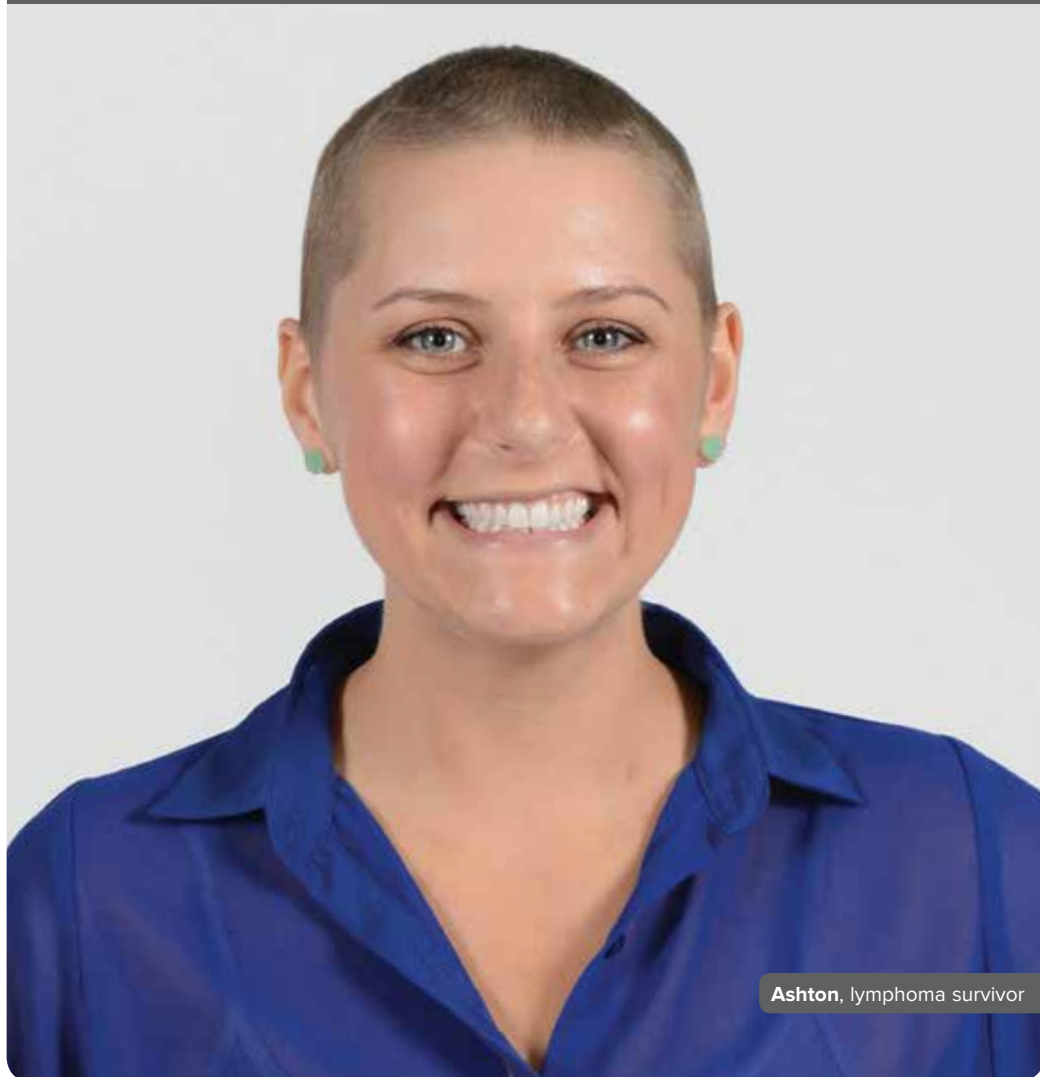


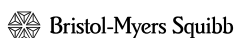
The Lymphoma Guide

Information for Patients and Caregivers



Ashton, lymphoma survivor

This publication
was supported by



Revised 2016

The Leukemia & Lymphoma Society wants you to have the most up-to-date information about blood cancer treatment. See below for important new information that was not available at the time this publication was printed.

- In November 2017, the Food and Drug Administration (FDA) approved obinutuzumab (Gazyva®) in combination with chemotherapy, followed by Gazyva alone in those who responded, for people with previously untreated advanced follicular lymphoma (stage II bulky, III or IV).
- In November 2017, the Food and Drug Administration (FDA) approved brentuximab vedotin (Adcetris®) for treatment of adult patients with primary cutaneous anaplastic large cell lymphoma (pcALCL) or CD30- expressing mycosis fungoides (MF) who have received prior systemic therapy.
- In October 2017, the Food and Drug Administration (FDA) approved acalabrutinib (Calquence™) for the treatment of adults with mantle cell lymphoma who have received at least one prior therapy.
- In October 2017, the Food and Drug Administration (FDA) approved axicabtagene ciloleucel (Yescarta™) for the treatment of adult patients with relapsed or refractory large B-cell lymphoma after two or more lines of systemic therapy, including diffuse large B-cell lymphoma (DLBCL) not otherwise specified, primary mediastinal large B-cell lymphoma, high-grade B-cell lymphoma, and DLBCL arising from follicular lymphoma. Yescarta is a CD19-directed genetically modified autologous T cell immunotherapy FDA approved. Yescarta is not indicated for the treatment of patients with primary central nervous system lymphoma.
- In September 2017, the Food and Drug Administration (FDA) approved copanlisib (Aliqopa™) for the treatment of adult patients with relapsed follicular lymphoma (FL) who have received at least two prior systemic therapies.
- In July 2017, the Food and Drug Administration (FDA) approved rituximab and hyaluronidase human (Rituxan Hycela™), which is a combination of rituximab, a CD20-directed cytolytic antibody, and hyaluronidase human, an endoglycosidase, for patients with
 - Follicular Lymphoma (FL)
 - Relapsed or refractory, follicular lymphoma as a single agent
 - Previously untreated follicular lymphoma in combination with first line chemotherapy and, in patients achieving a complete or partial response to rituximab in combination with chemotherapy, as single agent maintenance therapy
 - Non-progressing (including stable disease), follicular lymphoma as a single agent after first-line cyclophosphamide, vincristine, and prednisone (CVP) chemotherapy
 - Diffuse Large B-cell Lymphoma (DLBCL)
 - Previously untreated diffuse large B-cell lymphoma in combination with cyclophosphamide, doxorubicin, vincristine, prednisone (CHOP) or other anthracycline-based chemotherapy regimens
 - Chronic Lymphocytic Leukemia (CLL)
 - Previously untreated and previously treated CLL in combination with fludarabine and cyclophosphamide (FC)

Limitations of Use:

- Initiate treatment with RITUXAN HYCELA only after patients have received at least one full dose of a rituximab product by intravenous infusion.
- In May 2017, the Food and Drug Administration (FDA) approved nivolumab (Opdivo®) for the treatment of adult patients with classical Hodgkin lymphoma (HL) that has relapsed or progressed after 3 or more lines of systemic therapy that includes autologous hematopoietic stem cell transplantation (HSCT). It is also approved for the treatment of adult patients with classical HL that has relapsed or progressed after autologous HSCT and brentuximab vedotin.
- In March 2017, the Food and Drug Administration (FDA) approved pembrolizumab (Keytruda®) for the treatment of adult and pediatric patients with refractory classical Hodgkin lymphoma (cHL), or who have relapsed after 3 or more prior lines of therapy.
- In January 2017, the Food and Drug Administration (FDA) approved ibrutinib (Imbruvica®) for patients with marginal zone lymphoma (MZL) who require systemic therapy and have received at least one prior anti-CD20-based therapy.
Ibrutinib is also 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's macroglobulinemia (WM).

For more information, contact an Information Specialist at (800) 955-4572 or infocenter@lls.org.

A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Since 1954, we have invested more than \$1 billion in research specifically targeting blood cancers to advance therapies and save lives. We will continue to invest in research for cures, programs and services to improve the quality of life for people with lymphoma.

We know that understanding lymphoma can be tough.

We are here to help and are committed to providing you with the most up-to-date information about lymphoma, your treatment and your support options. We know how important it is for you to understand your health information. We want you to be able to use that information, along with the help of members of your healthcare team, on your pathway toward good health, remission and recovery.

Our vision is that one day all people with lymphoma will be cured or be able to manage their disease and have a better quality of life.

Until then, we trust the information in this *Guide* will help you along your journey.

We wish you well.

A handwritten signature in black ink, appearing to read "Louis J. DeGennaro". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Louis J. DeGennaro, PhD

*President and Chief Executive Officer
The Leukemia & Lymphoma Society*

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This LLS Guide about lymphoma is for information only. LLS does not give medical advice or provide medical services.

Introduction

Lymphoma is a blood cancer that develops in the lymphatic system, an important part of our immune system, which fights off diseases in our bodies. Hodgkin lymphoma and non-Hodgkin lymphoma are the two main types.

About 90 percent of people with lymphoma have non-Hodgkin lymphoma (NHL). The rest have Hodgkin lymphoma (HL). Some types of lymphoma are curable. For other types, many patients are able to keep their disease under control and have good quality of life with medical treatment. Progress in treating lymphoma gives patients more hope than ever before.

There are an estimated 788,939 people either living with, or in remission from, lymphoma in the US. This number includes

- About 181,967 people with Hodgkin lymphoma
- About 606,972 people with non-Hodgkin lymphoma

The Lymphoma Guide has sections with information for all types of lymphoma, for 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 40. Or, call our Information Specialists at (800) 955-4572.

Resources and Information

The Leukemia and Lymphoma Society (LLS) offers free information and services for patients and families affected by blood cancers. This section of the *Guide* 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 a.m. to 9 p.m. ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/information specialists.

Free Information Booklets. LLS offers free education and support booklets that can be read online or ordered. For more information, please visit www.LLS.org/booklets.

Telephone/Web Education Programs. LLS offers free telephone/Web education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

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

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

Sign Up for an e-Newsletter. Read the latest disease-specific news, learn about research studies and clinical trials, and find support for living with blood cancer. Please visit www.LLS.org/signup.

Community Resources and Networking

Online Blood Cancer Discussion Boards and Chats. Online discussion boards and moderated online chats can help cancer patients reach out, share information and provide and receive support. For more information, please visit www.LLS.org/discussionboard and www.LLS.org/chat.

LLS Community. LLS Community is an online social network and registry for patients, caregivers, and supporters of those with blood cancer. It is a place to ask questions, get informed, share your experience and connect with others. To join visit www.LLS.org/community.

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.

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, locating summer camps and other needs. For more information, please visit www.LLS.org/resourcedirectory.

Clinical Trials (Research Studies). New treatments for patients are under way. Many are part of clinical trials. 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 a clinical-trial search.

Advocacy. The LLS Office of Public Policy (OPP) engages volunteers to advocate for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information, please

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

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). For more information, please visit www.LLS.org/espanol.

Language Services. Let your doctor know if you need a language interpreter or other resource, 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 to help a child with cancer smoothly return to school. 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 call the Department of Veterans Affairs at (877) 222-8387 or visit www.publichealth.va.gov/exposures/agentorange.

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.

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: National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov, enter “depression” in the search box.

Feedback. To provide your opinion of this *Guide* please visit: www.LLS.org/publicationfeedback.

Want more information?



You can view, print or order the free LLS booklets *Hodgkin Lymphoma* and *Non-Hodgkin Lymphoma* at www.LLS.org/booklets or contact our Information Specialists for copies.

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.

About Marrow, Blood and Blood Cells

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

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

Blood cells are made in the marrow. They begin as stem cells. Stem cells become red blood cells, white blood cells and platelets in the marrow. Then the red blood cells, white blood cells and platelets enter the blood.

Platelets help stop bleeding by getting blood to stick 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, the condition is called **anemia**. Anemia may make you feel tired or short of breath. It may make the skin look pale.

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

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)

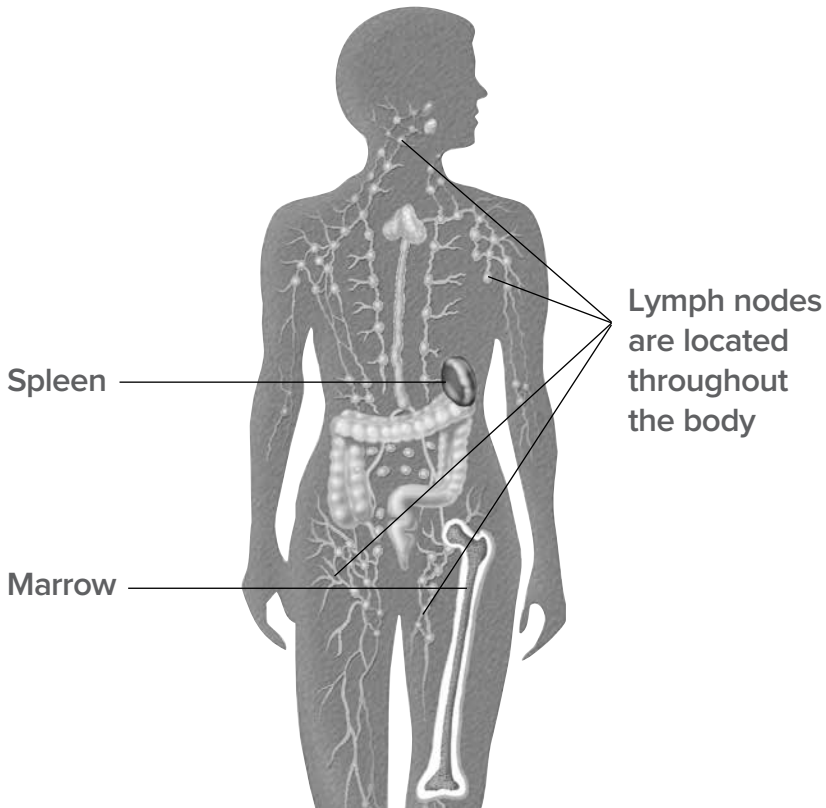
- Shows the part of the blood made up of different types of white cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

The Immune System

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

- **The marrow and the lymphocytes** (see page 7).
- **Lymph nodes**, which are bean-sized collections of lymphocytes. There are about 600 lymph nodes found throughout the body—in the neck, armpits, chest, abdomen, groin and some other parts of the body. Lymphatic vessels connect the lymph nodes. They contain lymph, a fluid that carries lymphocytes.
- **The spleen**, which is an organ on the left side of the body near the stomach. It contains lymphocytes and removes old or damaged cells from the blood.

Some Parts of the Immune System



The healthy immune system helps to protect the body from infection.

About Lymphoma

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

The change to the lymphocyte causes it to become a 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 other parts of the body.

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**. Or your local cancer specialist can work with a lymphoma specialist. Always check to see if the doctor or 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 our Information Specialists at LLS at (800) 955-4572.
- Use online doctor-finder resources, such as
 - The American Medical Association's (AMA) "DoctorFinder."
 - The American Society of Hematology's (ASH) "Find a Hematologist."

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 or 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 your own care and to make decisions. This *Guide* includes questions to ask your doctor about lymphoma treatment (see pages 45 to 47).

It may be helpful to write down the answers to your questions and review them later. You may want to have a caregiver, family member or friend with you when you talk to your doctor. This person can listen, take notes and offer support. Some people like to record information from the doctor and then listen to the recording later on.

People with lymphoma who are unsure about their treatment options are encouraged to get a second opinion.

Pretreatment Considerations

Adults of childbearing age and parents of children diagnosed with lymphoma should ask their doctor for options that may lessen the risk of infertility.

Want more information?



For a list of healthcare question guides about second opinions and other topics that you can print, go to www.LLS.org/whattoask. You can view, print or order the free LLS fact sheet *Fertility Facts* at www.LLS.org/booklets or contact our Information Specialists for a copy.

Hodgkin Lymphoma

Want more information?



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

Hodgkin lymphoma (HL) is one of the most curable forms of cancer. HL is distinguished from other types of lymphoma by the presence of “Reed-Sternberg cells” (named for the scientists who first identified them). Reed-Sternberg cells are large, abnormal lymphocytes.

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.

Signs and Symptoms

The most common sign 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. It is usually painless.

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.

Other signs and symptoms of HL may include

- Cough and shortness of breath
- Fever
- Night sweats
- Tiredness

- Weight loss
- Itchy skin.

Diagnosis and Staging

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 lymph node is examined under a microscope by a pathologist (a doctor who diagnoses diseases by studying cells and tissues under a microscope).

It may be important to get another opinion about the biopsy results from a second pathologist to confirm the diagnosis.

The doctor will do other tests to stage the disease (the stage will tell the doctor how far the disease has spread). See *Lymphoma Stages* on page 15 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 are also done to check for other signs of disease
- Bone marrow tests – to look for HL cells in the bone marrow
- 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 a computed [CT] tomography scan)
- MRI (magnetic resonance imaging).

How are the Blood and Bone Marrow Tests Done?

Blood tests. Usually a small amount of blood is taken from the patient's arm with a needle. The blood is collected in thin glass containers (vials) and sent to a lab.

Bone marrow aspiration. A liquid sample of cells is usually taken from the bone marrow of a patient's hip bone using a special needle.

Bone marrow biopsy. A very small amount of bone filled with marrow cells is removed through a needle, usually from the hip bone.

Blood and bone marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and a bone marrow biopsy are almost always done together. Both tests are done with a special needle. Some patients are awake for the procedure. They get medication first 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.

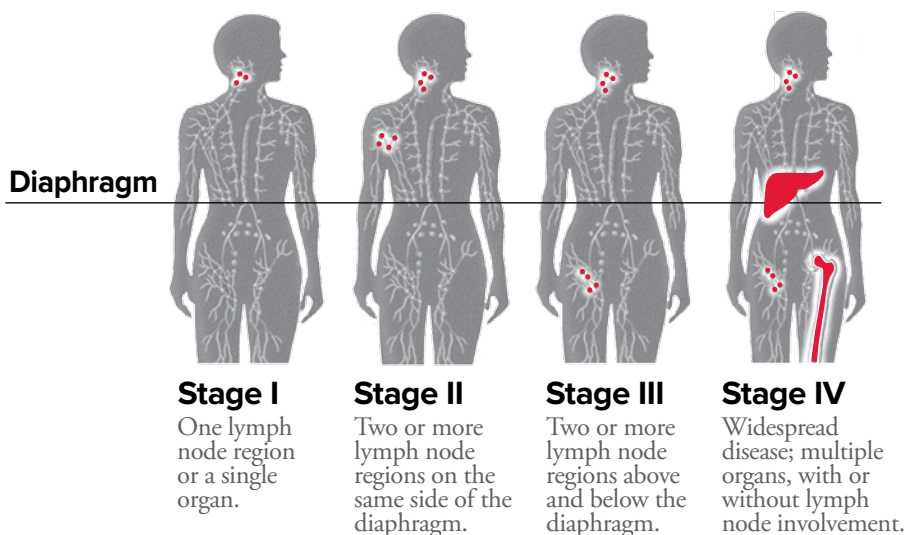
Blood and bone marrow tests may be done both during and after treatment. The tests are repeated to see if treatment is working by destroying lymphoma cells.

Want more information?



You can view, print or order the free LLS booklet *Understanding Lab and Imaging Tests* to learn more about lab tests and what to expect at www.LLS.org/booklets or contact our Information Specialists for a copy.

Lymphoma Stages



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.

All stages of lymphoma can be treated.

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 – 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

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

Treatment

HL can be cured in about 80 percent of all patients. The cure rate in younger patients is approaching 90 percent.

There are different types of HL. Talk to your doctor about the type of HL that you have and your treatment choices.

Factors that may affect treatment include

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

Combination chemotherapy (treatment using more than one drug) is the most common treatment. 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.

Nodular Lymphocyte-Predominant Hodgkin Lymphoma. Patients with nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) need treatment different from patients with other HL subtypes. NLPHL is slow-growing (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. For patients with more advanced disease, combination chemotherapy may be needed. For more information, see the free LLS booklet *Hodgkin Lymphoma*.

Examples of Some Treatment Approaches Used for Hodgkin Lymphoma

ABVD – Adriamycin® (doxorubicin), bleomycin, vinblastine and dacarbazine

BEACOPP – bleomycin, etoposide, Adriamycin (doxorubicin), cyclophosphamide, Oncovin® (vincristine), procarbazine and prednisone

Brentuximab vedotin (Adcetris®)

Nivolumab (Opdivo®)

Stanford V – mechlorethamine, doxorubicin, vinblastine, vincristine, bleomycin, etoposide and prednisone (rarely used)

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® (darbepoetin alfa) and Procrit® (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 or you can 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.

Neupogen® or Neulasta® (also called **granulocyte-colony stimulating factor** or **G-CSF**) and Leukine® (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 35 for more information.

Relapsed Hodgkin Lymphoma. In some patients HL may come back (this is called a **recurrence** or **relapse**). The doctor will treat these patients again with chemotherapy. The treatment often gives patients very long disease-free periods. One treatment option for relapsed HL is brentuximab vedotin (Adcetris®). This drug has been FDA-approved for the treatment of HL after failure of autologous stem cell transplant and in HL patients who are not autologous stem cell transplant candidates after failure of at least two multiagent chemotherapy regimens. Another treatment option for relapsed HL is nivolumab (Opdivo®). The FDA has approved this drug for HL patients whose disease has relapsed or progressed after autologous stem cell transplant followed by Adcetris®.

Stem Cell Transplantation

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 patient's disease, subtype, stage, other treatment received and the patient's physical ability to have the transplant. While a stem cell transplant is not an option for every patient, it can be an important addition to the treatment plan for some patients.

Additional information about the different kinds of transplants that are available for some HL patients start on the next page. Talk to your doctor about whether a stem cell transplant is a treatment option for you.

Want more information?



You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation* at www.LLS.org/booklets or contact our Information Specialists for a copy.

Autologous Stem Cell Transplantation. Autologous transplantation is more frequently used than allogeneic transplantation for HL patients.

The goal of autologous stem cell transplantation is to help the body start a new supply of blood cells after high-dose chemotherapy.

With an autologous transplant

- The patient's own stem cells are collected from the his/her blood or marrow and stored after the first cycles of drug therapy are completed.
- The patient is then given high-dose chemotherapy to kill the lymphoma cells. This treatment also kills normal stem cells in the marrow.
- The last step is to infuse the patient's own stored stem cells back into their own body.

Allogeneic Stem Cell Transplantation. An allogeneic transplant is a treatment that uses stem cells from a donor. The donor may be a brother or sister. The donor can also be an unrelated person with stem cells that “match” the patient's. Stem cells may also come from a cord blood unit (the blood in the umbilical cord after a baby's birth). Allogeneic transplants are generally done in the hospital.

- First, the patient is given high-dose chemotherapy and/or radiation therapy to kill the lymphoma cells in the body.
- Stem cells are collected from a donor.
- 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.

Reduced-intensity allogeneic stem cell transplantation (also called a **nonmyeloablative transplant**) 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 transplantation is a treatment option for you.

Childhood Hodgkin Lymphoma

Children and teens with Hodgkin lymphoma 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
- Lab test results.

Doctors use this information about the patient's disease to determine the most effective therapy. Children and young adults with Hodgkin lymphoma are usually treated with combination chemotherapy.

See *Pretreatment Considerations* on page 11 and *About Clinical Trials* on page 34 for more information.

Non-Hodgkin Lymphoma

Want more information?



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

There are many types of non-Hodgkin lymphoma (NHL). Most people with NHL have a B-cell type of NHL (about 85 percent). The others have a T-cell type or an NK-cell type of lymphoma.

NHL that is

- Slow-growing is called **indolent** or **low-grade**
- Fast-growing is called **aggressive** or **high-grade**.

Talk to your doctor about the type of NHL that you have and your treatment choices.

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.

Some Types of Non-Hodgkin Lymphoma

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)

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

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 or contact our Information Specialists for copies.

Signs and Symptoms

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

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.

Other signs and symptoms of NHL may include

- Fever
- Night sweats
- Tiredness
- Loss of appetite
- Weight loss
- Rash.

Diagnosis and Staging

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 the patient's specific subtype of NHL. Sometimes a biopsy is done to examine 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 under a microscope by a pathologist (a doctor who identifies diseases by studying cells and tissues under a microscope).
- 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 pathologist if there is any doubt about the diagnosis or to confirm the diagnosis in more rare NHL cases.

Immunophenotyping is done to find out if the patient's NHL cells are B cells, T cells, or NK cells. This is a lab test that can be done using the sample of cells from the lymph node biopsy or with sample cells from blood or a bone marrow biopsy.

The doctor will do other tests to find out the stage of the disease. See *Lymphoma Stages* on page 15 for descriptions of the stages.

A physical exam and 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 (for example, in the abdomen or the chest or in both parts of the body)

- Whether any cancer cells are in other parts of the body besides the lymph nodes or lymphatic system, such as the lungs or liver.

The 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 – to look for NHL cells in the bone marrow.
- 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-computed tomography) scan (two tests done at the same time)
 - MRI (magnetic resonance imaging)
 - PET (positron emission tomography) scan.

Other staging tests may be done for some types of NHL.

Treatment

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 – an 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 – not often the sole or principal treatment, this is an important added treatment given along with chemotherapy for some types of NHL
- Stem cell transplantation – a procedure used for some types of NHL
- New types of treatment – now under study in clinical trials (see page 34).

Chemotherapy is given in “cycles,” usually several weeks apart. The total time of treatment may last from six to ten months.

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) – can increase the red blood cell count

- Neupogen® or Neulasta® (also called **granulocyte-colony stimulating factor or G-CSF**) and Leukine® (also called **granulocyte-macrophage colony stimulating factor or GM-CSF**) – 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 or you can contact our Information Specialists for a copy.

Most treatment for NHL usually takes place in an outpatient setting. Some patients may need to stay in the hospital 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 rituximab (Rituxan®) – a monoclonal antibody therapy. Monoclonal antibody therapies kill certain types of cancer cells. They can cause side effects, but do not cause many of the side effects caused by chemotherapy.

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

R-CVP Rituximab plus cyclophosphamide, vincristine and prednisone

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

R-EPOCH: Rituximab plus etoposide, prednisone, vincristine, cyclophosphamide, doxorubicin

B-R: Bendamustine hydrochloride (Bendeka™) and rituximab

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 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. It is sometimes actually 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.

Patients may be treated with one to five drugs. 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.

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 the problem. 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.

Some Other FDA-Approved Drugs Used to Treat NHL

Adcetris[®] (brentuximab vedotin) – for the treatment of patients with systemic anaplastic large cell lymphoma (ALCL) after at least one previous multi-drug chemotherapy regimen did not work.

Folotyn[®] (pralatrexate) – for patients with relapsed or refractory peripheral T-cell lymphoma (PTCL).

Istodax[®] (romidepsin) – for the treatment of patients with PTCL who have received at least one previous therapy.

Bendeka[™] (bendamustine hydrochloride) – to treat patients with relapsed, slow-growing, B-cell NHL that has progressed during or within six months of treatment with rituximab or a rituximab-containing regimen. Bendeka[™] is also approved to treat patients with chronic lymphocytic leukemia (CLL).

Velcade[®] (bortezomib) – to treat mantle cell lymphoma (MCL), and is also being studied in clinical trials for some other types of NHL.

Zevalin[®] (ibrutinomab) – a monoclonal antibody to treat NHL, is also called **radioimmunotherapy**. This means the drug carries a radioactive substance that targets the lymphoma cells, reducing radiation side effects that hurt normal cells. Zevalin is approved for relapsed or refractory CD20-positive, low-grade, follicular or transformed B-cell lymphomas, and is also for previously untreated follicular NHL patients who achieve a partial or complete response to initial chemotherapy.

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.

For patients with refractory or relapsed NHL, doctors can either change the patient's treatment or give added treatment. There are many drug choices and approaches to treatment. 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 treatment options are used. Patients with refractory or relapsed NHL should also ask the doctor about the risks and benefits of participating in a clinical trial.

Stem Cell Transplantation

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 patient's disease, subtype, stage and other treatment received as well as the patient's physical ability to have the transplant. While a stem cell transplant is not an option for every patient, it can be an important addition to the treatment plan for some patients.

Additional information about the different kinds of transplants that are available for some NHL patients start on the next page. Some of these transplants are for patients with slow-growing lymphomas and some are more appropriate for patients with fast-growing lymphomas. Talk to your doctor about whether a stem cell transplant is a treatment option for you.

Want more information?



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

Autologous Stem Cell Transplantation. Autologous transplantation is more frequently used than allogeneic transplantation as a treatment for NHL patients.

The goal of autologous stem cell transplantation is to help the body start a new supply of blood cells after high-dose chemotherapy. With an autologous transplant

- The patient's own stem cells are collected from the his/her blood or bone marrow and stored after the first cycles of drug therapy are completed.
- The patient is then given high-dose chemotherapy to kill the lymphoma cells in the body. This treatment unfortunately also kills normal stem cells in the marrow.
- The last step is to infuse the stem cells that were removed earlier and stored back into the patient.

Allogeneic Stem Cell Transplantation. An allogeneic transplant uses stem cells from a donor. The donor may be a brother or sister. The donor can also be an unrelated person with stem cells that “match” the patient's. Stem cells may also come from a cord blood unit (the blood in the umbilical cord after a baby's birth). Allogeneic transplants are generally done in a hospital setting.

- First, the patient is given high-dose chemotherapy and/or radiation therapy to kill the lymphoma cells in the body.
- Stem cells are collected from a donor.
- 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 bone marrow and help start a new supply of red blood cells, white blood cells and platelets.

Reduced-intensity allogeneic stem cell transplantation (also called a **nonmyeloablative transplant**) 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 transplantation is a treatment option for you.

Childhood Non-Hodgkin Lymphoma

Burkitt lymphoma is the most common type of NHL in children ages 5 through 14 years. NHL accounts for 5 percent of all cancers expected to be diagnosed in children and adolescents younger than age 15.

Children and teens with NHL 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 NHL
- Stage of the disease
- Fertility concerns
- 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 *Pretreatment Considerations* on page 11 and *About Clinical Trials* on page 34 for more information.

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. For example, changing the dose of the drug or giving the drug along with another type of treatment may be more effective in treating the disease. Some clinical trials combine drugs for lymphoma in new sequences or dosages.

There are clinical trials for

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

A carefully conducted clinical trial may provide the best available therapy.

Ask your doctor if treatment in a clinical trial is right for you. You can also call our Information Specialists for information about clinical trials.

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 or contact our Information Specialists for a copies.

Side Effects and Follow-Up Care

Side Effects of Lymphoma Treatment

Lymphoma patients should talk with their doctors about side effects before they begin any type of treatment. The aim of treatment for HL and NHL is to kill the lymphoma cells. The term side effect is used to describe how treatment affects healthy cells. Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult or sometimes serious and last a long time, but they usually go away once treatment ends. Ask your doctor about the side effects that often happen with your type of treatment.

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 also have a drop in the number of platelets. A platelet transfusion may be needed to prevent bleeding if a patient's platelet count is very low.
- A severe drop in white blood cells may lead to an 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
- Lung, heart or nerve problems.

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 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.

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

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 think may be related to their treatment. 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.

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 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 more treatment is needed.

Children and adults who have been treated for lymphoma should see their primary care doctor and an 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 received so that your doctor can follow up on specific long-term effects that may be associated with your treatment.

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.

Tracking Your Lymphoma Tests

These tips may help you save time and know 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.

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.

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 procedure using a special needle to remove and examine marrow cells to see if they are normal. A liquid sample containing cells is taken from the bone marrow and then the cells are looked at under a microscope. Bone marrow aspiration and biopsy are usually done together.

Bone marrow biopsy. A procedure using a special needle to remove and examine bone marrow cells to see if they are normal. A very small amount of bone filled with marrow cells is taken from the body, and the cells are looked at under a microscope. Bone marrow aspiration and biopsy are usually done together.

Central line. Special tube the doctor puts into a large vein in the upper chest to prepare a patient for chemotherapy treatment. The central line is used to give the patient chemotherapy drugs and blood cells and to remove blood samples.

Chemotherapy or drug therapy. Treatment with chemical agents to treat lymphoma and other cancers.

Chromosome. Any of the 23 pairs of certain basic structures in human cells. Chromosomes are made up of genes. Genes give instructions that tell each cell what to do. The number or shape of chromosomes may be changed in blood cancer cells.

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

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

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

FDA. The short name for the US Food and Drug Administration. Part of the FDA's job is to assure the safety and effectiveness of drugs, medical devices and the US food supply.

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.

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 the type of lymphoma cells.

Lymph node. Small bean-shaped structure that contains a large number of lymphocytes. The lymph nodes are part of the body's immune system.

Monoclonal antibody therapy. A type of therapy that targets and kills specific cancer cells. It does not cause many of the side effects of chemotherapy.

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

Pathologist. A doctor who identifies diseases by studying cells and tissues under a microscope.

Platelet. A type of blood cell that helps prevent or stop bleeding. Platelets clump together in the blood vessels in a process called **clotting** at the site of an injury.

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

Radioimmunotherapy. A treatment that uses antibodies to carry a radioactive substance to lymphoma cells to kill them.

Red blood cell. A type of blood cell that contains hemoglobin which binds oxygen and carries it to the tissues of the body.

Refractory lymphoma. Lymphoma that has not responded to initial treatment. Refractory disease may 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.

White blood cell. A kind of cell that fights infection in the body. There are two major types of white blood cells: germ-eating cells (neutrophils and monocytes) and infection-fighting lymphocytes (B cells, T cells and natural killer (NK) cells).



Questions to Help You Choose a Specialist

Asking questions will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What is your board certification and licensing? Are you a member of any professional societies?

- 2.** How much experience do you have treating patients who have my disease?

- 3.** Is your hospital, university, center or clinic accredited and experienced in treating blood cancers?

- 4.** How long would I usually have to wait for appointments or return of my phone calls?

5. Will there be nurses, social workers and case managers available to help me with support needs and quality-of-life concerns?

6. Do you know of other oncologists who specialize in treating blood cancers? Would you recommend that I speak to any of them?

7. What types of things should I call you about? What types of things should I call my family doctor about?

8. How should I contact you when I have questions?

9. How do I contact you at night? On weekends? On holidays?

To print additional copies of this question guide, or to print copies of question guides on other topics, go to www.LLS.org/whattoask. You may also request that copies be sent to you by contacting our Information Specialists at (800) 955-4572.



Asking your healthcare provider questions at any phase of your treatment will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What are my (my child's) treatment options? What is the goal of the treatment?

- 2.** What are the FDA-approved treatments, and are there treatments being studied in clinical trials (study treatments), for my (my child's) diagnosis?*

- 3.** What are the benefits and risks of the treatment(s) available to me (my child)? What are the expected side effects?

- 4.** Is there one treatment option (FDA-approved or study treatment) that you recommend over the others? Please explain.

5. If I (my child) enroll(s) in a clinical trial, who will be in charge of my (my child's) treatment?

6. When do you think I (my child) will need to begin treatment?

7. How long will I (my child) be treated and how many treatments will be needed?

8. Will I (my child) need to be hospitalized for all or part of the treatment?

9. What kind of testing will be done to monitor my (my child's) disease and treatment? How often will testing be needed?

10. If I am treated at an out-patient clinic or at the doctor's office, will I be able to drive/get myself home after treatments or will I need someone to assist me?

11. What are the risks if I don't (my child doesn't) get treatment?

12. How will I know if the treatment is effective? What options are available if the treatment is not effective?

13. How do I find out if my insurance will cover the costs of my (my child's) treatment or the study treatment? Who can help answer any medical questions my insurance company or health plan asks?

14. If I do not have insurance coverage, how can the healthcare team help me (my child) get treatment? Is there someone I need to speak to for assistance?

15. If I'm (my child is) getting a study treatment, will I be responsible for paying any treatment-related costs, such as tests, travel or the clinical trial drug(s)?

16. Will the healthcare team continue to check on me (my child) after the treatment is over? If so, for what period of time?

17. I (My child) would like to continue some type of lifelong follow-up care in order to be monitored for long-term and late effects of treatment. Can I (my child) follow up with you?

*For definitions of an FDA-approved treatment and a clinical trial (study treatment), visit www.LLS.org or contact an Information Specialist.

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**For more information,
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For a complete directory of our patient services programs, contact us at

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