MY CHILD'S DIET IMPORTANT DURING TREATMENT?

Yes. Research has shown that well-nourished children tolerate therapy better and experience fewer treatment delays. Nausea and vomiting can be a distressing side effect of treatment, and your child's healthcare team will prescribe medications to help prevent and treat these side effects. Your child may have difficulty eating normal meals during treatment. Foods that are appealing to your child will be tolerated better. Offer foods that are high in calories, protein, and carbohydrates. Small, frequent meals are often better tolerated than three larger meals. When possible, avoid junk foods and foods that are high in salt in favor of more nutritious foods.

If your child is on steroid medications, such as prednisone or decadron (dexamethasone), his or her appetite will likely be increased. While on these medicines your child may be constantly hungry and may crave unusual foods. Your child may want one particular food constantly. Try to keep healthy snacks on hand. Steroids may cause your child to gain weight and develop a round face and puffy appearance; these side effects are temporary.

Your child's hydration status is also an important part of his or her well being. It is important to offer your child fluids to drink frequently throughout the day. If your child is not drinking enough fluids, he or she may become dehydrated. Signs of dehydration include decreased urine output, dizziness, and a dry mouth.

Multivitamins, herbs, and medicines should be avoided unless approved by your child's healthcare team. They can interact with your child's chemotherapy.

A dietician is a part of your child's healthcare team. He or she is trained in the calorie and nutritional needs of children. The dietician can provide you with information regarding your child's dietary needs as well as ideas about how you can meet these needs during treatment. Your child's healthcare team will monitor your child's nutritional status, height, and weight during and after treatment in order to try to prevent problems. When there is a concern about nutritional problems, your child's healthcare team will intervene.

CAN MY CHILD ATTEND SCHOOL DURING TREATMENT?

Your child's ability to attend school during therapy will depend on the intensity of the treatment as well as your child's response to treatment. There may be extended periods when your child is unable to attend school because of hospitalizations or treatments. However, it is important that, even during these times, your child keep up with his or her schoolwork. Talk with your child's healthcare team and school about arranging for homebound services, including a tutor, until he or she is able to return to school. Many children's hospitals have school programs that allow patients to attend school while hospitalized. These programs often help coordinate home tutors as well as obtain homework and schoolwork.

Discuss your child's ability to attend school with the healthcare team. Some children are able to attend school between hospitalizations or treatments and use homebound services. The healthcare team can help coordinate the school services your child needs. When a child returns to school for the first time after starting treatment or at the end of therapy, many healthcare teams go to the school to educate teachers and students prior to a student's return. Once your child does return to school, the healthcare team can continue to assist you with getting any special services your child may need.

WHERE CAN I GET MORE INFORMATION ABOUT NON-HODGKIN LYMPHOMA?

The following Web sites have useful information about non-Hodgkin lymphoma:

American Cancer Society
www.cancer.org

The Children's Oncology Group
www.curesearch.org

The Leukemia and Lymphoma Society
www.lls.org

The National Cancer Institute
www.cancer.gov

The National Children's Cancer Society
www.nationalchildrenscancersociety.org
www.beyondthecure.org

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IMPORTANT PHONE NUMBERS

NOTES

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