

# The Lymphoma Guide



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## A six-word narrative about living with blood cancer from patients in our LLS Community

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Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at  
[www.LLS.org/Community](http://www.LLS.org/Community)

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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## INTRODUCTION

Thank you for picking up this book about lymphoma. Lymphoma is a type of blood cancer. This easy-to-understand guide will provide you with information about your diagnosis, types of treatment and questions to ask your healthcare team. If you are interested in finding out more information about Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL), you can view, print or order two free LLS booklets: *Hodgkin Lymphoma* and *Non-Hodgkin Lymphoma*. Go online to [www.LLS.org/booklets](http://www.LLS.org/booklets) to order copies or download PDFs. You can also call an LLS Information Specialist at (800) 955-4572 for copies.

Lymphoma is a blood cancer that develops in a single white blood cell called a **lymphocyte**. White blood cells are an important part of our immune system because they fight off diseases. Infection-fighting lymphocytes are present in a vast system in our bodies called the **lymphatic system**. Throughout the system are hundreds of bean-shaped groups where lymphocytes gather together. These groups are called **lymph nodes**. See *Health Terms* on page 49.

Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL) are the two main types of lymphoma. About 90 percent of people with lymphoma have non-Hodgkin lymphoma. The other 10 percent have Hodgkin lymphoma. Some types of lymphoma are curable. Many patients with other types of lymphoma are able to keep their disease under control. They can have a good quality of life with medical treatment. Progress in treating lymphoma gives patients more hope than ever before.

There are an estimated 845,076 people either living with or in remission from (with no sign of disease) lymphoma in the United States. This number includes

- About 191,423 people with Hodgkin lymphoma
- About 653,653 people with non-Hodgkin lymphoma

The *Lymphoma Guide* has sections with information about Hodgkin lymphoma and for non-Hodgkin lymphoma. A key at the bottom of each page shows you whether the section has

-  L Lymphoma information
-  HL Hodgkin lymphoma information
-  NHL Non-Hodgkin lymphoma information

Some words in the *Guide* may be new to you. Check *Health Terms* beginning on *page 49*. Or call our Information Specialists at (800) 955-4572.

Drugs may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

## PART 1 Understanding Lymphoma

### Overview of This Section

- The two main types of lymphoma are non-Hodgkin lymphoma and Hodgkin lymphoma.
- Blood cells are made in the bone marrow. They begin as stem cells. Stem cells develop while still in the bone marrow, and they become red blood cells, white blood cells or platelets. Then they leave the marrow and enter the blood.
- Lymph nodes are bean-sized collections of the white blood cells called **lymphocytes**. Some lymphocytes stay in the bloodstream, but most enter the lymphatic system, a network that runs all through the body.
- Lymphoma starts with a change to just one lymphocyte.
- If you get lymphoma, choose a doctor who specializes in treating it (a hematologist-oncologist).
- Adults with lymphoma who may want children, and parents of children who have lymphoma, should ask about future fertility (ability to have a child).

# Understanding Lymphoma

Lymphoma is the general term for many different types of blood cancer. Non-Hodgkin lymphoma and Hodgkin lymphoma are the two main types of lymphoma.

## About Bone Marrow, Blood and Blood Cells

The definitions in this section about normal blood and bone marrow may help you understand the lymphoma information in the rest of this *Guide*.

**Bone marrow** is the spongy center located inside the bones, where blood cells are made.

**Blood cells** begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After they have matured, the red blood cells, white blood cells and platelets enter the bloodstream.

**Platelets** help stop bleeding by clumping together (called **clotting**) at the site of an injury.

**Red blood cells** carry oxygen around the body. When the number of red blood cells is below normal, a condition called **anemia** usually develops. Anemia may make you feel tired or short of breath. It may make your skin look pale.

**White blood cells** fight infection in the body. There are two major types of white blood cells: (1) infection-fighting cells called **lymphocytes** and (2) germ-eating cells.

- The lymphocytes are
  - B cells
  - T cells
  - NK cells
- The germ-eating cells are
  - Neutrophils
  - Monocytes

**Plasma** is the liquid part of the blood. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

## Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. They may be a little different from lab to lab and for children and teens.

### Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

### Hematocrit (the part of the blood made up of red cells)

- Men: 42% to 50%
- Women: 36% to 45%

### Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

### Platelet count

- 150,000 to 450,000 platelets per microliter of blood

### White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

### Differential (also called diff)

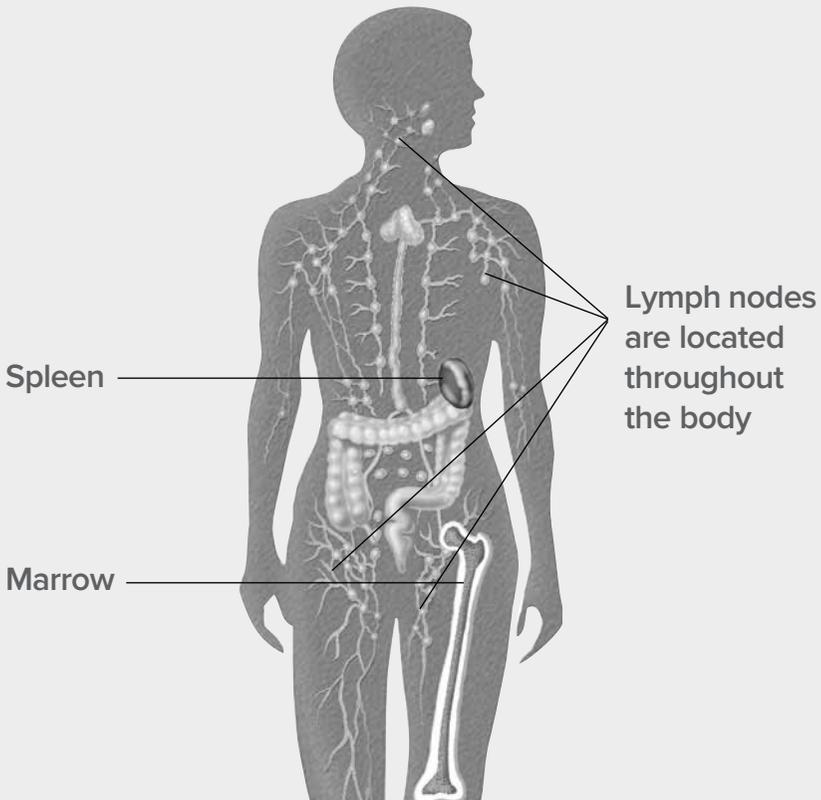
- Shows the part of the blood made up of different types of white cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

# About the Immune System

The immune system is the body's defense against infection. It includes

- **Bone marrow and lymphocytes;** inside bones, marrow produces white cells called lymphocytes that fight infection.
- **Lymph nodes,** bean-sized collections of lymphocytes. About 600 lymph nodes are found throughout the body—in the neck, armpits, chest, abdomen, groin and other body parts. Fluid channels throughout the body called **lymphatic vessels** connect the lymph nodes. Lymphocytes also travel through the bloodstream.
- **The spleen,** an organ on the left side of the body near the stomach. It contains lymphocytes and removes old or damaged blood cells.

## Some Parts of the Immune System



**Figure 1.** The healthy immune system helps protect the body from infection.

# About Lymphoma

Lymphoma starts with a change to a single lymphocyte (a type of white blood cell).

The lymphocyte undergoes an unnatural change and becomes a cancerous lymphoma cell. Lymphoma cells divide faster and live longer than normal cells. The lymphoma cells form masses. These masses gather in the lymph nodes or in other parts of the body. The cause of lymphoma is not known.

## WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Hodgkin Lymphoma* and *Non-Hodgkin Lymphoma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Finding the Right Doctor

Choose a doctor who specializes in treating lymphoma and knows about the most up-to-date treatments. This type of specialist is called a **hematologist-oncologist**. A hematologist is a doctor who has special training in disorders of the blood, and an oncologist is a doctor who has special training in cancer. A hematologist-oncologist specializes in both diseases. Your local cancer specialist may work with a lymphoma specialist. Always check to see if the doctor and the doctor's affiliated hospital or your chosen hospital is covered under your insurance.

### How to Find a Lymphoma Specialist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- Reach out to doctor and/or health plan referral services.
- Call an LLS Information Specialist at (800) 955-4572.
- Use online doctor-finder resources, such as
  - The American Medical Association's (AMA) "DoctorFinder" online at <https://apps.ama-assn.org/doctorfinder/>
  - The American Society of Hematology's (ASH) "Find a Hematologist" online at [www.hematology.org/Patients/FAH.aspx](http://www.hematology.org/Patients/FAH.aspx)

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works. See *page 55* for a full list of questions.

NOTE: The use of "I (we)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decisions. A parent, relative, or caregiver may be assisting or making the decision.

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. Is there a release form available so my family/caregiver can be given medical information?

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time speaking with the staff and at the treatment center.

### **WANT MORE INFORMATION?**



You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or you can contact our Information Specialists for a copy.

# Ask Your Doctor

Talk with the doctor and ask questions about how he or she plans to treat your lymphoma. This will help you to be actively involved in making decisions about your care.

When you meet with your doctor

- Ask questions. See *pages 55-60* of this *Guide* for a full list of questions. Find other “What to Ask” healthcare question guides at [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk). Examples of some questions include:
  - What are the treatment choices?
  - Are there any clinical trials that I could join?
  - When do you think treatment should begin?
  - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Tape record information from the doctor and then listen to the recording later on. Ask the doctor and staff if recording is okay (smart phones have a “record” function, ask someone how to use it).
- Bring a caregiver, friend or family member along with you who can listen to the doctor, take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain.

If you need more information or are not sure about your treatment choices, consider getting another opinion (a “second opinion”) from a different qualified doctor. If you are unsure or feel uncomfortable about how to tell your doctor you are getting a second opinion, call our Information Specialists to discuss a way that makes you comfortable.

## Before-Treatment Factors

Adults who have lymphoma and may want to have children in the future, and parents of children who have lymphoma, should ask the doctor about ways to lessen the risk of infertility (inability to have children that may be caused by treatment) in their future.

## Here are some questions you may want to ask your healthcare team.

See *pages 55-60* for a full list of questions in this Guidebook.

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make any decisions?

### WANT MORE INFORMATION?



You can view, print or order the free LLS fact sheet *Fertility Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## PART 2 Hodgkin Lymphoma

### Overview of This Section

- Hodgkin lymphoma (HL) is one of the most curable forms of cancer.
- The most common sign of HL is one or more enlarged (swollen) lymph nodes.
- Knowing the subtype of your HL helps the doctor make treatment decisions.
- There are different types of HL. Talk to your doctor about the type of HL that you have and your treatment choices.

### Hodgkin Lymphoma (HL)

Hodgkin lymphoma (HL) is one of the most curable forms of cancer. Hodgkin lymphoma is distinguished from other types of lymphoma by the presence of two types of cells—Hodgkin cells and Reed-Sternberg cells. These cells are named for the scientists who first identified them. Reed-Sternberg cells are large, abnormal lymphocytes. When Hodgkin cells and Reed-Sternberg cells are seen with a microscope, the diagnosis is called **classical Hodgkin Lymphoma (cHL)**.

Doctors do not know what causes most cases of HL. There is no way to prevent lymphoma, and you cannot catch lymphoma from someone else. It is commonly diagnosed among young adults in their 20s or early 30s. It is less common in middle age and becomes more common again after age 60.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Hodgkin Lymphoma* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for a copy.

## Signs and Symptoms of HL

A **sign** is a change in the body that the doctor sees in an exam or a test result. A **symptom** is a change in the body that a patient can see or feel.

The most common symptom of HL is one or more enlarged (swollen) lymph nodes. The enlarged lymph node may be in the neck, upper chest, armpit, abdomen or groin. The swollen lymph node is usually painless.

Other signs and symptoms of HL may include

- Fever\*
- Drenching night sweats\* requiring you to change your pajamas and/or sheets
- Weight loss, especially loss of more than 10 percent of your body weight\*
- Cough and shortness of breath
- Tiredness
- Itchy skin

**\*B Symptoms.** Fever, drenching night sweats and loss of more than 10 percent of body weight in 6 months are called **B symptoms**. B symptoms are important to the prognosis—the likely course or outcome of a disease. B symptoms are also important to staging of the disease—in cancer, the “stage” tells the doctor how far the cancer has spread (see *Diagnosis and Staging of HL* on page 12).

# Diagnosis and Staging of HL

**Diagnosis.** Having the correct diagnosis is important for getting the right treatment. Some patients may need to get a second medical opinion about the diagnosis before they begin treatment. Talk to the doctor about the tests used to make the diagnosis.

Doctors do a test called a **lymph node biopsy** to find out if a patient has HL.

## How Is a Lymph Node Biopsy Done?

- A surgeon removes all or part of an enlarged lymph node using a special needle.
- The cells of the node are examined by a doctor who studies blood cells and tissues under a microscope to identify disease (this type of doctor is called a **hematopathologist**).

It may be important to get another opinion about the biopsy results from a second hematopathologist to confirm the diagnosis. There are many tests used to diagnose HL. Talk to your doctor about what tests you need. You may want to call your insurance company case manager to find out if there will be any out-of-pocket costs for you.

**Here are some questions you may want to ask your healthcare team.** See *pages 55-60* for a full list of questions.

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results back?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

**Staging.** The doctor will do other tests to find the stage of the disease (how far the disease has spread throughout the body). See **Figure 3. Lymphoma Stages** on *page 14* for descriptions of the stages.

The tests for staging include

- Blood tests. To check red blood cell, white blood cell and platelet counts; blood tests also check for other signs of disease

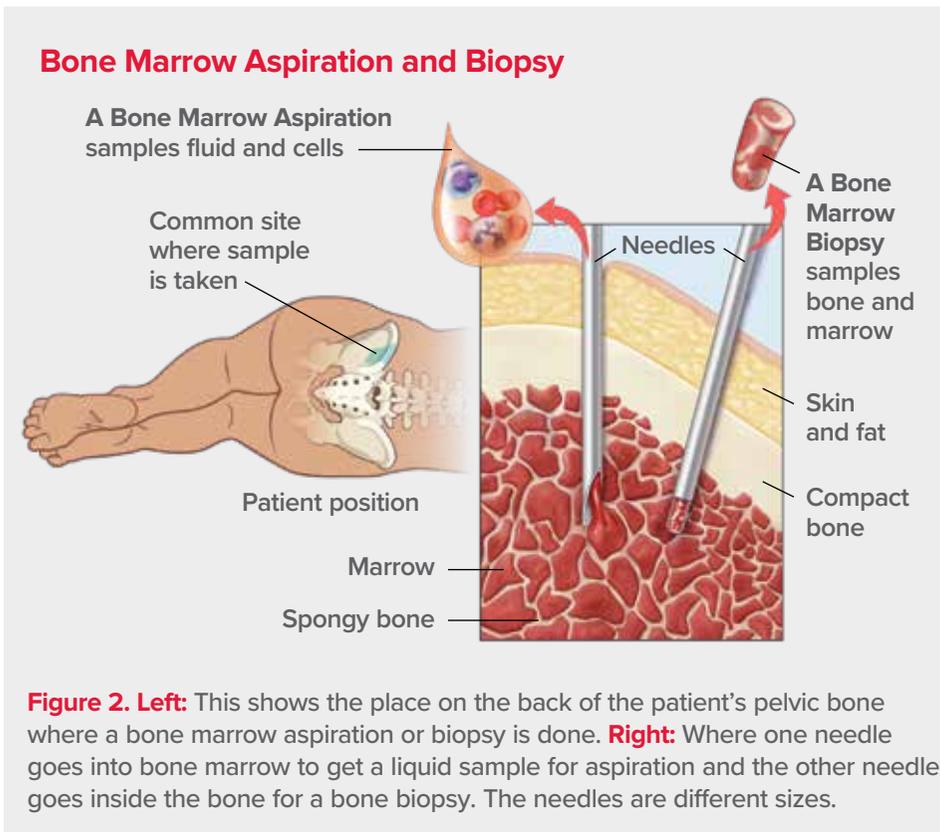
- Bone marrow tests. To look for HL cells in the bone marrow (see **Figure 2, below**)

Bone marrow aspiration and bone marrow biopsy are two tests that may be done in the doctor's office or in a hospital. These tests are often done at the same time.

- A bone marrow aspiration removes a certain amount of fluid from the bone marrow.
- A bone marrow biopsy is done with a slightly larger needle and removes a solid portion of bone.

Some patients are awake for this procedure. Medication may be used to numb the body area where the procedure will take place. This is usually the area near the patient's hip bone. Some patients are given a drug and sedated (asleep) for the procedure.

Blood and bone marrow tests may be done both during and after treatment. The tests are repeated to see if treatment is working.

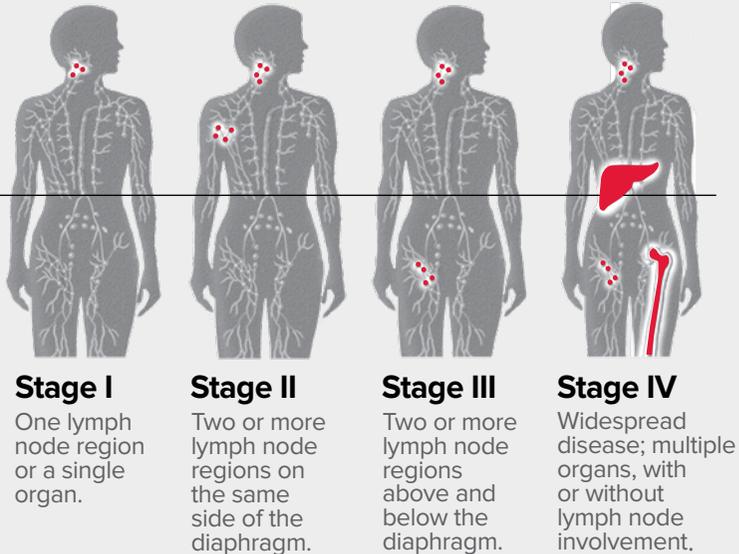


- Imaging tests. To create “pictures” of the chest and abdomen to see if there are lymphoma masses in the lymph nodes, liver, spleen or lungs. Examples of imaging tests include
  - Chest x-ray
  - PET-CT (positron emission tomography [PET] scan and computed [CT] tomography scan) two tests done at the same time
  - MRI (magnetic resonance imaging)
- Heart and lung tests. Some HL treatments may weaken or damage the heart and lungs. The healthcare team may decide to test how well these organs work to plan for treatment.

## Lymphoma Stages

### Diaphragm

(at about the waist)



**Figure 3.** Patients are also divided into “A” or “B” categories. “B” category patients have fever, a lot of sweating and/or weight loss. “A” category patients do not have these symptoms.

All stages of lymphoma can be treated.

**Prognosis Factors.** Prognosis is a medical term for “the likely outcome of a disease.” In HL, this forecast is based in part on what are called **risk factors**. Hodgkin lymphoma is generally classified into the following three subgroups. The subgroups are called

- Early-stage favorable: Disease is stage I-II with no unfavorable risk factors
- Early-stage unfavorable: Disease is stage I-II with unfavorable risk factors
- Advanced-stage: Disease is stage III-IV

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Hodgkin Lymphoma* for more information about the staging system and *Understanding Lab and Imaging Tests* to learn more about lab tests and what to expect at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

## Hodgkin Lymphoma Subtypes

Knowing the subtype of your HL helps the doctor make treatment decisions. Below are the names of the different HL subtypes.

- Classical Hodgkin Lymphoma (cHL)—about 95 percent of patients have this type, which has been further subdivided into these categories:
  - Nodular sclerosis
  - Mixed cellularity
  - Lymphocyte-rich
  - Lymphocyte-depleted
- Nodular Lymphocyte-Predominant Hodgkin Lymphoma (NLPHL)—about 5 percent of all HL cases



**Write down your HL subtype here:** \_\_\_\_\_

Treatment for these subtypes may vary. For more information, see *Treatment of HL* on page 16 and our free LLS booklet *Hodgkin Lymphoma*.

# Tracking Your Lymphoma Tests

These tips may help you save time and learn more about your health.

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports in a file folder or binder. Organize the reports by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

## Treatment of HL

Drugs may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

A patient has two options for treatment: standard care or a clinical trial. It is important to talk to the healthcare team about the best treatment option.

There are different types of HL and it can be cured in about 88 percent of patients. The cure rate in younger patients is about 94 percent. Talk to your doctor about the type of HL that you have and your treatment choices.

**Fertility Concerns.** Some cancer treatments can limit a person's ability to have a baby. Talk to your doctor for information that may help lessen the risk of becoming unable to have children (infertile). See *Before-Treatment Factors* on page 9.

Factors that may affect treatment include

- The type of HL
- The stage and category of the disease
- Disease that has not responded to treatment, called **refractory** disease
- Disease that has come back after treatment, called **relapsed** disease
- Patient age
- Other medical problems, such as diabetes or heart or kidney disease

**Treatment Options.** Combination chemotherapy (treatment using more than one drug) is the most common treatment and can also include drug therapy.

Chemotherapy is given in cycles, usually several weeks apart. A number of cycles are needed. The total treatment time may last from six to ten months. It is outpatient treatment for most patients. Some patients may have to stay in the hospital for a short time if they develop a fever or have other signs of infection. Some patients who need antibiotics may stay in the hospital until the infection is gone.

Combination chemotherapy, along with radiation therapy may also be a treatment option. The radiation targets the lymph node regions that have the disease and treats the lymphoma. Involved site radiation therapy (ISRT), a type of focused radiation, treats the lymph nodes in which the cancer first started and the cancer near those nodes. It keeps the size of the radiation area smaller to reduce radiation exposure to other non-cancerous organs.

In the process of killing the cancer cells, chemotherapy may also kill normal blood-forming cells in the bone marrow. Chemotherapy may cause very low counts of red blood cells, white blood cells or platelets.

Some patients may need a blood transfusion or drugs called **growth factors** until the side effects of chemotherapy wear off. Examples of red blood cell growth factor drugs are **Aranesp**<sup>®</sup> (darbepoetin alfa) and **Procrit**<sup>®</sup> (epoetin alfa). These can increase red blood cell counts.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Blood Transfusion* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

HL affects the body's ability to fight infection. Chemotherapy and radiation can add to the problem. Good treatment and following the doctor's advice will help lower the risk of infection.

White blood cell growth factors may be part of treatment. The body needs neutrophils (white blood cells) to fight infection. **Neupogen**<sup>®</sup> (filgrastim) or **Neulasta**<sup>®</sup> (pegfilgrastim), both also called **granulocyte-colony stimulating factor** or **G-CSF**, and **Leukine**<sup>®</sup> (sargramostim), also called **granulocyte-macrophage colony stimulating factor** or **GM-CSF** can increase the number of neutrophils (white blood cells).

See *Side Effects of Lymphoma Treatment* on page 41 for more information.

## Some Treatment Approaches for Classical Hodgkin Lymphoma

### Early-stage classical Hodgkin lymphoma (cHL)

- Chemotherapy combinations
  - **ABVD** (Adriamycin® [doxorubicin], bleomycin, vinblastine, dacarbazine)
  - Dose-escalated **BEACOPP** (for early-stage unfavorable) (bleomycin, etoposide, Adriamycin® [doxorubicin], cyclophosphamide, Oncovin® [vincristine], procarbazine, prednisone)
- Combination chemotherapy is administered with or without radiation therapy

### Advanced-stage cHL

- Chemotherapy combinations
  - **ABVD**: (Adriamycin® [doxorubicin], bleomycin, vinblastine, dacarbazine)
  - **A+AVD**: (Adcetris® [brentuximab vedotin], Adriamycin® [doxorubicin], vinblastine, dacarbazine)
  - **Dose-escalated BEACOPP**, in selected younger patients: (bleomycin, etoposide, Adriamycin® [doxorubicin], cyclophosphamide, Oncovin® [vincristine], procarbazine, prednisone)
  - Occasionally, chemotherapy is followed by involved site radiation therapy (ISRT)

### Relapsed/Refractory cHL

- Additional chemotherapy is given, such as
  - **ICE** (ifosfamide, carboplatin, etoposide)
  - **DICE** (dexamethasone, ifosfamide, cisplatin, etoposide)
  - **ESHAP** (etoposide, Solu-Medrol® [methylprednisolone], high-dose Ara-C [cytarabine], Platinol® [cisplatin])
  - **GND** (gemcitabine [Gemzar®], Navelbine® [vinorelbine], Doxil® [liposomal doxorubicin])

- **Brentuximab vedotin (Adcetris®)**, is given IV to adults
  - In combination with chemotherapy for previously untreated patients
  - As treatment after autologous transplantation for patients at high risk of relapse or progression
  - After autologous transplant didn't work or after trying at least two multi-agent chemotherapy regimens in patients for whom transplant is not an option
- Stem cell transplantation
- **Nivolumab (Opdivo®)**, is given IV to adults after three or more treatments that included autologous stem cell transplantation, and is also given after transplant with Adcetris
- **Pembrolizumab (Keytruda®)** is given IV to adults and pediatric patients who have relapsed after three or more treatments.

Terms: cHL = classical Hodgkin Lymphoma; IV = intravenously, which means into a vein; Relapsed (Recurrence)/Refractory (Resistant) = disease that comes back or does not respond to treatment.

**Table 1.** This table includes treatment approaches for Hodgkin lymphoma. See [www.LLS.org/drugs](http://www.LLS.org/drugs) for more information.

Drugs may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

**Nodular Lymphocyte-Predominant Hodgkin Lymphoma.** Patients with nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) need treatment that is different from that received by patients with other HL subtypes. NLPHL is slow-growing (this is called **indolent**), and it is associated with excellent long-term survival. The most common treatment for patients with early-stage NLPHL is involved site radiation therapy (ISRT). For patients with more advanced disease, combination chemotherapy may be needed.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Hodgkin Lymphoma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

Use the lines provided on *page 61* to write down what your treatments are and when they were prescribed to you.

**Relapsed and Refractory Hodgkin Lymphoma.** In some patients, HL may come back (this is called a **recurrence** or **relapse**). The doctor will usually treat these patients with chemotherapy and drug therapy. The treatment often gives patients very long disease-free periods. Three drugs have been FDA-approved for relapsed and refractory HL.

- **Brentuximab vedotin (Adcetris®)**
- **Nivolumab (Opdivo®)**
- **Pembrolizumab (Keytruda®)**

For information about each drug, see **Table 1** on *pages 18-19*.

**Stem Cell Transplantation.** This is a procedure in which patients receive healthy stem cells to replace their own stem cells that have been destroyed by cancer or cancer treatments. The goal of stem cell transplant is to help the body start a new supply of blood cells after the patient gets high-dose chemotherapy.

When doctors are planning treatment, they use a number of factors to determine a patient's need for a stem cell transplant. These factors may include the individual's disease, subtype, stage, other treatment received and physical ability to have the transplant. A stem cell transplant is not for every patient, but it can be helpful for some.

There are two basic types of stem cell transplantation, one that replaces the patient's blood with his or her own stem cells (autologous), and one that gets replacement stem cells from a donor (allogeneic). Talk to your doctor about whether a stem cell transplant is a possible treatment for you.

**Autologous Stem Cell Transplantation.** Autologous transplantation is more frequently used than allogeneic transplantation for HL patients. Autologous transplants are generally done in the hospital. With an autologous transplant

- The patient's own stem cells are collected from his/her blood or marrow are frozen and stored.
- The patient is then given high-dose chemotherapy and sometimes radiation therapy to kill the lymphoma cells in his or her body. This treatment also kills normal stem cells in the marrow.

- The patient’s stored stem cells are returned to their body through an intravenous (IV) or central line.
- The donor stem cells go from the patient’s blood to the marrow and help start a new supply of red blood cells, white blood cells and platelets.

**Allogeneic Stem Cell Transplantation.** An allogeneic transplant is a treatment that uses stem cells from a donor. But the donor must be a “match” to the patient. The donor may be a brother or sister (siblings are most often the best match). The donor could also be an unrelated person with stem cells that match the patient’s. Stem cells may also come from cord blood (the blood in the umbilical cord after a baby’s birth). Allogeneic transplants are done in the hospital. With an allogeneic transplant

- Stem cells are collected from a donor and are frozen and stored.
- The patient is given high-dose chemotherapy and sometimes radiation therapy to kill the lymphoma cells in the body.
- The donor stem cells are given to the patient through an intravenous (IV) line or central line.
- The donor stem cells go from the patient’s blood to the marrow and help start a new supply of red blood cells, white blood cells and platelets.

For patients who may not be able to get the high doses of chemotherapy that are given to patients during stem cell transplant, there is another type of allogeneic stem cell transplant. Reduced-intensity allogeneic stem cell transplant (also called a **nonmyeloablative transplant**) is less harsh. This type uses lower doses of chemotherapy than a standard allogeneic transplant. Some older or sicker patients may be helped by this treatment. Talk to your doctor about whether stem cell transplant might work for you.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation* and *Cord Blood Stem Cell Transplantation Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# Childhood HL

Children and teens with HL should be treated at medical centers that have a pediatric oncology team.

It is important for young adults and parents of children to talk to members of the oncology team about the

- Specific subtype of the disease
- Stage of the disease
- Fertility concerns for the child's future (See *Before-Treatment Factors* on page 9)
- Other potential risk factors
- Response to treatment

Doctors use this information about the patient's disease to find the most effective treatment. Children and young adults with HL are usually treated with combination chemotherapy.

See *Before-Treatment Factors* on page 9 and *About Clinical Trials* on page 39 for more information.

## PART 3 Non-Hodgkin Lymphoma

### Overview of This Section

- There are treatments for every type of non-Hodgkin lymphoma (NHL).
- The most common sign of NHL is one or more painless swollen lymph nodes in the neck, armpit or groin.
- Doctors do a test called a **lymph node biopsy** to find out the patient's specific subtype of NHL.
- Having the correct diagnosis is important for getting the right treatment.
- There are many types of treatment including "watch-and-wait," chemotherapy, drug therapy, radiation therapy, stem cell transplantation and new types of treatment.
- Treatments used for children with NHL may be different from those used for adults with NHL.

# Non-Hodgkin Lymphoma (NHL)

Non-Hodgkin lymphoma is the term that encompasses a group of blood cancers that all start from a lymphocyte. Lymphocytes are white blood cells that are part of the immune system.

## Subtypes of NHL

There are many subtypes of non-Hodgkin lymphoma (NHL). Remember that there are three types of lymphocytes: B cells, T cells, and NK cells. Most people with NHL have a B-cell NHL (about 85 percent). The others have a T-cell or an NK-cell NHL.

NHL is classified by how fast it grows:

- Slow-growing, called **indolent** or **low-grade** NHL
- Fast-growing, called **aggressive** or **high-grade** NHL



**Write down if you have been diagnosed with indolent/low-grade or aggressive/high-grade NHL:**

---

Talk to your doctor about the type of NHL that you have. Each type of NHL requires different treatment. Ask your doctor about your treatment options.

There are treatments for every type of NHL. Some patients with fast-growing NHL can be cured. For patients with slow-growing NHL, treatment may keep the disease in check for many years. This can be true even when tests show that disease remains in some parts of the body.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Non-Hodgkin Lymphoma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Some Types of Non-Hodgkin Lymphoma

### Types of Slow-Growing or Indolent NHL

- Cutaneous T-cell Lymphoma (CTCL)
- Follicular Lymphoma (FL) – the most common slow-growing NHL
- Lymphoplasmacytic Lymphoma/Waldenström Macroglobulinemia (LPL/WM)
- Marginal Zone B-cell Lymphoma (MZL)
- Mucosa-Associated Lymphoid Tissue (MALT) Lymphoma
- Small Lymphocytic Lymphoma (SLL)/Chronic Lymphocytic Leukemia (CLL)

### Types of Fast-Growing or Aggressive NHL

- Anaplastic Large Cell Lymphoma (ALCL)
- Burkitt Lymphoma
- Diffuse Large B-Cell Lymphoma (DLBCL) – the most common fast-growing NHL
- Lymphoblastic Lymphoma
- Mantle Cell Lymphoma (MCL)
- Peripheral T-Cell Lymphoma (PTCL) (most types)
- Transformed Follicular and Transformed MALT Lymphomas



**Write down your subtype:** \_\_\_\_\_

#### WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Mantle Cell Lymphoma Facts*; *Cutaneous T-Cell Lymphoma Facts*; *Waldenström Macroglobulinemia Facts*; *Peripheral T-Cell Lymphoma Facts* and *Chronic Lymphocytic Leukemia* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

## Signs and Symptoms of NHL

A **sign** is a change in the body that the doctor sees in an exam or a test result.

The most common sign of NHL is one or more painless enlarged lymph nodes in the neck, armpit or groin. Less often, enlarged lymph nodes can be near the ears, the elbow or in the throat near the tonsils. They are usually painless.

A **symptom** is a change in the body that a patient can see or feel.

Other signs and symptoms of NHL may include

- Fever\*
- Drenching night sweats\* requiring you to change your pajamas and/or sheets
- Weight loss, especially loss of more than 10 percent of your body weight\*
- Tiredness
- Loss of appetite
- Abdominal pain
- Itchy skin
- Rash

**\*B Symptoms.** Fever, drenching night sweats and loss of more than 10 percent of body weight in 6 months are called **B symptoms**. B symptoms are important to the prognosis and staging of the disease, see *below*.

## Diagnosis and Staging of NHL

**Diagnosis.** Having the correct diagnosis is important for getting the right treatment. Some patients may need to get a second medical opinion about their diagnosis before they begin treatment. Talk to the doctor about the tests used to make the diagnosis.

Doctors do a test called a **lymph node biopsy** to find out the patient's specific subtype of NHL. Sometimes the doctor will biopsy cells from other parts of the body, such as the lungs.

## How Is a Lymph Node Biopsy Done?

- A surgeon removes all or part of an enlarged lymph node using a special needle.
- The lymph node is examined by a doctor who identifies diseases of the blood and marrow by studying cells and tissues under a microscope (this doctor is called a **hematopathologist**).
- The doctor may look at the cells from the biopsy to see if there are changes in the chromosomes of the NHL cells. (Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do.)

It may be important to get another opinion about the biopsy results from a second hematopathologist if there is any doubt about the diagnosis, or to confirm the diagnosis.

There are many tests that are used to diagnose NHL. Talk with your doctor about what tests you need. You may want call your insurance case manager to see if there will be any out of pocket costs for you.

**Here are some questions you may want to ask your healthcare team.**  
See *pages 55-60* for a full list of questions.

1. What kind of testing will monitor this disease and treatment?
2. How long does it take to get the test results back?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

**Staging.** A physical exam plus lab and imaging tests help the doctor see how widespread the disease is. The doctor will check

- The number of lymph nodes that are affected
- Where the affected lymph nodes are located throughout the body (for example, in the abdomen or chest or both places)
- Whether any cancer cells are in other parts of the body besides the lymph nodes or lymphatic system, such as in the lungs or liver

The doctor will do other tests to find out the stage of the disease (the stage will tell the doctor how far the disease has spread throughout the body). See **Figure 5. Lymphoma Stages** on page 29 for descriptions of the stages.

Besides the staging tests listed below, other tests may also be recommended to stage some types of NHL. Some tests for staging include

- Blood tests. To check red blood cell, white blood cell and platelet counts. Blood tests are also used to look for other signs of disease.
- Bone marrow tests. Bone marrow aspiration and bone marrow biopsy look for NHL cells in the bone marrow (See **Figure 4.** on page 28)

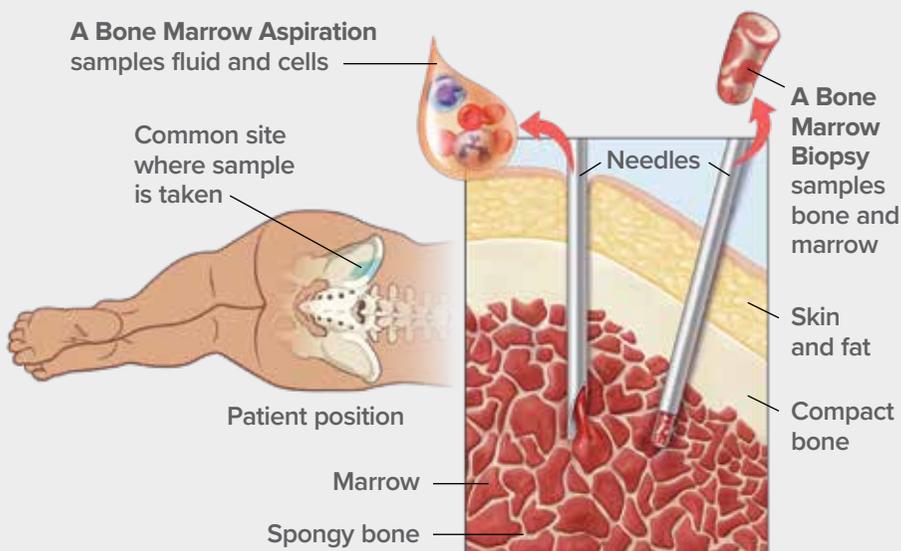
Bone marrow aspiration and bone marrow biopsy are two tests that may be done in the doctor's office or in a hospital. These tests are often done at the same time.

- A bone marrow aspiration removes a certain amount of fluid from the bone marrow.
- A bone marrow biopsy is done with a slightly larger needle and removes a solid portion of bone.

Some patients are awake for this procedure. Medication may be used to numb the body area where the procedure will take place. This is usually the area near the patient's hip bone. Some patients are given a drug and sedated (asleep) for the procedure.

Blood and bone marrow tests may be done both during and after treatment. The tests are repeated to see if treatment is working.

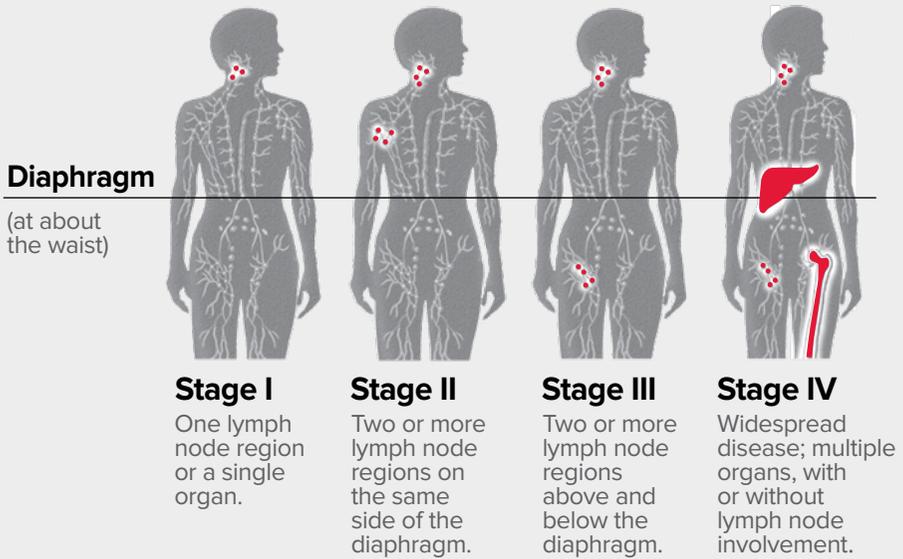
## Bone Marrow Aspiration and Biopsy



**Figure 4. Left:** This shows the place on the back of the patient’s pelvic bone where a bone marrow aspiration and biopsy is done. **Right:** Where one needle goes into bone marrow to collect the liquid sample for aspiration and the other needle goes inside the bone to get a sample for bone biopsy. The needles are different sizes.

- Heart tests. To check how a patient’s heart functions before treatment. Some cancer treatments can damage the heart. The doctors want to see how well a patient’s heart functions before treatment starts.
- Imaging tests. These create “pictures” of the chest and abdomen to see if there are lymphoma masses in the lymph nodes, liver, spleen or lungs. Examples of imaging tests include
  - Chest x-ray
  - PET-CT (positron emission tomography–computed tomography) scans, two tests done at the same time
  - MRI (magnetic resonance imaging)
  - PET (positron emission tomography) scan
  - FDG-PET (fluorodeoxyglucose [FDG]–positron emission tomography [PET]) scan, a PET scan that uses FDG, a dye, to find disease

## Lymphoma Stages



**Figure 5.** Patients are also divided into “A” or “B” categories. “B” category patients have fever, a lot of sweating and/or weight loss. “A” category patients do not have these symptoms.

All stages of lymphoma can be treated.

Additional tests may be done to find out about your specific type of NHL.

**Immunophenotyping.** This test can find out if the patient’s NHL cells are B cells, T cells, or NK cells. This is a lab test that can use the sample cells from the lymph node, the bone marrow biopsy, or from blood.

**Flow cytometry.** This is similar to immunophenotyping. It is a technique that analyzes lymphoma cells as they flow through a machine.

**Fluorescent in situ hybridization (FISH).** This is a type of molecular test that uses special dyes to look for abnormalities in chromosomes. These abnormalities are important to identify your NHL subtype and choose the best treatment.

**Polymerase chain reaction (PCR).** This technique has become useful in discovering a very low amount of left-over lymphoma cells—too few to be seen with a microscope. This test is a possible predictor of how well a patient will respond to treatment with specific therapies.

**Gene expression profiling and microarray analysis.** These tests identify cancer subtypes and risk factors. The test helps doctors predict how patients will respond to treatment. It also helps doctors tell which patients may be at increased risk for disease relapse. These tests are still mostly used as research tools.

## Tracking Your Lymphoma Tests

The tips listed below may help you save time and learn more about your health.

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports in a file folder or binder. Organize the reports by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

## Treatment of NHL

Drugs may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

A patient has two options for treatment: standard care or a clinical trial. It is important to talk to the healthcare team about the best treatment option.

The doctor has to take into account many factors to make a treatment plan for a patient with NHL, including

- The type of NHL
- The stage and category of the disease
- Factors such as fever, drenching night sweats and weight loss of more than 10 percent of body weight, referred to as “B symptoms”
- The presence of lymphoma in areas of the body outside the lymph nodes
- The patient’s age and overall health

Types of treatment are

- Watch-and-wait—a medical approach for some types of NHL

- Chemotherapy—the main type of treatment for NHL
- Drug therapy—Rituximab (Rituxan®) and certain other drugs are used to treat some types of NHL
- Radiation therapy—an important added treatment given along with chemotherapy for some types of NHL (but not usually the only or main treatment)
- Stem cell transplantation—a procedure used for some types of NHL
- New types of treatment—now under study in clinical trials (see *About Clinical Trials* on page 39)

**Here are some questions you may want to ask your healthcare team.**  
See pages 55-60 for a full list of questions.

1. What is the subtype?
2. What are the treatment options, including clinical trials?
3. What is the goal of treatment?
4. What are the benefits and risks of these treatments?
5. Is there one treatment recommended over the others?
6. How can potential side effects be prevented or managed?

**Watch-and-Wait.** In most cases, a patient begins treatment for NHL right away. But when a patient has NHL that is not growing—or is growing very slowly—the doctor may recommend a watch-and-wait approach.

The watch-and-wait approach means that a doctor watches a patient's condition but does not treat the patient with drugs or radiation therapy. Patients may think that they should have treatment right away. But watch-and-wait is a real medical approach that is proven to work. It is sometimes truly better not to start treatment for patients with slow-growing disease and no symptoms. This allows the patient to avoid the side effects of therapy until treatment is needed.

Patients in a watch-and-wait situation are not ignored and **do** need frequent follow-up visits with their doctor. At each office visit, the doctor will check for any health changes. The results of exams and lab tests over time will help the doctor advise the patient about when to start treatment with drugs or radiation.

Treatment will begin if a patient develops symptoms or there are signs that the NHL is starting to grow.

### WANT MORE INFORMATION?



You can view, print or order the free LLS Fast Facts *Watch and Wait* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Drug Therapy.** Patients may be treated with one to five drugs at a time. The goal of treatment is a series of remissions – each remission can last a number of years. This can be true even when tests show that the disease remains in some parts of the body. Many patients lead active, good-quality lives.

The dosage of chemotherapy depends on many different factors.

High-dose chemotherapy may also unfortunately kill normal blood-forming cells in the marrow. Chemotherapy may cause very low counts of red blood cells, white blood cells or platelets. A red blood cell transfusion or drugs called **blood cell growth factors** may be needed until the side effects of chemotherapy wear off.

Examples of these growth-factor drugs are

- **Aranesp**® (darbepoetin alfa) and **Procrit**® (epoetin alfa) – these can increase the red blood cell count
- **Neupogen**® (filgrastim) or **Neulasta**® (pegfilgrastim) (also called **granulocyte-colony stimulating factor** or **G-CSF**) and **Leukine**® (sargramostim) (also called **granulocyte-macrophage colony stimulating factor** or **GM-CSF**) – these can increase the number of neutrophils (white blood cells)

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Blood Transfusion* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

Most treatment for NHL takes place in an outpatient setting. Some patients may need to stay in the hospital (inpatient) for a short time – for example, if they develop a fever or have other signs of infection. Some patients who need antibiotics may stay in the hospital until the infection is gone.

## Some Drug Combinations Used to Treat NHL

Many drug combinations are used to treat NHL. The drug choice depends on the type of NHL and the stage of the disease.

A number of drug combinations include the drug **rituximab (Rituxan®)**. Rituximab kills certain types of cancer cells. It can cause side effects, but, in general, it does not cause as many side effects as chemotherapy.

**R-CHOP:** Rituximab (Rituxan®) plus cyclophosphamide, hydroxydoxorubicin (doxorubicin), Oncovin® (vincristine) and prednisone

**R-HCVAD:** Rituximab plus cyclophosphamide, vincristine, Adriamycin® (doxorubicin) and dexamethasone

**R-EPOCH:** Rituximab plus etoposide, prednisone, Oncovin® (vincristine), cyclophosphamide, hydroxydaunorubicin

**DHAP:** Dexamethasone, High-dose Ara-C® (cytarabine), Platinol® (cisplatin)

**ICE:** Ifosfamide, carboplatin, etoposide

**m-BACOD:** Methotrexate, bleomycin, Adriamycin® (doxorubicin), cyclophosphamide, Oncovin® (vincristine), dexamethasone

**MACOP-B:** Methotrexate, Adriamycin® (doxorubicin), cyclophosphamide, Oncovin® (vincristine), prednisone plus bleomycin

**ProMACE CytaBOM:** Prednisone, Adriamycin® (doxorubicin), cyclophosphamide, etoposide, cytarabine, bleomycin, Oncovin® (vincristine), methotrexate

**CNOP:** Cyclophosphamide, mitoxantrone, Oncovin® (vincristine), prednisone

**Table 2.** This table includes treatment approaches for non-Hodgkin lymphoma subtypes. See [www.LLS.org/drugs](http://www.LLS.org/drugs) for more information.

Drugs may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

## Some Other FDA-Approved Drugs Used to Treat NHL

**Brentuximab vedotin (Adcetris®)** – for treatment of patients with systemic anaplastic large cell lymphoma (ALCL) after at least one previous chemotherapy combination did not work. It has also been approved for treatment of adult patients with primary cutaneous anaplastic large cell lymphoma (pcALCL) or mycosis fungoides (MF) who also received prior therapy.

**Copanlisib (Aliqopa™)** – for treatment of adult patients with relapsed follicular lymphoma (FL) who have received at least two prior therapies.

**Bendamustine hydrochloride (Bendeka®)** – to treat patients with relapsed, slow-growing B-cell NHL that has progressed within six months of treatment with rituximab or a regimen that contains rituximab. Bendeka® is also approved to treat patients with chronic lymphocytic leukemia (CLL).

**Acalabrutinib (Calquence®)** – for treatment of adults with mantle cell lymphoma (MCL) who have received at least one prior therapy.

**Pralatrexate (Folotyn®)** – for patients with relapsed or refractory peripheral T-cell lymphoma (PTCL).

**Obinutuzumab (Gazyva®)** – for patients with relapsed or refractory follicular lymphoma (FL) in combination with chemotherapy, followed by Gazyva alone in those who responded to it, and for people with previously untreated advanced FL

**Ibrutinib (Imbruvica®)** – Ibrutinib is approved for patients with

- Mantle cell lymphoma (MCL) who have received at least one prior therapy
- Chronic lymphocytic leukemia (CLL)/small lymphocytic lymphoma (SLL)
- Chronic lymphocytic leukemia (CLL)/small lymphocytic lymphoma (SLL) with 17p deletion
- Waldenström macroglobulinemia (WM)
- Marginal zone lymphoma (MZL) who have received at least one prior therapy

**Romidepsin (Istodax®)** – for treatment of patients with PTCL and CTCL who have received at least one previous therapy

**Rituximab and hyaluronidase human (Rituxan Hycela®)\*** – rituximab and hyaluronidase human, combined into one (injection) treatment, for patients with

- Follicular Lymphoma (FL)
  - Relapsed or refractory FL, as a single agent
  - Previously untreated FL, in combination with first-line chemotherapy
  - In patients who have achieved a complete or partial response to rituximab in combination with chemotherapy, as single-agent maintenance therapy
  - Non-progressing low-grade B-cell NHL, as a single agent after first-line cyclophosphamide, vincristine and prednisone (CVP) chemotherapy
- Diffuse Large B-cell Lymphoma (DLBCL) - for previously untreated DLBCL, in combination with CHOP or other anthracycline-based chemotherapy regimens
- Chronic Lymphocytic Leukemia (CLL) - for previously untreated and previously treated CLL in combination with fludarabine and cyclophosphamide (FC)

\*Limitations of Use of Rituxan Hycela: Initiate treatment with Rituxan Hycela only after patients have received at least one full dose of a rituximab product by intravenous infusion.

**Duvelisib (Copiktra™)** - for treatment of relapsed or refractory CLL, SLL or FL after two prior therapies.

**Mogamulizumab-kpkc (Poteligeo®)** - for the treatment of adult patients with relapsed or refractory mycosis fungoides or Sézary syndrome after at least one prior systemic therapy.

**Bortezomib (Velcade®)** – to treat mantle cell lymphoma (MCL).

**Axicabtagene ciloleucel (Yescarta®)** – a type of immunotherapy, called chimeric antigen receptor (CAR) therapy, for treatment of adult patients with relapsed or refractory large B-cell lymphoma after two or more lines of therapy, including DLBCL, primary mediastinal large B-cell lymphoma, high-grade B-cell lymphoma, and DLBCL arising from FL. Yescarta is not indicated for the treatment of patients with primary central nervous system lymphoma.

**Tisagenlecleucel (Kymriah™)**, a type of immunotherapy, called chimeric antigen receptor (CAR) therapy, for treatment of adult patients with relapsed or refractory large B-cell lymphoma after two or more lines of therapy including DLBCL, high grade B-cell lymphoma and DLBCL arising from FL. Kymriah is not indicated for treatment of patients with primary central nervous system lymphoma.

**Ibritumomab tiuxetan (Zevalin®)** – a type of immunotherapy called **radioimmunotherapy** (carries a radioactive substance that targets only lymphoma cells and reduces side effects that hurt normal cells). Approved for relapsed or refractory low-grade or follicular lymphoma. It is also approved for previously untreated follicular NHL patients who achieve a partial or complete response to initial chemotherapy.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Chimeric Antigen Receptor (CAR) T-Cell Therapy Facts* and *Immunotherapy Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

Use the lines provided on **page 61** to write down what your treatments are and when they were prescribed to you.

**Maintenance for Slow-Growing NHL.** People with some types of slow-growing lymphoma may continue treatment to stay in remission. This is called **maintenance therapy**. **Rituximab** is a drug that is approved for maintenance therapy for patients with follicular lymphoma.

**Radiation Therapy.** Radiation uses high-energy rays to kill lymphoma cells in one area of the body. Radiation can be used along with chemotherapy when there are very large masses of lymphoma cells in a small area of the body. Radiation can also be used when large lymph nodes are pressing on an organ (such as the bowel), and chemotherapy cannot control it. But radiation alone usually is not the only treatment for NHL because the lymphoma cells are likely to be in many areas of the body.

**Stem Cell Transplantation.** This is a procedure in which patients receive healthy stem cells to replace their own stem cells that have been destroyed by cancer or cancer treatments. The goal of stem cell transplant is to help the body start a new supply of blood cells after the patient gets high-dose chemotherapy.

When doctors are planning treatment, they use a number of factors to determine a patient's need for a stem cell transplant. These factors may include the individual's disease, subtype, stage, other treatment received and physical ability to have the transplant. A stem cell transplant is not for every patient, but it can be helpful for some.

There are two main types of stem cell transplantation, one that replaces the patient's blood with his or her own stem cells (autologous), and one that gets replacement stem cells from a donor (allogeneic). Talk to your doctor about whether a stem cell transplant is a treatment for you.

**Autologous Stem Cell Transplantation.** Autologous transplantation is more frequently used than allogeneic transplantation for NHL patients. Autologous transplants are generally done in the hospital. With an autologous transplant

- The patient's own stem cells are collected from his/her blood or marrow and are frozen and stored.
- The patient is then given high-dose chemotherapy and sometimes radiation to kill the lymphoma cells in his or her body. This treatment also kills normal stem cells in the marrow.
- The patient's stored stem cells are returned to their body through an intravenous (IV) or central line.
- The donor stem cells go from the patient's blood to the marrow and help start a new supply of red blood cells, white blood cells and platelets.

**Allogeneic Stem Cell Transplantation.** An allogeneic transplant is a treatment that uses stem cells from a donor. But the donor must be a "match" to the patient. The donor may be a brother or sister (siblings are most often the best match). The donor could be an unrelated person with stem cells that match the patient's. Stem cells may also come from cord blood (the blood in the umbilical cord after a baby's birth). Allogeneic transplants are done in the hospital. With an allogeneic transplant

- Stem cells are collected from a donor and are frozen and stored.
- The patient is given high-dose chemotherapy and sometimes radiation therapy to kill the lymphoma cells in the body.
- The donor stem cells are given to the patient through an intravenous (IV) line or central line.
- The donor stem cells go from the patient's blood to the marrow and help start a new supply of red blood cells, white blood cells and platelets.

For patients who may not be able to get the high doses of chemotherapy that are given to patients during stem cell transplant, there is another type of allogeneic stem cell transplant. Reduced-intensity allogeneic stem cell transplant (also called a **nonmyeloablative transplant**) is less harsh. This type uses lower doses of chemotherapy than a standard allogeneic transplant. Some older or sicker patients may be helped by this treatment. Talk to your doctor about whether stem cell transplant might work for you.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation* and *Cord Blood Stem Cell Transplantation Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Refractory or Relapsed NHL.** In some patients, NHL does not respond to initial treatment. This is called **refractory** NHL. And in some patients, disease can come back months or years after treatment ends. This condition is called **relapsed** NHL.

There are many drug choices and approaches to treatment for patients with relapsed or refractory NHL. If relapse occurs long after treatment, the same drugs that were used for the patient before may be tried again. In other cases, new drugs or treatments are used in clinical trials (see *page 39*). Patients with refractory or relapsed NHL should also ask the doctor about participating in a clinical trial.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Non-Hodgkin Lymphoma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# Childhood NHL

Burkitt lymphoma is the most common type of NHL in children ages 5 through 14 years.

Children and teens with NHL should be treated at medical centers that have a pediatric hematology-oncology team. It is important for young adults and parents of children to talk to members of the oncology team about the

- Specific subtype of NHL
- Stage of the disease
- Fertility concerns (see *Before-Treatment Factors* on page 9)
- Lab test results

Doctors use this information about the patient's disease to determine the most effective therapy. Treatments used for children with NHL may be different from those used for adults with NHL.

See *Before-Treatment Factors* on page 9 and *About Clinical Trials*, below for more information.

## PART 4 Clinical Trials

### About Clinical Trials

There are new treatments under study for lymphoma patients of all ages. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments, such as changing the dose of the drug, giving the drug along with another type of treatment, or ordering drugs in new sequences. Different approaches may be more effective in treating the disease.

There are clinical trials for

- Newly diagnosed lymphoma patients
- Patients who did not get a good response to treatment (refractory disease)
- Patients whose disease returned (relapsed disease)
- Patients who need to continue treatment after remission (maintenance)

A carefully conducted clinical trial may provide the best available therapy for patients with HL or NHL.

**Here are some questions you may want to ask your healthcare team.**

See *pages 55-60* for full list of questions.

1. Is a clinical trial a treatment option?
2. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs, such as testing?
3. Who pays for the travel costs to get to the trial?

Ask your doctor if treatment in a clinical trial may be right for you. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can provide more information about clinical trials and help search for a clinical trial for you. When appropriate, personalized clinical-trial navigation by trained nurses is also available.

**WANT MORE INFORMATION?**



You can view, print or order the free LLS booklets *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

**PART 5 Side Effects and Follow-up Care**

**Overview of This Section**

- Treatment side effects vary depending on the type of treatment (for example, chemotherapy, targeted therapy, radiation, etc).
- Some of the common side effects of treatment for HL and NHL may include mouth sores, nausea, diarrhea and/or constipation, or changes in blood counts.
- Parents should talk to the doctor if they think their child’s learning skills may have been affected by lymphoma or its treatment. The child’s learning skills should be checked.
- Children and adults who have been treated for lymphoma should see their primary care doctor and a cancer specialist for follow-up care.

## Side Effects and Follow-Up Care

The side effects of lymphoma depend on many factors. It is important to follow up with your doctor about any side effects while on treatment as well as long-term and late effects that develop.

## Side Effects of Lymphoma Treatment

The aim of treatment for HL and NHL is to kill the lymphoma cells. Treatment side effects depend on the type of treatment. The term side effect is used to describe how treatment affects people's bodies, and often defines the negative or undesirable effects from a treatment. Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Some side effects are serious and last a long time. Lymphoma patients should talk with their doctors about side effects before they begin any type of treatment.

**Here are some questions you may want to ask your healthcare team.**

See *pages 55-60* for a full list of questions.

1. What side effects should be reported to the team right away?
2. What are the common side effects of treatment?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?

Lymphoma treatment may affect your blood counts.

- The number of red blood cells may decrease (this is called **anemia**).
  - Blood transfusions may be needed to increase red blood cells.
  - Drugs called **growth factors** such as **Aranesp®** and **Procrit®** may be given to increase the red blood cell count.
- Patients may have a drop in the number of platelets in their blood. A platelet transfusion may be needed to prevent bleeding if the platelet count is very low.

- A severe drop in white blood cells may lead to infection.
  - Infections caused by bacteria or fungi are treated with antibiotics.
  - To help improve a patient's white blood cell count
    - The amount of chemotherapy drugs may be reduced.
    - The time between treatments may be increased.
    - Growth factors such as **Neupogen®**, **Neulasta®** and **Leukine®** may be given to increase white blood cell counts.

**Common Side Effects.** Some of the common side effects of treatment for HL and NHL may include

- Mouth sores
- Nausea
- Vomiting
- Diarrhea
- Constipation
- Bladder irritation
- Blood in the urine

Other side effects of treatment may include

- Extreme tiredness
- Fever
- Cough
- Rash
- Hair loss
- Weakness
- Tingling sensation in fingertips and toes
- Lung, heart or nerve problems

There may be other side effects that are not listed here that you should watch for when taking a specific treatment. Talk to your doctor about the possible side effects of your treatment. You can also call our Information Specialists.

Not all patients have these side effects. Treatment to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable.

## WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Understanding Side Effects of Drug Therapy* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Long-Term and Late Effects

**Long-term effects** are side effects of treatment that may last for months or years after treatment ends. Fatigue is an example of a long-term side effect. In children, learning skills may be affected.

**Late effects** are side effects of treatment that may not show up until years after treatment ends. Heart disease is an example of a possible late side effect.

Not everyone who is treated for lymphoma develops long-term or late effects. It depends on the patient's age, overall health and specific treatment.

Patients should talk with their doctors about any long-term or late effects that they experience. Parents should talk to the doctor if they think their child's learning skills may have been affected by lymphoma or treatment and should be checked.

### **Here are some questions you may want to ask your healthcare team.**

See *pages 55-60* for full list of questions.

1. Who should I (we) work with to ensure life-long follow up?
2. How can I (we) be monitored for long-term and late effects of treatment?
3. What types of long-term and late effects should be brought to the healthcare team's attention?

## WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma Facts*; *Learning and Living with Cancer: Advocating for your Child's Educational Needs*; and *Long-Term and Late of Effects of Treatment in Adults Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

## Follow-Up Care

Follow-up medical care is important for every lymphoma patient. Follow-up care helps the doctor monitor you to see if disease has recurred or relapsed, or to see if more treatment is needed.

Children and adults who have been treated for lymphoma should see their primary care doctor and a hematologist-oncologist (cancer specialist) for follow-up care. Patients should talk to the doctor about how often to have follow-up visits. You can ask your doctor what tests will be needed and find out how often you should have these tests. It is important to get a record of the cancer treatment including the drugs you receive and the time you receive them, so that your doctor can follow up on specific long-term effects that may be associated with your treatment.

**Here are some questions you may want to ask your healthcare team.**

See *pages 55-60* for a full list of questions.

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. What information can be provided to my primary doctor about past treatment and what may be needed in the future?

Follow-up care includes physical exams and blood tests. Sometimes bone marrow tests are also needed. The doctor may advise longer periods of time between follow-up visits if a patient

- Continues to be free of signs of lymphoma
- Does not need medical care for any long-term or late effects

To find a survivorship clinic and other resources for child and adult survivors, contact our Information Specialists at (800) 955-4572.

## Take Care of Yourself

- Keep all appointments with the doctor.
- Discuss how you feel with the doctor at each visit. Ask any questions you have about side effects.
- People with lymphoma may have more infections. Follow the doctor's advice for preventing infection.

- Eat healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. See your primary care doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. When family and friends know about lymphoma and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It can be treated at the same time that a person is being treated for lymphoma. Treatment for depression has benefits for people living with cancer.

## RESOURCES AND INFORMATION

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date information about disease, treatment and support. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)
- Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)
- Visit: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Free Information Booklets.** LLS offers free education and support publications that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial assistance to individuals with blood cancer. Visit [www.LLS.org/finances](http://www.LLS.org/finances) for more information.

**Co-Pay Assistance Program.** LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please

- Call: (877) 557-2672
- Visit: [www.LLS.org/copay](http://www.LLS.org/copay)

**One-on One Nutrition Consultations.** Access free one-on-one nutrition consultations by a registered dietitian with experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Podcast.** Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. For more information and to subscribe, visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline).

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

## Community Resources and Networking

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**LLS Chapters.** LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups and other great resources. For more information about these programs or to contact your chapter, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/ChapterFind](http://www.LLS.org/ChapterFind)

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to obtain our directory.

**Clinical Trials (Research Studies).** New treatments for patients are under-way. Patients can learn about clinical trials and how to access them. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches. When appropriate, personalized clinical-trial navigation by trained nurses is also available. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Advocacy.** The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/advocacy](http://www.LLS.org/advocacy)

### **Additional Help for Specific Populations**

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let your doctor know if you need a language interpreter or other helper, such as a sign language interpreter. Often, these services are free.

**Children's Concerns.** Parents of a child with lymphoma may want to talk to members of their child's healthcare team about how to find enough time for everything, pay for treatment, and best help their children. For more information, see the free LLS booklet *Coping With Childhood Leukemia and Lymphoma*.

### **The Trish Greene Back to School Program for Children With Cancer.**

This program helps doctors, nurses, parents and school personnel work together for a smooth return to school for children with cancer. For more information, contact your LLS chapter or call (800) 955-4572.

**Information for Veterans.** Veterans with lymphoma who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information visit [www.publichealth.va.gov/exposures/agentorange](http://www.publichealth.va.gov/exposures/agentorange) or call the Department of Veterans Affairs at (877) 222-8387.

**World Trade Center Survivors.** People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: [www.cdc.gov/wtc/faq.html](http://www.cdc.gov/wtc/faq.html)

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

**Feedback.** To make suggestions about the content of this booklet, go to [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback).

## Health Terms

**Antibiotic.** A drug that is used to treat infections caused by bacteria and fungi. Penicillin is one type of antibiotic.

**Antibody.** A protein made by plasma cells. Antibodies help fight infection in the body.

**Bone marrow aspiration.** A test that checks to see if a patient's fluid in their bone marrow is normal. A sample of cells is taken from the patient. The cells are looked at under a microscope. Bone marrow aspiration and biopsy are usually done at the same time.

**Bone marrow biopsy.** A test that checks the marrow cells in the bone to see if they are normal. A very small amount of bone is removed from the body. The cells within it are looked at under a microscope. Bone marrow aspiration and bone marrow biopsy are usually done at the same time.

**Central line.** A special tube the doctor puts into a large vein of the patient. The vein is usually in the upper chest. The central line is used to give the patient chemotherapy drugs and blood cells. It can also be used to take blood samples from the patient.

**Chemotherapy or drug therapy.** Chemical agents that treat lymphoma and other cancers.

**Chromosome.** These are 23 pairs of certain basic structures in human cells. Chromosomes are made up of genes. Genes give instructions that tell the cells what to do. In cancer, the number or the shape of chromosomes may be altered or not normal.

**Clinical trials.** Careful studies done by doctors to test new drugs or treatments. Trials also find new uses for approved drugs or treatments. The goal of clinical trials is to improve treatment and quality of life for patients, and to find cures for blood cancer.

**Combination chemotherapy or drug therapy.** The use of two or more drugs together to treat lymphoma and other cancers.

**Diagnose.** To determine a disease from a person's signs, symptoms and test results. The doctor diagnoses a patient.

**Fertility.** Ability to have children.

**FDA.** The short name for the United States Food and Drug Administration. Part of the FDA's job is to assure that drugs are safe and that they really work. The FDA also checks on medical devices (like implants) and ensures the safety of the US food supply.

**FDG-PET (fluorodeoxyglucose[FDG]-positron emission tomography[PET]) scan.** A PET scan is a test that produces a 3D image of what is going on in the body. A FDG-PET scan uses a small amount of a radioactive sugar called **FDG** to show the difference between healthy and diseased tissue.

**Hemoglobin.** The part of the red blood cell that carries oxygen throughout the body.

**Hematologist.** A doctor who has special training in the treatment of blood diseases.

**Hematopathologist.** A doctor who studies blood cells and tissues under a microscope to identify disease.

**Immune system.** A network of cells and organs that help defend the body from infection. Lymphocytes, lymph nodes and the spleen are some parts of the immune system.

**Immunophenotyping.** A lab test that can be used to identify types of lymphoma cells.

**Immunotherapy.** Treatments that help the body's immune system fight lymphoma and other diseases. Some types of immunotherapy are monoclonal antibody therapy, radioimmunotherapy and vaccines.

**Lymph node.** Small bean-shaped structure that contains a large number of lymphocytes (white blood cells). They are a part of the body's immune system. There are about 600 lymph nodes in the body.

**Lymphatic system.** The system that connects the lymph nodes. This network runs all throughout the body to carry infection-fighting cells. It is an important part of the immune system.

**Lymphocytes.** White blood cells that fight infection. They are carried through the lymphatic system and cluster together in lymph nodes.

**Monoclonal antibody therapy.** A treatment that targets and kills certain cancer cells. In general, it does not cause as many side effects as chemotherapy.

**Oncologist.** A doctor who has special training to treat patients who have cancer.

**Pathologist.** A doctor who identifies diseases by looking at cells and tissues under a microscope.

**Platelets.** Blood cells that help prevent or stop bleeding. Platelets clump together at the site of an injury and “clot” so that bleeding will stop.

**Radiation therapy.** Treatment with x-rays or other high-energy rays.

**Radioimmunotherapy.** Treatment that uses antibodies to carry a radioactive substance to lymphoma cells to kill them.

**Red blood cells.** Blood cells that contain hemoglobin that binds to oxygen and carries it to the tissues of the body.

**Refractory lymphoma.** Lymphoma that does not respond to treatment. Refractory lymphoma may also be disease that is getting worse or staying the same.

**Relapsed lymphoma.** Lymphoma that at first, or for a time, responded to treatment, but then returns.

**Remission.** No sign of disease, usually as a result of treatment.

**Spleen.** An organ found on the left side of the body near the stomach. It contains lymphocytes and removes old or damaged cells from the blood.

**Stem cell.** A type of cell found in bone marrow that makes red blood cells, white blood cells and platelets.

**Systemic therapies.** Drugs that spread throughout the body to reach the affected cells.

**White blood cells.** Cells that fight infection in the body. There are two major types of white blood cells: infection-fighting lymphocytes (B cells, T cells and natural killer [NK] cells; and germ-eating cells [neutrophils and monocytes]).

## My Healthcare Team Contact List

Use this list to remember names and contact information for members of your healthcare team.

### CAREGIVER NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

### PRIMARY CARE DOCTOR NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

### PHARMACY NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Additional information: \_\_\_\_\_

### Information Specialists:

Phone: 1-800-955-4572

Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)

Website: [www.LLS.org/InformationSpecialist](http://www.LLS.org/InformationSpecialist)

**HEMATOLOGIST-ONCOLOGIST NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Website/Portal: \_\_\_\_\_

Additional information: \_\_\_\_\_

**NURSE/NURSE PRACTITIONER NAME:**

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**SOCIAL WORKER NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**INSURANCE CASE MANAGER/  
CARE COORDINATOR NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Website or email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**PHYSICIAN ASSISTANT NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email Address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**NURSE NAVIGATOR NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**OTHER:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**OTHER:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

## Question Guide: My First Doctor's Visit

Asking questions will help you take an active role in managing your (or your loved one's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works.

(Note: The use of "I (we)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

### Questions for the Doctor

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

1. How many patients have you treated who have my disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive return of a phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form available so my family/caregiver can be given medical information?

## Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

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1. How long would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive return of a phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.

## Question Guide: Treatment and Follow-up Care

Talk with the doctor and ask questions about how he or she plans to treat your (your loved one's) lymphoma. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

(Note: The use of "I (we)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

**DOCTOR'S NAME:** \_\_\_\_\_

**Date of appointment or phone call:** \_\_\_\_\_

**Write down your diagnosis:**

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**Write down your lymphoma subtype:**

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## Before Treatment Begins

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make any decisions?
5. What is the subtype?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

## Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results back?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

## Treatment

1. Will this be an in-hospital or an outpatient treatment?  
If the treatment is outpatient:  
Is work or attending school during treatment going to be all right?  
Will someone be needed to drive me home after treatment?
2. What kind of testing will be done to monitor this disease and treatment? How often will testing be needed? Where is the testing done?
3. How can it be known if the treatment is effective? What options are available if the treatment is not effective?
4. What is the likely outcome of the disease (prognosis)?

## Side Effects

1. What are the common side effects for this treatment?
2. What side effects should be reported to the team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?
5. How should I report side effects (phone call, at the office visit, etc).

## **Social/Financial Concerns**

1. Are there any side effects that will affect appearance or ability to do a job/go to school?
2. What kind of financial and social support services are available to me and my family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone who can be spoken to for assistance?
6. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical trial drugs?
7. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs such as testing?

## **Follow-Up Care and Long-Term and Late Effects**

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I (we) be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If I have side effects later, how can the healthcare team be reached?
6. What information can be provided to my primary doctor about past treatment and what may be needed in the future?

**To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.**

## My List of Treatments

Use this space to write down what your treatments are and when they were prescribed to you.

DATE: \_\_\_\_\_

Treatment: \_\_\_\_\_

\_\_\_\_\_









Get support.

Reach out to our

## **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches



Contact us at

**800-955-4572** or

**[www.LLS.org/  
informationspecialists](http://www.LLS.org/information specialists)**

(Language interpreters can be requested)



For more information, please contact our Information Specialists **800.955.4572** (Language interpreters available upon request).

**BEATING  
CANCER  
IS IN  
OUR BLOOD.**

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**National Office** 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).