

Hodgkin Lymphoma



Hodgkin Lymphoma



HODGKIN LYMPHOMA

A HANDBOOK FOR FAMILIES

Author

Susanne B. Conley, MSN RN AOCNS CPON®

Contributor

Amy L. Billett, MD

Content Reviewers

2012 Steering Council

ABOUT THIS COVER

This cover is specially designed for your child to color and personalize. When your child finishes decorating the cover, return it to the clinic or doctor's office where you received the handbook. Your child's healthcare provider will then send it to APHON for posting on the APHON website.

This handbook is published by the Association of Pediatric Hematology/Oncology Nurses (APHON) for educational purposes only. The material has been developed by sources believed to be reliable. The material is not intended to represent the only acceptable or safe treatment of Hodgkin lymphoma. Under certain circumstances or conditions, additional or different treatment may be required. As new research and clinical experience expand the sources of information available concerning the treatment of Hodgkin lymphoma, adjustments in treatment and drug therapy may be required.

APHON makes no warranty, guarantee, or other representation, express or implied, concerning the validity or sufficiency of the treatments or related information contained in this handbook.

Copyright © 2012 by the Association of Pediatric Hematology/Oncology Nurses

4700 W. Lake Avenue • Glenview, IL 60025-1485 • 847.375.4724

Fax 847.375.6478 • info@aphon.org • www.aphon.org

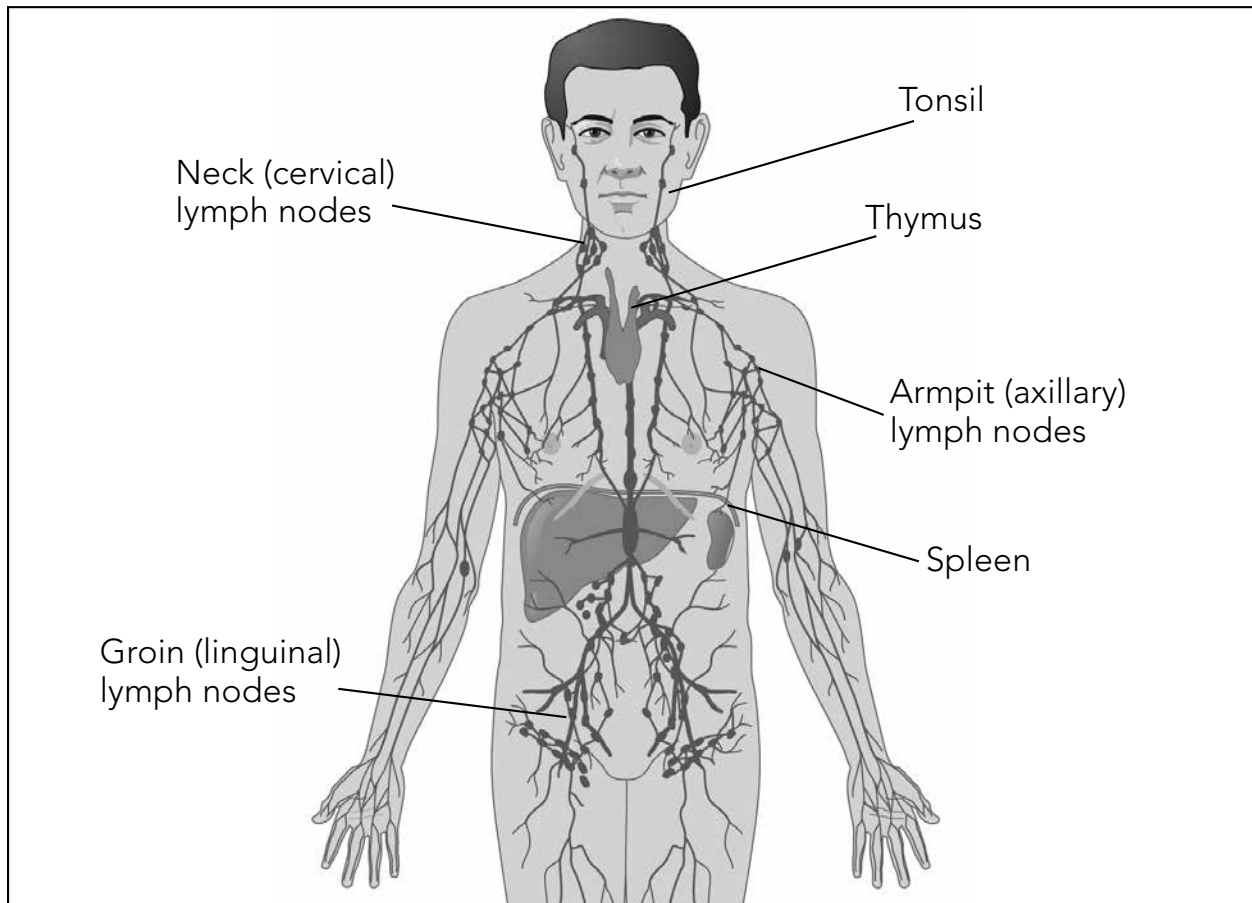
■ WHAT IS HODGKIN LYMPHOMA?

Hodgkin lymphoma, also known as Hodgkin disease, is a cancer of the lymphatic system. The lymphatic system is part of the body's immune system, which protects the body from infection and disease. The lymphatic system is made up of a network of tissues and organs, including lymph nodes, tonsils, bone marrow, spleen, and thymus. There is also lymph tissue found in other parts of the body including the gut, skin, and brain. The lymphatic system circulates watery fluid called *lymph* throughout the body. Lymph fluid includes a type of white blood cell called *lymphocytes* that helps the immune system filter viruses, bacteria, and other foreign substances out of the body.

Because lymph tissue is found throughout the body, Hodgkin lymphoma can develop almost anywhere and spread to almost any tissue or organ. Researchers have determined it is a cancer that develops from an abnormal lymphocyte (white blood cell) that divides too rapidly and grows without order or control.

The diagnosis of Hodgkin lymphoma depends on having a particular type of abnormal blood cells present, which are called *Reed-Sternberg cells*, a specific kind of large abnormal lymphocyte.

The Lymphatic System



© Clinical Skills Ltd

■ WHAT ARE SOME SYMPTOMS OF HODGKIN LYMPHOMA?

Most patients with Hodgkin lymphoma experience swollen lymph nodes that are usually painless, firm, and movable. They are most commonly found in the neck and chest and less commonly found under the arms or in the groin.

Other symptoms of Hodgkin lymphoma include

- fever
- night sweats
- weight loss for no known reason
- difficulty breathing
- itchy skin.

■ WHAT CAUSES HODGKIN LYMPHOMA?

The causes of Hodgkin lymphoma are unknown, but immune system malfunction and exposure to pesticides, herbicides, viruses, and bacteria may play a role. Individuals who have the following may be at a higher risk for developing Hodgkin lymphoma:

- Epstein-Barr virus (EBV) infection (EBV is the virus that causes mononucleosis. However, most people who have an EBV infection never develop Hodgkin lymphoma.)
- human immunodeficiency virus (HIV) infection
- family history of Hodgkin lymphoma (although hereditary cases are very rare).

■ WHO GETS HODGKIN LYMPHOMA?

Hodgkin lymphoma is a rare disease and accounts for 5% of childhood cancers in the United States. Hodgkin lymphoma occurs most often in young adults between the ages of 15 and 34 years. It rarely occurs before the age of 5 years, but the risk of developing Hodgkin lymphoma increases in the second decade of life, making it most common in teenagers.

■ IS HODGKIN LYMPHOMA INHERITED?

Some cases of Hodgkin lymphoma have been reported within families of certain ethnic groups, leading to the thought that there may be some genetic predisposition that may increase the risk for developing Hodgkin lymphoma. There is a slightly increased chance for Hodgkin lymphoma to occur in siblings and cousins of those who have or have had the disease. Although the risk is 2–5 times higher for siblings, the likelihood that a sibling will get Hodgkin lymphoma is still very low.

■ WHAT IS METASTASIS?

Metastasis refers to the spread of a tumor from its original location (i.e., primary site) to other parts of the body. Hodgkin lymphoma often spreads from one lymph node to another and can also spread to organs outside the lymphatic system. If a biopsy reveals Hodgkin lymphoma, additional tests will be performed to find out if the cancer has spread to other parts of the body.

■ WHAT IS STAGING?

Staging is the process of determining the location and extent of the disease at the time of diagnosis. The information gathered from the staging process determines the stage of Hodgkin lymphoma; treatment is then based on the stage and other factors that affect prognosis. There are four stages, stages 1 through 4, that are determined by the locations of the lymph node chains that have tumors. A higher stage number indicates that the disease has spread further throughout the body.

Hodgkin Lymphoma Staging

Within each stage, the letters “E” and “S” are used to further classify the disease. *E* indicates that cancer has extended into an organ or tissue that is not part of the lymphatic system but is next to an involved lymph node. *S* indicates that cancer is found in the spleen.

STAGE I

STAGE I: Cancer is found in one group of lymph nodes.

STAGE IE: Cancer is found in one group of lymph nodes and has extended into a nearby organ or tissue that is not part of the lymphatic system.

STAGE II

STAGE II: Cancer is found in two or more lymph-node groups on the same side of the diaphragm. (The *diaphragm* is the breathing muscle that separates the chest and belly areas.)

STAGE IIE: Cancer is found in two or more lymph-node groups on the same side of the diaphragm and has extended from one of those lymph nodes to a nearby organ or tissue that is not part of the lymphatic system.

STAGE III

STAGE III: Cancer is found on both sides of the diaphragm.

STAGE IIIE: Cancer is found on both sides of the diaphragm and has extended from one of these lymph nodes to a nearby organ or tissue that is not part of the lymphatic system.

STAGE IIIS: Cancer is found on both sides of the diaphragm and in the spleen.

STAGE IIIE+S: Cancer is found on both sides of the diaphragm and in the spleen and has extended from one of these lymph-node groups to a nearby organ or tissue that is not part of the lymphatic system.

STAGE IV

STAGE IV: Cancer is found throughout one or more organs that are not part of the lymphatic system and may be in lymph nodes that are near or far from those organs.

Each stage is then further classified as either "A" or "B." A refers to *asymptomatic disease*, meaning there are no B symptoms. B indicates the individual has experienced specific symptoms including unexplained fever that exceeds 100.4 °F/ 38.0 °C, drenching night sweats, or weight loss of at least 10% of body weight during a 6-month period.

Risk Groups

Hodgkin lymphoma is divided into risk groups based on the amount of tumor and whether the patient has B symptoms. Once the risk group is determined, the treatment team will use this information to decide which type of treatment is needed.

■ WHICH TESTS AND PROCEDURES WILL MY CHILD NEED?

To diagnose Hodgkin lymphoma and determine the extent of your child's disease, several tests and procedures are necessary. The lymph nodes, chest, and abdomen will be examined. An enlarged spleen or liver may indicate Hodgkin lymphoma is present in those organs. The presence of small, soft lymph nodes in children may be misleading because only lymph nodes that have been increasing in size or are significantly enlarged are a concern.

To determine the best treatment possible, it is very important to identify the exact type of Hodgkin lymphoma and where it is located throughout the body. Your child's physician will decide which tests and procedures are needed.

Tests and Procedures Most Commonly Performed

TISSUE BIOPSY

The removal of all or part of a lymph node or other tissue is necessary to diagnosis Hodgkin lymphoma and determine the most effective treatment. A lymph-node tissue biopsy can be performed either in an operating room or in a hospital's radiology department. Your child's comfort and anxiety level will always be considered when planning procedures that involve needles.

Once the biopsy sample is obtained, a pathologist will examine the tissue under a microscope to look for cancer cells, especially Reed-Sternberg cells, which are common in Hodgkin lymphoma.

X RAY

A chest X ray, which takes a picture of the organs and bones inside the chest, may be necessary to determine whether Hodgkin lymphoma is present in the lungs.



CT SCAN

A computerized axial tomography (CT) scan is a computer-assisted X ray that provides very detailed images of areas inside the body from different angles. The scan is painless and quick, but your child must be able to lie completely still during the scan. Some children may require sedation to help them lie still. Your child might not be allowed to eat or drink for several hours before the exam. To make the CT images clearer, it also may be necessary for your child to have a small amount of dye injected into a vein or to drink a liquid containing a flavorless dye. Generally, side effects do not occur from either type of dye; however, allergic reactions are possible.



PET SCAN

A positron emission tomography (PET) scan provides images of the body that show the size and shape of organs and tumors. PET scans are similar to CT and magnetic resonance imaging (MRI) scans, except they are able to show the chemical and functional changes within the body. A PET scan has three steps: injection of a radioactive material; a waiting period, usually 30–60 minutes; and scanning by the PET machine. During the waiting period and the actual scanning, your child must be able to lie completely still. The scanning process is painless; however, some children may require sedation to help them lie still.

BONE MARROW BIOPSY AND ASPIRATION

Some children may need a bone marrow biopsy and aspiration, which is a procedure that collects a sample of the bone marrow. Bone marrow is the hollow part of the bone where white blood cells, red blood cells, and platelets are made. Once the sample is collected, it is examined under a microscope by a pathologist to see if Hodgkin lymphoma is present and to determine the exact type. Because the procedure is performed with a biopsy needle, children usually require sedation or anesthesia.

Tests and Procedures that May Be Performed

MRI

Magnetic resonance imaging (MRI) is a scan that produces very exact pictures of organs and tumors inside the body. During an MRI scan, your child will lie on a table that is then moved into a tube-like machine that surrounds him or her with a magnetic field. The scan is painless; however, the machine makes a loud banging noise that may frighten some children. Your child must be able to lie completely still during the scan. If your child is unable to remain still, sedation may be necessary.



BLOOD TESTS

Blood tests are performed to monitor your child's blood cells, body salts, and chemistries. A complete blood count (CBC) is useful in detecting a drop in the number of red blood cells (oxygen carriers), white blood cells (infection fighters), or platelets (cells that help blood clot properly). Blood chemistries such as blood urea nitrogen (BUN) and creatinine are performed to detect changes in kidney function. Other chemistries, such as alanine aminotransferase (ALT), aspartate aminotransferase (AST), and bilirubin, may be needed to assess liver function. These tests may be administered to rule out other diseases, but they are not diagnostic for Hodgkin lymphoma. Other blood tests are the erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP), which are sometimes elevated in Hodgkin disease and may be used to measure response to treatment. Blood tests are used throughout therapy to monitor both your child's response to treatment and any possible side effects of therapy.

VENOUS ACCESS DEVICE

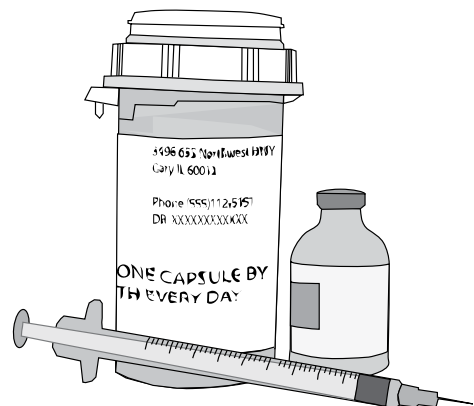
When chemotherapy is needed to treat Hodgkin lymphoma, there are several options to help with your child's treatment. Because treatment for Hodgkin lymphoma is often brief, a temporary catheter called a peripherally inserted central catheter (PICC) may be used. Sometimes a surgeon will insert a small plastic tube called a venous access line or device (i.e., port) into a large blood vessel, usually under your child's collar bone. These venous access devices (VADs) can be used for blood tests and to give medications, chemotherapy, blood products, and nutritional support when needed. You and your child's treatment team will decide whether a VAD is necessary. A VAD is usually left in place for the duration of treatment and then removed after completion of therapy.

■ HOW IS HODGKIN LYMPHOMA TREATED?

The goal of treatment for Hodgkin lymphoma is to cure the disease while minimizing any treatment-related side effects or adverse reactions. Chemotherapy and radiation therapy are the two most common therapies used to treat Hodgkin lymphoma.

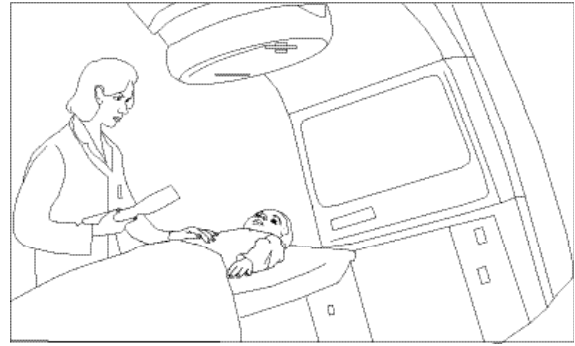
Chemotherapy

Chemotherapy is medicine that helps kill cancer cells and prevents the cancer from spreading. Because no single chemotherapy medicine can control the disease by itself, a variety of medications are given in combination to kill the cancer cells. The exact combination of chemotherapy agents your child receives will depend on the stage of the disease and other treatment considerations. Many chemotherapy medications are administered through a vein or VAD, although some are given by mouth. Many chemotherapy treatments are administered in an outpatient clinic; however, some treatments may require hospitalization. Some of the medicines can be taken by mouth at home. When chemotherapy is given, close monitoring of your child will be a priority. Your child's treatment team will explain the possible side effects of the specific chemotherapy medicines your child receives.



Radiation Therapy

Radiation therapy uses a special type of X-ray treatment that kills or damages rapidly growing cells (e.g., cancer cells). Radiation may be given before or after chemotherapy. If radiation therapy is necessary for your child, the radiation therapy doctor will explain to you exactly how the radiation will be given and how long the treatments will last. Most children experience very few side effects while they are receiving radiation therapy. However, some children may feel more tired, have a decreased appetite, or experience redness or darkness of the treated skin. The side effects most likely to occur generally depend on the area of the body being treated. In general, most side effects stop after treatment; however, they can occur after treatment stops as well. Your child's treatment team will explain any possible late effects in detail.



■ HOW LONG WILL MY CHILD'S THERAPY LAST?

The length of your child's therapy depends on the type and stage of disease at the time of diagnosis. Usually, treatment is given for 2–6 months, but it can be longer depending on the specific treatment plan. Treatment duration may be modified based on your child's response to treatment after 4–8 weeks.

■ WHAT IF THE CANCER RECURS?

It is possible for Hodgkin lymphoma to recur, which is called a recurrence or relapse. If your child has a relapse, his or her treatment may involve additional chemotherapy and radiation therapy. A stem cell transplant is another potential treatment option. During a stem cell transplant, high-dose chemotherapy is administered and then followed by the infusion of stem cells. Stem cells are used to restore blood and immune-cell formation after intense chemotherapy, radiation therapy, or both.

■ WHAT NEW METHODS OF TREATMENT ARE AVAILABLE?

Hodgkin lymphoma has been studied more than any other type of lymphoma. With the many rapid advances in diagnosis and treatment, high survival rates have been reported in children with Hodgkin lymphoma using different treatment strategies. Children with stage I or II disease have 10-year survival rates higher than 95%. Children with stage III and IV disease generally achieve 5-year survival rates close to 90%.

Most advances in the treatment of childhood cancer have been made through a process known as *clinical trials*. During clinical trials, the best known (or standard) treatment for a particular cancer is compared with a new (or experimental) treatment that is believed to be at least 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. Because clinical trials involve new treatment plans that are experimental, all of the possible risks cannot be known ahead of time, and unknown side effects may occur. However, children who participate in clinical trials can be among the first to benefit from new treatment approaches. Before making a decision about your child's participation in a clinical trial, you should discuss all of the risks and potential benefits with your child's treatment team.

Additional information about clinical trials is available in the free booklet *Taking Part in Clinical Trials: What Cancer Patients Need to Know* by the National Cancer Institute (Publication No. 98-4250). To obtain the booklet and other useful information about childhood cancer, call 800.4CANCER (800.422.6237). The booklet also can be downloaded from the National Cancer Institute website at www.cancer.gov/clinicaltrials/learning.

■ WHAT ARE THE POTENTIAL LATE EFFECTS OF TREATMENT?

Like all patients treated with chemotherapy and radiation, survivors of Hodgkin lymphoma may be at risk for developing side effects months or even years after treatment ends. Children who received radiation to the chest area as part of their cancer treatment are at risk for breast and cardiac complications. Other late effects may include delayed puberty in males, infertility, thyroid or lung problems, increased risk of developing another cancer, delayed growth and development, and bone-health issues.

To help patients monitor their overall health after treatment is completed, cancer survivors should seek appropriate cancer-related follow-up care. There are many survivor clinics located at cancer centers throughout the country that offer access to experts who can address a wide range of follow-up concerns.

To obtain additional information about specific long-term side effects of cancer treatment, visit www.curesearch.org.

■ HOW CAN I WORK WITH MY CHILD'S TREATMENT TEAM?

Your child's care and treatment requires a team approach. As a parent or guardian, you are an integral part of the team and your input is important. Because you know your child better than anyone else, the treatment team will need your help in managing your child's disease. It is important to communicate openly with your child's treatment team. Be sure to question your child's doctor or nurse whenever there is anything you are not sure about. It often helps to write down your questions when you think of them. Examples of some questions to ask include the following:



- Has the cancer spread beyond the primary site?
- What treatment options are available?
- What treatment do you recommend and why?
- What are the risks or side effects of the recommended treatment?
- What should we do to prepare for treatment?
- What is my child's outlook for survival?
- What are the chances of a recurrence?
- If my child's cancer recurs, are other treatment options available?

Use this space to write down some additional questions.

■ ARE MY FEELINGS NORMAL?

Learning that your child has cancer can be shocking and overwhelming. At first you may not believe it or hope the diagnosis is wrong. However, the changes you see in your child and the experience of being in the hospital and beginning treatment will no doubt confirm the reality of your child's situation. Many family members feel they are somehow responsible for the child's disease or feel guilty that they were not able to detect it sooner. Remember that this disease was not caused or triggered by anything anyone did to the child, anything the child ate, or anything that happened during pregnancy. Hodgkin lymphoma also does not develop from a child's activity in sports. In addition to shock and guilt, you and your family may feel anger and sadness. Even the youngest family members are likely to be affected. These feelings are normal, and each family member will express them in different ways and at different times. It can be very difficult to feel so many strong emotions all at once. Talking honestly with each other about feelings, reactions, and questions will help everyone in the family. It may seem difficult to talk to friends, family, or even medical staff, but expressing your feelings will help you to better cope with this situation. Your child will also benefit if family members continue to show their care through support and communication.

■ HOW CAN I HELP MY CHILD?

You will often notice changes in your child during the treatment for Hodgkin lymphoma. These changes or symptoms may make you feel even more helpless. It is important to remember that, in spite of changes on the outside, your child is still the same person on the inside. Hair loss and other changes in physical appearance are temporary and often bother adults more than the child or his or her siblings and friends. All of your feelings about what your child is going through during treatment for cancer must be balanced by remembering that treatment provides an opportunity to cure the disease and have your child go on to live a full and meaningful life. It is important to reinforce to your child that nothing he or she did or said caused this disease. Telling your child that your angry or sad feelings are directed at the cancer and not at him or her will help preserve honesty and closeness in your relationship. Like you, your child will need someone with whom to share feelings. Do not hesitate to ask your child to express his or her feelings, and do not be afraid to explain what is happening and why.



In spite of the disease, your child is still developing and learning. All children, both sick and well, need love, attention, discipline, limits, and the opportunity to learn new skills and try new activities. As you begin to learn about your child's special needs, it is important to remember that he or she still has all the needs and rights of any growing, developing person. Many patients with Hodgkin lymphoma are adolescents, which presents special considerations. Do not avoid using direct terms and explanations with your child. Children will tolerate treatment better if they understand it and are allowed to be active decision makers whenever possible. The same is true for parents and family members.

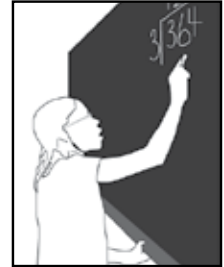
■ IS MY CHILD'S DIET IMPORTANT DURING TREATMENT?

Yes. We know from research that well-nourished children tolerate therapy better and have fewer treatment delays from illness. It may be difficult for your child to resume normal eating habits while receiving therapy, so you will need to be flexible and creative. Your child's food preferences and tastes may change throughout therapy. Often, numerous small meals are tolerated better than three large ones. Children usually are more interested in eating foods they help prepare. It is important to include your child in the social activity of family meals even if full meals are not eaten. Remember, nobody wins food fights—it is best not to force your child to eat. Make sure foods high in protein and carbohydrates are readily available. Multivitamins, herbs, supplements, and all other medicines should be approved by your treatment team before giving them to your child because they may cause an interaction with your child's chemotherapy. A dietitian trained in the calorie and energy needs of children with cancer can offer you guidance. Your child's treatment team can intervene if there is a nutritional problem.



■ CAN MY CHILD ATTEND SCHOOL DURING TREATMENT?

Most children being treated for Hodgkin lymphoma can attend school. Some children tolerate chemotherapy and radiation better than others, so there may be times when they will need to miss school. You should discuss school attendance with your child's doctor. School is important because it helps children and adolescents maintain social contact with their peers. It is important for your child to return to school as soon as he or she is medically able to do so.



■ HELPFUL WEBSITES

www.curesearch.org

Website of the National Childhood Cancer Foundation and the Children's Oncology Group

www.cancer.gov

Website of the National Cancer Institute



■ SUGGESTED READING

www.cancer.gov/clinicaltrials/learning

Web page from which the *Taking Part in Clinical Trials: What Cancer Patients Need to Know* booklet can be downloaded

IMPORTANT PHONE NUMBERS

NOTES



8735 W. Higgins Road, Suite 300
Chicago, IL 60631
847.375.4724 • Fax 847.375.6478
info@aphon.org
www.aphon.org