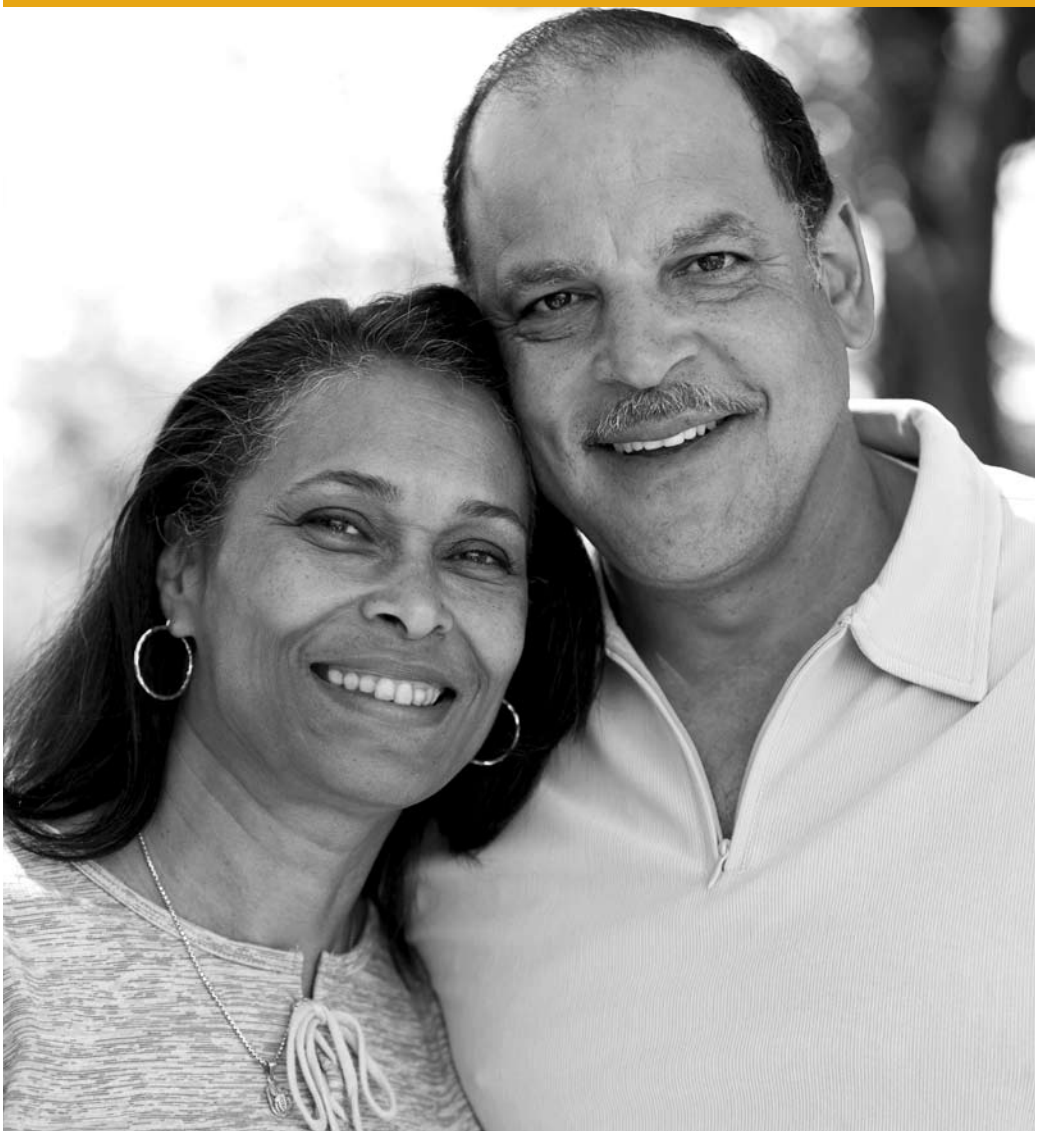
The Leukemia & Lymphoma Society®
Fighting Blood Cancers

# Lymphoma: A Guide for Patients and Caregivers

LEUKEMIA | LYMPHOMA | MYELOMA

HODGKIN AND NON-HODGKIN LYMPHOMA



# Introduction

About 138,530 people in the United States will be diagnosed with a blood cancer in 2008. About 74,430 people in the United States will be diagnosed with lymphoma in 2008.

**Lymphoma** is the name for a group of blood cancers that develop in the lymphatic system. **Hodgkin lymphoma** and **non-Hodgkin lymphoma** are the two main types.

This booklet will help patients, families and caregivers learn about the different types of lymphoma and their treatments.

Progress in treating Hodgkin and non-Hodgkin lymphoma gives patients more hope than ever before. Some types of lymphoma are curable. For other types, many patients are able to keep their disease under control and live good quality lives with medical treatment.

*This booklet about lymphoma is from The Leukemia & Lymphoma Society (LLS). It is for information only. LLS does not give medical advice or medical services.*



**Questions?** Contact an **Information Specialist** at **The Leukemia & Lymphoma Society** at **www.LLS.org** or **(800) 955-4572**.

# Inside This Booklet



Some words in the booklet may be new to you. Check **Medical Terms** at the back of this booklet.

**For more information on Hodgkin lymphoma and different types of non-Hodgkin lymphoma, order the free LLS booklets *Hodgkin Lymphoma* and *Non-Hodgkin Lymphoma.***

# Part 1—Understanding the Lymphomas

Lymphoma is a type of blood cancer that develops in the lymphatic system. It will help to know a little about the blood, bone marrow and the lymphatic system before you read more about lymphoma.

## The Blood and Marrow

**Marrow** is the spongy center inside of bones where blood and immune cells are made. The marrow is really two organs in one: the blood cell-forming organ and the lymphocyte-forming organ, which is part of the immune system.

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

**Platelets** prevent bleeding and form plugs that help stop bleeding after an injury.

**Red cells** carry oxygen around the body. When the number of red cells is below normal it is called **anemia**. Anemia can make you tired, pale or short of breath.

**White cells** fight infection in the body. There are two major types of white cells: germ-eating cells (**neutrophils** and **monocytes**) and **lymphocytes**. Lymphocytes can be B lymphocytes, T lymphocytes or natural killer cells. All of these cell types help fight infection.

**Plasma** is another part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals.

## The Lymphatic System

The lymphatic system is part of the body's immune system—the body's defense against infection. The marrow and lymphocytes are part of the immune system.

These are some other parts of the immune system:

Lymph nodes are bean-sized collections of lymphocytes found throughout the body. There are about 600 lymph nodes 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 liquid that carries lymphocytes.

The spleen is an organ found on the left side of the body, near the abdomen. It contains lymphocytes and removes worn-out cells from the blood.

Lymphoma starts with a change to a type of white blood cell called a **lymphocyte**. The change to the lymphocyte causes it to become a lymphoma cell.

The lymphoma cells pile up and form lymphoma cell masses. These masses gather in the lymph nodes or other parts of the lymphatic system.

About 11 percent of people with lymphoma have Hodgkin lymphoma. The rest have non-Hodgkin lymphoma.

There are many different kinds of non-Hodgkin lymphoma. Non-Hodgkin lymphoma is described in Part 3 beginning on page 15.



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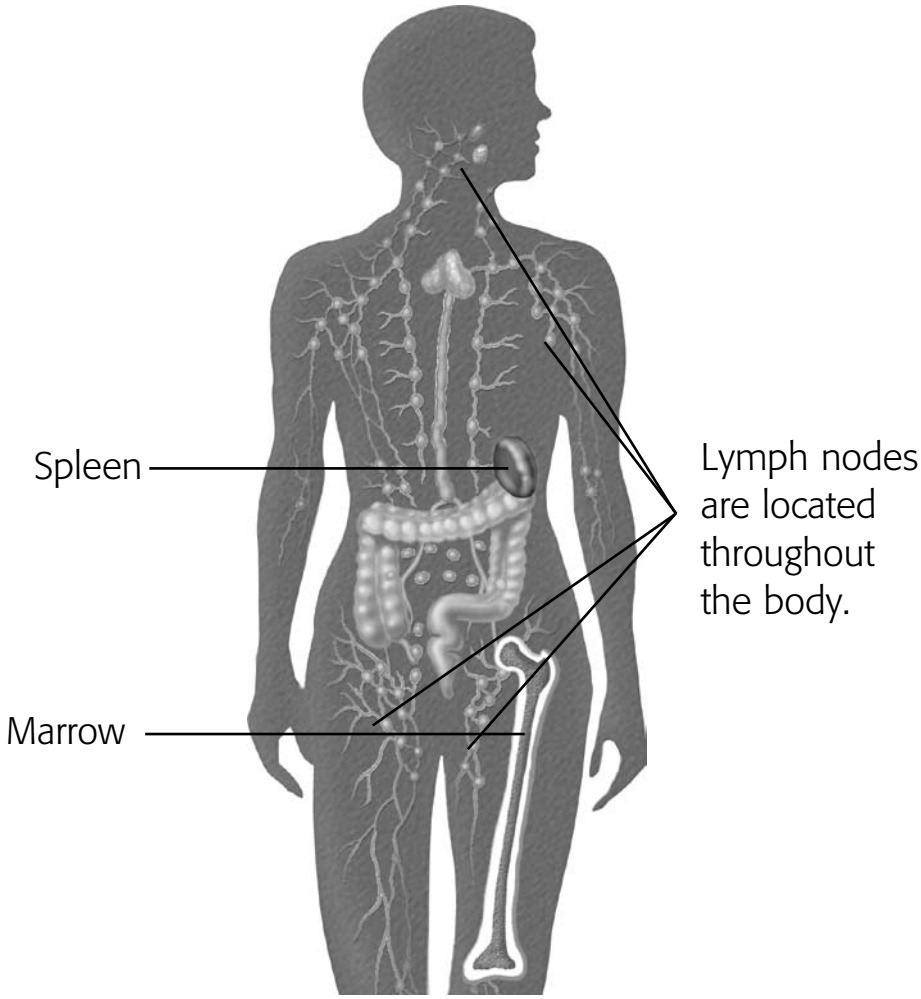
## Some Parts of the Lymphatic System




The normal immune system helps to protect the body from infection. The marrow, lymph nodes, lymphocytes and spleen are some of the parts of the immune system. There are about 600 lymph nodes throughout the body.

# Part 2—Hodgkin Lymphoma

Hodgkin lymphoma is one of the most curable forms of cancer. Doctors don't know what causes most cases of Hodgkin lymphoma. Hodgkin lymphoma is most likely to start when a person is in his or her 20s or 30s. It is less common in middle age and becomes more common again after age 60.

The most common sign of Hodgkin lymphoma is one or more enlarged lymph nodes. The enlarged lymph node is usually painless. It may be in the neck, upper chest, armpit, abdomen or groin.

Signs and symptoms of Hodgkin lymphoma may include

- Swollen lymph nodes
- Cough and shortness of breath
- Fever
- Night sweats
- Tiredness
- Weight loss
- Itchy skin

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



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## Tests for Hodgkin Lymphoma

Doctors do a test called a **lymph node biopsy** to find out if a patient has Hodgkin lymphoma. To do the biopsy, a surgeon removes an enlarged lymph node. The lymph node is examined under a microscope by a pathologist—a doctor who studies cells and tissues to detect disease. It may be important to get a another medical opinion from a second pathologist. Patients or caregivers should talk to the doctor about the diagnosis. Having the correct diagnosis is important for getting the right treatment.

The patient's doctor will do other tests to see how widespread the disease is. This is called **staging**. The tests include

- Blood tests—to look for low red cells, white cells or platelets. Blood tests are also done to check for other signs of disease.
- Bone marrow tests—to look for Hodgkin lymphoma cells in the marrow.
- Imaging tests—to create pictures of the chest and abdomen and see if there are lymphoma masses in the deep lymph nodes, liver, spleen or lungs.

Examples of imaging tests are:

- Chest x-ray
- CT (Computed Tomography) scans
- MRI (Magnetic Resonance Imaging)
- FDG-PET (FDG-Positron Emission Tomography).

# How are the Blood and Bone Marrow Tests Done?

For a **blood test** usually a small amount of blood is taken from the patient's arm with a needle. The blood is collected in tubes and sent to a lab.

A **bone marrow aspiration** is done by removing a sample of cells from the marrow. A bone marrow biopsy is done by removing a very small amount of bone filled with marrow cells.

Both bone marrow tests are done with a special needle. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to get the sample of cells. This is usually the patient's hip bone. Some patients are sedated (asleep) for the procedure.

Blood and marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and biopsy are almost always done together.

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



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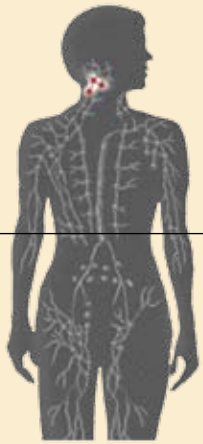
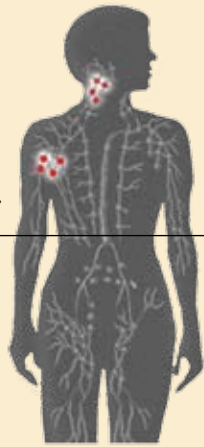
# Lymphoma Stages

**Stage I**
One lymph node region or a single organ.

**Diaphragm**

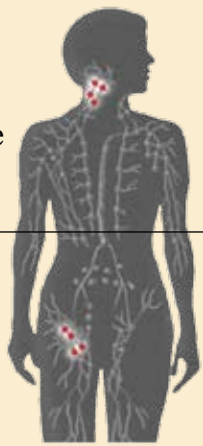


**Stage II**
Two or more lymph node regions on the same side of the diaphragm.



**Stage III**
Two or more lymph node regions above and below the diaphragm.

**Diaphragm**



**Stage IV**
Widespread disease in lymph nodes and/or other parts of the body.

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

All stages of lymphoma can be treated.

## Treatment for Hodgkin Lymphoma

Hodgkin lymphoma can be cured in about 75 percent of all patients. The cure rate in younger patients is about 90 percent.

Each patient should talk to his or her doctor about Hodgkin lymphoma and treatment. There are different types of Hodgkin lymphoma. It is important for patients and caregivers to speak to the doctor about the type and the treatment for that type. A patient with Hodgkin lymphoma is usually treated by a doctor called a **hematologist** or **oncologist**.

It is important to get treatment in a center where doctors are experienced in the diagnosis and care of patients with Hodgkin lymphoma. Some patients may need to get a second medical opinion about the diagnosis before they begin treatment.

Some factors that may affect the type of treatment for a patient are

- The type of Hodgkin lymphoma
- The stage and category
- Disease has not responded to treatment
- Disease has come back after treatment
- Other problems, such as very low red cell count (anemia) diabetes mellitus, heart or kidney disease.

The most common treatment is chemotherapy with involved field radiation therapy. Involved field radiation therapy uses high-energy rays to target the Hodgkin lymphoma cells. Other parts of the body are protected to reduce harm.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Combination chemotherapy is used with radiation therapy to kill nearby Hodgkin lymphoma cells. Some drugs are injected, given by IV or taken by mouth.

## Examples of Drugs Used to Treat Hodgkin Lymphoma

**Chemotherapy combinations**

- ABVD (Adriamycin® [doxorubicin], bleomycin, vinblastine and dacarbazine)
- BEACOPP (bleomycin, etoposide, Adriamycin® [doxorubicin], cyclophosphamide, Oncovin® [vincristine], procarbazine and prednisone)
- Stanford V (mechlorethamine [Mustargen®], doxorubicin, vinblastine, vincristine, bleomycin, etoposide and prednisone)

See *Treatment Side Effects*, page 30.

Chemotherapy without radiation therapy may be the treatment for patients with widespread Hodgkin lymphoma and fever, night sweats or weight loss.

Chemotherapy is given in "cycles," usually several weeks apart. A number of cycles are needed. The treatment may last from 6 to 10 months—it is outpatient treatment for most patients. Some patients may have to be in the hospital for a short time—if the patient develops a fever or other signs of infection. Some patients who need antibiotics may stay in the hospital until the infection is gone.

High doses of chemotherapy may also kill normal blood-forming cells in the marrow. Chemotherapy may cause red cells, white cells or platelets to drop to very low counts in the blood. A red blood cell transfusion or drugs called "blood cell growth factors" may be needed until the effect of chemotherapy wears off.

Examples of growth factors are

- Darbepoetin alfa (Aranesp®) and epoetin alfa (Procrit®, EPO)—these can increase the red cell count.
- G-CSF (Neupogen® or Neulasta®) and GM-CSF (Leukine®)—these can increase the number of neutrophils.

Hodgkin lymphoma makes it harder for the body's immune system to fight off infection. Chemotherapy and radiation can add to the problem since they also lower the immune system's ability to fight infection.

Good treatment and following the doctor's advice will help lower the risk of infection.


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Hodgkin lymphoma patients who have high-dose chemotherapy may need an autologous stem cell transplant, also called "autologous stem cell infusion."

**Autologous** means the patient's own cells are used for the transplant. Stem cells are taken from the patient's blood or marrow and stored after the first cycles of chemotherapy are completed. Then the patient is given high-dose chemotherapy. The stem cells are injected back into the patient after chemotherapy ends. The goal of the autologous stem cell transplant is to restore the body's ability to make normal blood cells after high-dose chemotherapy.

## Relapsed Hodgkin Lymphoma

In some patients, Hodgkin lymphoma may come back (called a recurrence or relapse). The doctor will treat these patients again with chemotherapy. The treatment often gives patients very long disease-free periods.

# Part 3—Non-Hodgkin Lymphoma

Most non-Hodgkin lymphomas (NHL) are **B-cell lymphomas** (about 85 percent). The others are **T-cell** or **NK cell lymphomas**.

There are 30 to 40 types of B-cell and T-cell NHL. NHL that is

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

Patients should talk to their doctor about their particular type of NHL and its treatment. A patient with NHL is usually treated by a doctor called a **hematologist** or **oncologist**.

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 disease remains in some parts of the body.



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# Some Types of Non-Hodgkin Lymphoma

**Slow-growing or Indolent NHL**

Follicular lymphoma

Small cell lymphocytic lymphoma /Chronic lymphocytic leukemia

Cutaneous T-cell lymphoma

Waldenström macroglobulinemia

**Fast-growing B-cell or Aggressive NHL**

Diffuse large B-cell lymphoma

Mantle cell lymphoma

Burkitt lymphoma

Peripheral T-cell lymphoma

AIDS-associated lymphoma

**Diffuse large B-cell lymphoma** is the most common fast-growing NHL. **Follicular lymphoma** is the most common slow-growing NHL. Together these two types make up more than half of all NHL.

Sometimes non-Hodgkin lymphoma is described by its location in the body. **Primary central nervous system lymphoma** forms in the brain and/or the spinal cord. **Secondary central nervous system lymphoma** starts with lymphoma in other parts of the body, which spreads to the brain and/or the spinal cord. These 2 types are not common.

## Some Signs and Symptoms of Non-Hodgkin Lymphoma

The most common sign of NHL is one or more enlarged lymph nodes in the neck, armpit or groin. Enlarged lymph nodes also can be near the ears or elbow.

Signs and symptoms of NHL may include

- Swollen lymph nodes
- Fever
- Night sweats
- Feeling tired
- Loss of appetite
- Weight loss
- Rash

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

## Tests for Non-Hodgkin Lymphoma

Doctors do a test called a **lymph node biopsy** to find out if a patient has NHL. To do the biopsy, a surgeon removes an enlarged lymph node. Then a pathologist looks at the lymph node under a microscope. Sometimes the biopsy is done to examine cells from other parts of the body.



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The doctor may do a **cytogenetic analysis** of the cells from the biopsy. This is a lab test that looks to see if there are changes in the **chromosomes** of the NHL.

Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do.

Blood tests are done to look for low numbers of red cells, white cells or platelets. Bone marrow tests are done to look for NHL cells in the marrow.

A lab test called **immunophenotyping** can also be used to find out if the patient's NHL cells are B cells or T cells.

The correct diagnosis is very important to help the doctor to know what type of treatment the patient needs.

The patient's doctor will do other tests to see how widespread the disease is. This is called **staging**. See page 10, *Lymphoma Stages.*

The doctor looks for the signs below to identify the stage:

- The number of lymph nodes that are affected
- Where the affected lymph nodes are (for example, in the abdomen or the chest or 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.

Imaging tests are done to create pictures of the chest and abdomen—and see if there are lymphoma masses in the deep lymph nodes, liver, spleen or lungs.

Examples of imaging tests are:

- X-rays
- CT (Computed Tomography) scans
- MRI (Magnetic Resonance Imaging)
- FDG-PET (FDG-Positron Emission Tomography).

Blood and marrow and imaging tests also help the doctor to see how advanced the disease is.

Other staging tests may be done for a specific subtype diagnosis but are not necessary for all patients with NHL.

**LLS has free fact sheets for *Mantle Cell Lymphoma, Cutaneous T-Cell Lymphoma* and *Waldenström Macroglobulinemia.***

## Treatment for Non-Hodgkin Lymphoma

It is important to get treatment in a center where doctors are experienced in the care of the patient's type of NHL. Some patients may need to get a second medical opinion about their diagnosis before they begin treatment.

The doctor has to take into account many factors to make a treatment plan for NHL:

- The type of NHL
- The stage and category of the disease
- The patient's overall health.

## Treatment for Slow-Growing NHL

In most cases, a patient begins treatment for NHL right away. But when a patient has NHL that is widespread throughout the body, that is not growing or is slow-growing, the doctor may recommend **watch and wait**.

**Watch and wait** is when a doctor watches a patient's condition without giving any treatment. Patients may think they should have treatment right away. But for patients with slow-growing disease and no symptoms it is common not to start treatment. This allows the patient to avoid side effects of therapy until treatment is needed.

Patients in **watch and wait** need follow-up visits with the 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
- The type of treatment to have.

Treatment will begin if a patient develops symptoms or there are signs 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 lasting a number of years. This can be true even when tests show disease remains in some parts of the body. Many patients lead active, good-quality lives.

### Maintenance

Patients with some types of slow-growing lymphoma may stay in treatment to keep their remission. This is called "maintenance" treatment.

## Treatment for Fast-Growing NHL

Patients may be treated with four or more drugs. The goal of treatment is cure of the disease.

## Drugs 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 treatment.



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# Some Treatments for NHL

- Cyclophosphamide, vincristine, prednisone (CVP)
- Cyclophosphamide, doxorubicin, vincristine, prednisone (CHOP) (sometimes with Rituxan®)
- Fludarabine (sometimes with mitoxantrone or cyclophosphamide)
- Cladribine
- Chlorambucil (sometimes with prednisone)
- Rituxan®
- Bexxar®
- Zevalin®
- Bendamustine**
- Revlimid®*
- Velcade*
- Vaccines*

*These are being studied for the treatment of some types of NHL.

**Approved for CLL; being studied for other types of NHL.

Drug treatments may include up to five drugs. R-CHOP is Rituxan®, cyclophosphamide, doxorubicin, Oncovin® (vincristine), prednisone, a common drug combination for some types of NHL.

Chemotherapy is given in "cycles," usually several weeks apart. Patients need a number of cycles. The treatment may last from 6 to 10 months—it is outpatient treatment for most patients. Some patients may have to be in the hospital for a short time—if the patient develops a fever or other signs of infection. Some patients who need antibiotics may stay in the hospital until the infection is gone.

High doses of chemotherapy may also kill normal blood-forming cells in the marrow. Chemotherapy may cause red cells, white cells or platelets to drop to very low counts in the blood. A red blood cell transfusion or drugs called "blood cell growth factors" may be needed until the effect of chemotherapy wears off.

Examples of growth factors are

- Darbepoetin alfa (Aranesp®) and epoetin alfa (Procrit®, EPO)—these can increase red cell count.
- G-CSF (Neupogen® or Neulasta®) and GM-CSF (Leukine®)—these can increase the number of neutrophils.

Monoclonal antibody therapy is a type of drug therapy that targets and kills cancer cells. Monoclonal antibodies do not cause many of the side effects of chemotherapy.

Rituxan® is one monoclonal antibody therapy for NHL. It is used alone or with chemotherapy to treat some NHL types and treatment stages. Rituxan® does not attack stem cells in bone marrow. This lets healthy B cells grow back after treatment. Antibody-producing B cells (plasma cells) that help fight infection are not harmed by Rituxan®.


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Bexxar® and Zevalin® are two other monoclonal antibodies that are used to treat NHL. These are called **radioimmunotherapies**. This means that they carry a radioactive substance to the lymphoma cells. This reduces radiation side effects to normal cells. This treatment is approved for relapsed or refractory CD20-positive, low-grade, follicular or transformed B-cell lymphomas. It is being studied as a possible front-line therapy.

Several new monoclonal antibodies are being studied to treat NHL.

Vaccine therapy and immune cell-stimulating cytokine therapy are types of immunotherapy that are being studied to see if they are good treatments for NHL.

## Monoclonal Antibody Treatment for Some Disease-Types and Treatment-Stages

| Disease-Type | Treatment-Stage | Monoclonal Antibody alone or Monoclonal Antibody + Chemotherapy |
|---|---|---|
| Follicular, CD20-positive, B-cell | Newly diagnosed (first-line treatment) | R + CVP (Rituxan + cyclophosphamide, vincristine and prednisone) |
| Low-grade, CD20-positive, B-cell | Maintenance of stable disease or partial or complete response after first-line treatment with CVP | Rituxan |
| | Relapsed or refractory | |
| | Relapsed or refractory after initial Rituxan treatment | |
| CD20-positive Diffuse large B-cell | Newly diagnosed (first-line treatment) | R + CHOP (Rituxan + cyclophosphamide, doxorubicin, vincristine and prednisone) or certain other chemotherapies |



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## Radiation Therapy

Radiation uses high-energy rays to kill lymphoma cells in one area. Radiation can be used along with chemotherapy when there are very large masses of lymphoma cells in a small area of the body. Radiation also can be used when large lymph nodes are pressing on an organ (such as the bowel) and chemotherapy can't control the problem. Radiation usually isn't the only treatment for NHL because the lymphoma cells are likely to be in many areas of the body.

## Stem Cell Transplant

A **stem cell transplant** (sometimes called a bone marrow transplant) is used for some patients with NHL. Donated stem cells (**allogeneic transplant**) or the patient's own stem cells (**autologous infusion**) are injected into the patient's blood after **chemotherapy** ends.

More information about allogeneic stem cell transplant follows. Information about autologous stem cell infusion begins on page 28.

**The free LLS booklet, *Blood and Marrow Stem Cell Transplantation*, has more details on this topic.**

## Allogeneic Stem Cell Transplant

Stem cells from a donor are transfused into the patient's blood after chemotherapy ends. Sometimes the donor can be a brother or a sister. A person has about 1 chance in 4 of having stem cells that "match" his or her brother's or sister's stem cells. When there is no related donor, the donor can be an unrelated person with stem cells that "match" the patient's.

**High-dose chemotherapy** is given to patients to get rid of lymphoma cells in the body before a stem cell transplant.

The transplanted stem cells go from the patient's blood to the marrow. The cells start a new supply of red cells, white cells (including immune cells) and platelets.

The donated stem cells make immune cells that are not totally "matched" with the patient's cells. The donor immune cells may recognize the patient's lymphoma cells as foreign and kill them. This is called **graft versus lymphoma**.

Allogeneic stem cell transplantation can be a high-risk treatment.

The decision to do a transplant depends on

- Patient age
- Overall health
- How well the donor cells and patient cells "match"
- The patient's response to drug therapy.



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The decision also depends on the patient's understanding of the benefits and risks of the transplant. If the doctor thinks a patient might benefit from a transplant, he or she will talk about these factors with the patient.

Allogeneic stem cell transplant is most successful in younger patients. Patients up to about 60 years of age who have a matched donor may be considered.

Doctors are studying a type of stem cell transplant called a **nonmyeloablative stem cell transplant** or a **reduced-intensity transplant**. It may be helpful for older patients. See page 34 for more information.

## Autologous Stem Cell Infusion

Many patients with lymphoma cannot have an allogeneic stem cell transplant. Doctors are studying the use of a patient's own stem cells in these cases. This is called an **autologous stem cell infusion**.

High-dose chemotherapy plus autologous stem cell infusion is not a cure. It does give patients longer disease-free periods than standard-dose chemotherapy without stem cell transplant.

**Relapsed or Refractory NHL**

Some patients may not respond to treatment for newly diagnosed or relapsed NHL. This is called "refractory" NHL. Patients may have a return (relapse) of NHL months or years after treatment. Doctors can change the patient's treatment or give additional 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 effective. In other cases, new drugs or treatment approaches are used.

Patients with refractory NHL should talk with the doctor about the risks and benefits of participating in a clinical trial.



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# Part 4—Treatment Side Effects—Hodgkin and Non-Hodgkin Lymphoma

There are many possible side effects of treatment for Hodgkin and non-Hodgkin lymphoma. Patients react to lymphoma treatment in different ways. Most side effects are mild and last only a short time. Other side effects may be serious or last a long time. When side effects occur, most

- Can be helped with treatment.
- Do not last long.
- Clear up when treatment ends.

The number of red cells may decrease (this is called anemia) in patients treated with chemotherapy. Blood transfusions or growth factors to increase red cells may be needed.

Darbepoetin alfa (Aranesp®) and epoetin alfa (Procrit®, EPO) are drugs that might be given to increase red cell count.

A severe drop in white cells may lead to an infection. Infections caused by bacteria or fungi are treated with antibiotics.

To help a patient's white cell count to improve

- The amount of chemotherapy drugs may be reduced.
- The time between treatments may be increased.
- Growth factors to increase neutrophils may be given. A neutrophil is a type of white cell that fights infection in the body. G-CSF (Neupogen® or Neulasta®) and GM-CSF (Leukine®) are drugs that increase the number of neutrophils.

Common side effects from treatment for Hodgkin and non-Hodgkin lymphoma may include

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

Other side effects from treatment may include

- Extreme tiredness
- Fever
- Cough
- Rash
- Hair loss
- Weakness
- Tingling sensation
- Lung, heart or nerve problems.

Fertility (the ability to conceive a baby) may be affected by lymphoma treatment in both men and women. Patients who are concerned about fertility should to talk to their doctors before treatment begins.



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For example, men who plan to have children in the future may want to consider banking sperm before starting treatment. If a couple's ability to have children is not affected by treatment, their chance of having a healthy baby is the same as for a healthy couple.

**For more information, see the free LLS fact sheet *Fertility.***

Patients should talk with their health care providers about any long-term effects of treatment. **Cancer-related fatigue** is one type of long-term effect.

**For more information, order the free LLS booklet *Understanding Drug Therapy and Managing Side Effects* and the free fact sheets *Fatigue, Long-Term and Late Effects of Treatment in Adults* and *Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma.***

## Clinical Trials

Clinical trials are used to study new drugs, new treatments or new uses for approved drugs or treatments.

There are clinical trials for

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

Call the Information Resource Center at (800) 955-4572 to learn how you and your doctor can find out if participating in a clinical trial is right for you.

Gene expression profiling is being studied to design more specific treatments for the different types of lymphoma.

Cytokines are natural substances made by cells. They can also be made in the lab. Cytokines that affect lymphoma cells may one day be used to treat this disease.

Vaccines are being tested as a possible treatment for NHL. These types of vaccines would not prevent NHL. One type of vaccine being studied might be used to help a patient stay in remission.

## Stem Cell Transplants Under Study

A type of transplant called a reduced-intensity transplant is under study. A reduced-intensity transplant uses lower doses of chemotherapy in combination with an allogeneic stem cell transplant. This treatment is also called a nonmyeloablative transplant. Older and sicker patients may be able to be helped by this treatment.

Stem cells from umbilical cord blood are also used for some transplants. One cord blood unit provides enough stem cells for a child or small adult. Clinical trials are ongoing using multiple cord blood units from more than one donor to make this stem cell resource available for average-size adults.

## Coping with Lymphoma

**Patients with lymphoma should talk with their family, friends and caregivers about how they feel.** They can share what they know about the disease. Family, friends and caregivers can often help patients to cope with what lies ahead. Also, patients with lymphoma may get to know one another. These friendships help too.

Patients with Hodgkin or non-Hodgkin lymphoma or their caregivers should talk with the doctors about lymphoma and treatment. This will help them to be involved and make decisions.

**It may be helpful to write down questions to ask the doctor.** Then you can write down your doctor's answers and review them later.

**Patients may want to have a family member or friend come to the doctor with them.** This person can listen, take notes and offer support. Some patients record information and listen to it at home.

## What Should I Ask the Doctor?

- What do the blood tests show? How do the results compare to "normal"?
- When will these tests need to be repeated?
- Will you send copies of your notes and my test results to my family doctor?
- What types of things should I call you about? What types of things should I call my family doctor about?
- When do you think I will need treatment?
- What kind of treatment do you think I will need?
- How much experience do you have treating patients with my type of lymphoma?
- What side effects should be expected from treatment?
- What can I do to help deal with side effects?
- What can I do to reduce the risk of infection?
- Should I (or my child) be treated in a cancer clinical trial?
- Will the treatment be paid for by my health plan (or Medicare)?
- How will my treatment affect fertility, pregnancy or breastfeeding?



Check **Medical Terms** for words that are new to you.
Or call **The Leukemia & Lymphoma Society** at **(800) 955-4572**.

- How often and how long will I (or my child) need treatment/ follow-up visits?
- What type of follow-up tests will be needed?
- Will I (or my child) need to change our daily routine?
- How do I contact you after normal business hours?

## Patients can help take care of themselves by

- Keeping all appointments with the doctor.
- Discussing how they feel with the health care team at each visit.
- Following the doctor's advice for preventing infection.
- Eating healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contacting the doctor about tiredness or other symptoms.
- Not smoking. Patients who smoke should get help to quit.
- Getting enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keeping a health care file with copies of lab reports and treatment records.
- Seeing the family doctor to keep up with other health care needs.

Making treatment choices can cause stress. The time and money spent for medical care may be a burden. Patients and caregivers can ask their health care team for help. The team can give emotional support. They can refer patients to other sources of help.

It is important to seek medical advice if a patient's mood does not improve over time—for example, if a person is feeling depressed every day for a two-week period.

Depression is an illness. It should be treated even when a person is being treated for lymphoma. Treatment for depression has benefits for people living with cancer.

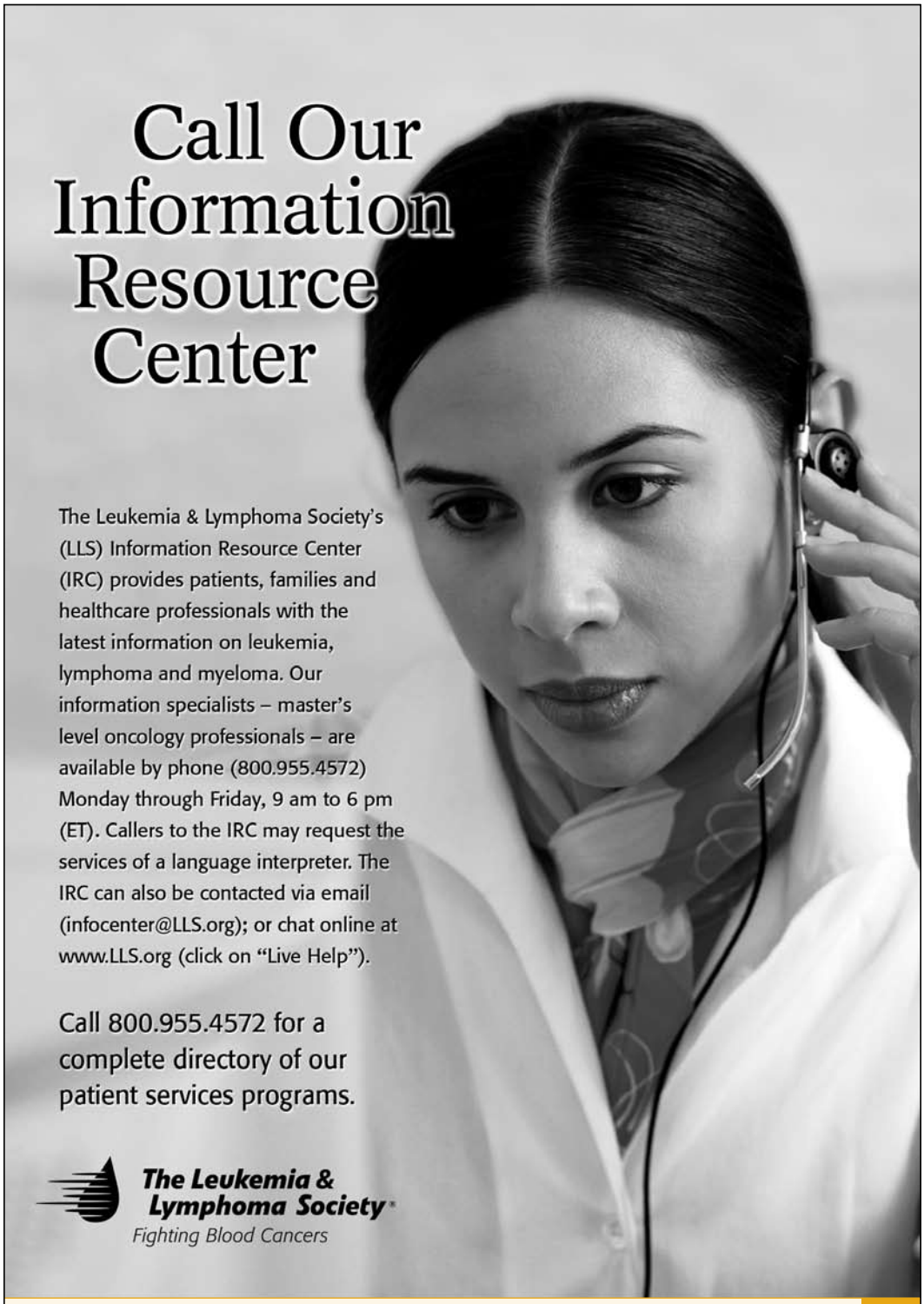
Children with a family member who has lymphoma may need special attention. They may feel bad that their family member is sick. They may be sad or angry that their parents are not around as much.

The outlook for patients with lymphoma continues to improve. New treatments and cures for more patients are on the horizon.

**The free LLS booklets *Each New Day: Ideas for Coping with Leukemia, Lymphoma or Myeloma* and *Coping: Support for People Living with Leukemia, Lymphoma or Myeloma* and *Financial Health Matters*, have more information about coping.**



**Questions?** Contact an **Information Specialist** at **The Leukemia & Lymphoma Society** at **www.LLS.org** or **(800) 955-4572**.




To order free booklets, contact **The Leukemia & Lymphoma Society** at **www.LLS.org** or **(800) 955-4572**.

## We're Here to Help

LLS has chapters around the nation. LLS chapters offer support groups and also can arrange for a lymphoma patient to talk with another person who has lymphoma. To find a chapter in your area, call (800) 955-4572. Or visit www.LLS.org.

## LLS has free booklets and fact sheets.

*Blood and Marrow Stem Cell Transplantation*
*Cutaneous T-Cell Lymphoma* fact sheet
*Each New Day: Ideas for Coping with Leukemia, Lymphoma or Myeloma*
*Financial Health Matters*
*Mantle Cell Lymphoma* fact sheet
*Hodgkin Lymphoma*
*Non-Hodgkin Lymphoma*
*Understanding Clinical Trials for Blood Cancers*
*Understanding Drug Therapy and Managing Side Effects*
*Vaccine Therapy Facts*
*Waldenström Macroglobulinemia* fact sheet

## About or For Children

*Coping with Childhood Leukemia and Lymphoma*
*Learning & Living with Cancer: Advocating for Your Child's Educational Needs*
*The Stem Cell Transplant Coloring Book*
*Pictures of My Journey—Activities for Kids with Cancer*

# Medical Terms

**Antibiotics**
Drugs that are used to treat infections caused by bacteria and fungi. Penicillin is one type of antibiotic.

**Antibodies**
Proteins that help to fight infection in the body.

**Chemotherapy**
Treatment with drugs or medicines to kill lymphoma cells.

**Clinical trials**
Studies that use volunteers to test new drugs, treatments or new uses for approved drugs or treatments.

**Cytokines**
Natural substances made by cells that can also be made in a lab. Blood cell growth factors are examples of cytokines. Cytokines that affect lymphoma cells may be used one day to treat lymphoma.

**Hematologist**
A doctor who treats blood cell diseases.

**Immune system**
Cells and proteins that defend the body against infection. Lymphocytes, lymph nodes and the spleen are some parts of the immune system.

# Medical Terms

**Immunophenotyping**
A lab test that can be used to find out if the patient's lymphoma cells are B cells or T cells.

**Lymph nodes**
Small bean-shaped organs around the body that are part of the body's immune system.

**Lymphatic vessels**
These connect the lymph nodes. They contain lymph – a fluid that carries lymphocytes.

**Lymphocyte**
A type of white blood cell. Lymphocytes help fight infection.

**Marrow**
The spongy center inside of bones where blood cells are made.

**Monoclonal antibody therapy**
A type of drug therapy that targets and kills cancer cells. Monoclonal antibodies are immune proteins made in the laboratory. They do not cause many of the side effects of chemotherapy.

**Oncologist**
A doctor who treats patients with cancer.

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


**Questions?** Contact an **Information Specialist** at **The Leukemia & Lymphoma Society** at **www.LLS.org** or **(800) 955-4572**.

# Medical Terms

**Platelet**
A type of blood cell that helps prevent bleeding by causing plugs to form.

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

**Relapse or recurrence**
When disease comes back after having been successfully treated.

**Remission**
No sign of the disease and/or a period of time when the disease is not causing any health problems for the patient.

**Spleen**
An organ found on the left side of the body, near the stomach. It contains lymphocytes and cleans cells that no longer work out of the blood.

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

**White cell**
A type of blood cell that helps the body fight infection.

For more information, please contact:

or:

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www.LLS.org

*Our Mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.*

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.

The Leukemia & Lymphoma Society®

*Fighting Blood Cancers*

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