



**The Leukemia &  
Lymphoma Society**  
*Fighting Blood Cancers*

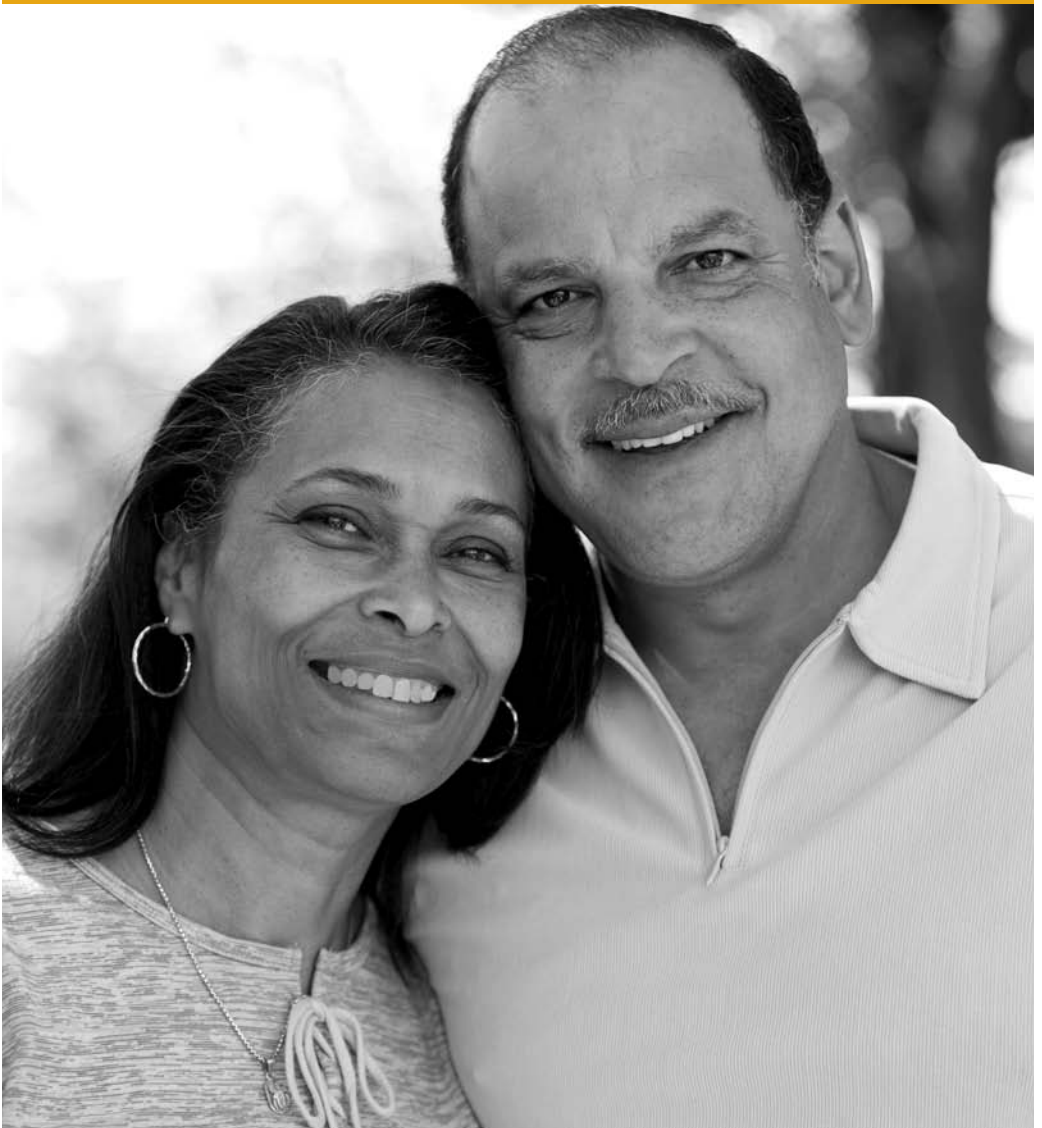
# The Lymphomas: A Guide for Patients and Caregivers

LEUKEMIA

LYMPHOMA

MYELOMA

HODGKIN AND NON-HODGKIN LYMPHOMA



# Introduction

**I**n the U.S.:

In 2007, about 71,380 people will be diagnosed with lymphoma.

In 2006, about 519,500 people were living with lymphoma.

**Lymphoma** is the name for a group of blood cancers that start 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 lymphomas 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. It is for information only. The Society does not give medical advice or medical services.*

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

# Inside This Booklet

**Part 1 – Understanding the Lymphomas**

**Part 2 – Hodgkin Lymphoma**

**Part 3 – Non-Hodgkin Lymphoma**

**Part 4 – Treatment Side Effects –  
Hodgkin and Non-Hodgkin Lymphoma**

**Medical Terms**

**We're Here to Help**

**S**ome 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 Society's free booklet, *The Lymphomas: Hodgkin Lymphoma and Non-Hodgkin Lymphomas*.**

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# Part 1 - Understanding the Lymphomas

Lymphomas are types of blood cancers that start in the lymphatic system.

It will help to know a little about the blood and the lymphatic system before you read more about lymphoma.

## The Blood and Marrow

The **blood** is made up of blood cells and plasma.

**Plasma** is mostly water with vitamins, minerals, proteins, hormones and other natural chemicals.

Normal **stem cells** in the marrow form three main cell-types.

**Red cells** carry oxygen to all the tissues of the body, such as the heart, lungs and brain.

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

**White cells** fight infection in the body. There are two major types of white cells: germ-ingesting cells (**neutrophils** and **monocytes**) and **lymphocytes** (immune cells), which provide an **immune response** to infection. There are three types of lymphocytes: **B cells**, **T cells** and **natural killer** (NK) cells. These cells all help fight infection.

**3** Check **Medical Terms** for words that are new to you.  
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## The Blood and Marrow (cont'd.)

**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.

### 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.

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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.

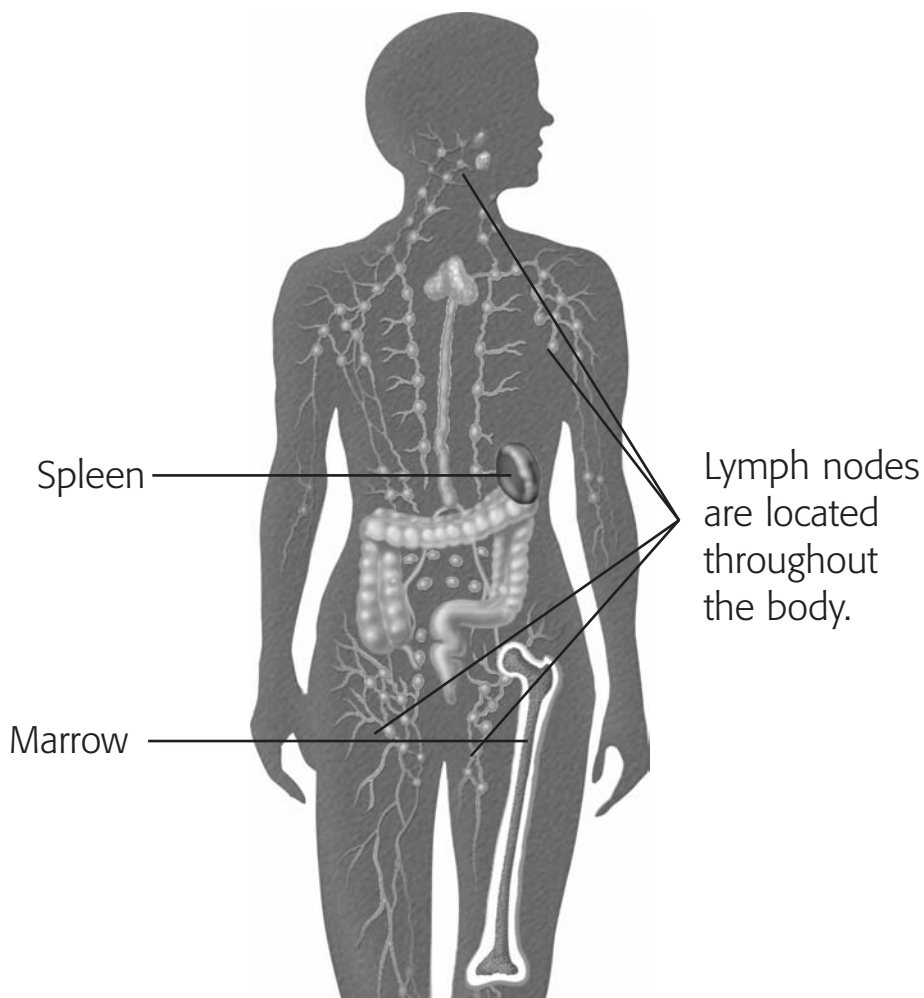
The lymphoma cells pile up and form lymphoma cell masses. These masses gather in the lymph nodes or other parts of the lymphatic system.

Hodgkin and non-Hodgkin lymphoma are the two main types of lymphoma. About 12 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 14.

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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.

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# 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 painless. It may be in the neck, upper chest, armpit, abdomen or groin.

## **Signs and symptoms of Hodgkin lymphoma may include:**

- Swollen lymph nodes
- 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.

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



## 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.

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

- Blood tests – to look for low red cells, white cells or platelets.
- 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:

- CT scans (Computed Tomography)
- MRI (Magnetic Resonance Imaging)
- PET scans (Positron Emission Tomography)

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# Hodgkin Lymphoma Stages

**Stage 1:** The lymphoma is in just one lymph node region.

**Stage 2:** The lymphoma is in two or three lymph node regions that are near each other. For example, the lymphoma is in the upper body regions (neck, chest and armpit) or the lymphoma is in the lower body regions (abdomen and groin).

**Stage 3:** The lymphoma is in several lymph node regions such as the neck, chest and abdomen.

**Stage 4:** The lymphoma is widespread in the lymph nodes and other parts of the body, such as the lungs, liver or bone.

**Patients are also divided into either “A” or “B” categories.**

“A” patients don’t have fever, a lot of sweating or weight loss.

“B” patients have fever, a lot of sweating or weight loss.

## 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. A patient with Hodgkin lymphoma is usually treated by a doctor called a **hematologist** or **oncologist**.

Some patients may want to get a second medical opinion. It is important to get treatment in a center where doctors are experienced in the care of patients with Hodgkin lymphoma.

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

- Enlarged chest nodes or abdominal lymph nodes
- Enlarged spleen
- Many affected groups of lymph nodes
- Affected lungs, liver, bone or other parts of the body
- Very low red cell count (anemia)
- Other problems such as diabetes mellitus, heart or kidney disease

Treatment includes chemotherapy or chemotherapy and **involved field radiation therapy**. Radiation uses high-energy rays to kill lymphoma cells in one area of the body. Involved field radiation targets the lymphoma masses. Other parts of the body are protected to prevent harm.

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Chemotherapy is used with radiation to kill nearby lymphoma cells. Four or more drugs may be used together. Drugs may be injected, given through an IV tube or taken by mouth.

## Examples of Drugs Used to Treat Hodgkin Lymphoma

Bleomycin (Blenoxane®)  
Cyclophosphamide (Cytosan®)  
Dacarbazine (DTIC-Dome®)  
Doxorubicin (Adriamycin®)  
Lomustine (CeeNU®)  
Prednisone  
Procarbazine (Matulane®)  
Vinblastine (Velban®)  
Vincristine (Oncovin®)

Treatment may include at least four drugs, for example, ABVD – Adriamycin® (doxorubicin), bleomycin, vinblastine and dacarbazine.

Chemotherapy may be the only treatment used for a patient if the Hodgkin lymphoma is widespread – and the patient has 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 on how to prevent infection will help lower the risk of infection. And when patients are cured, their immune system function may improve.

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Hodgkin lymphoma patients who have high-dose chemotherapy may need an autologous stem cell transplant.

**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

There are many types of non-Hodgkin lymphoma. Most non-Hodgkin lymphomas are **B-cell lymphomas** (about 90 percent). The other types are **T-cell** and **NK cell lymphomas** and immunodeficiency-associated **lymphoproliferative disorders**.

Non-Hodgkin lymphoma that is:

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

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

Some patients may want to get a second medical opinion. It is important to get treatment in a center where doctors are experienced in the care of the patient's type of non-Hodgkin lymphoma.

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## B-cell Non-Hodgkin Lymphomas

There are 14 different types of B-cell non-Hodgkin lymphomas. **Diffuse large B-cell lymphoma** (a fast-growing lymphoma) and **follicular lymphoma** (a slow-growing lymphoma) are the two **most common B-cell lymphomas**. Together these two types make up more than half of all non-Hodgkin lymphomas.

Some patients with fast-growing lymphomas can be cured. For patients with slow-growing lymphomas, 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.

## Examples of Non-Hodgkin Lymphomas

### Slow-growing B-cell or T-Cell Non-Hodgkin Lymphoma

Small cell lymphocytic lymphoma

Follicular lymphoma

Cutaneous T-cell lymphoma

### Fast-growing B-cell or T-cell Non-Hodgkin Lymphoma

Diffuse large B-cell lymphoma

Mantle cell lymphoma

Burkitt lymphoma

Acute adult T-cell lymphoma

HIV/AIDS-associated lymphoma



Sometimes non-Hodgkin lymphoma is described by its location in the body.

- Primary central nervous system lymphoma is in the brain or the spinal cord.
- Secondary central nervous system lymphoma is in the brain or the spinal cord and other parts of the body.

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

### **Some signs and symptoms of non-Hodgkin lymphoma are:**

- 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 **biopsy** to find out if a patient has non-Hodgkin lymphoma. To do the biopsy, a surgeon removes an enlarged lymph node and a pathologist studies the lymph node under a microscope to see if the patient has non-Hodgkin lymphoma. Sometimes the biopsy is done to examine cells from a tumor or the skin.

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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 non-Hodgkin lymphoma cells.

**E**ach 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 counts of red cells, low white cells or platelets. Bone marrow tests are done to look for non-Hodgkin lymphoma cells in the marrow.

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

These lab tests help the doctor to know what type of non-Hodgkin lymphoma the patient has and how to treat the disease.

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:

- CT scans (Computed Tomography)
- MRI (Magnetic Resonance Imaging)
- PET scans (Positron Emission Tomography)



For more information on different types of non-Hodgkin lymphoma, order the Society's free booklet, *The Lymphomas: Hodgkin Lymphoma and Non-Hodgkin Lymphomas* or the free fact sheets, *Mantle Cell Lymphoma* and *Cutaneous T-Cell Lymphoma*.

Once the doctor finds out a patient has non-Hodgkin lymphoma, the next step is to find out how widespread the disease is. This is called "staging." Blood, marrow and imaging tests also help the doctor to see how advanced the disease is.

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.

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# Non-Hodgkin Lymphoma Stages

**Stage 1:** The lymphoma is in just one lymph node region.

**Stage 2:** The lymphoma is in two or three lymph node regions that are near each other. For example, the lymphoma is in the upper body regions (neck, chest or armpit) or the lymphoma is in the lower body regions (abdomen and groin).

**Stage 3:** The lymphoma is in several lymph node regions in the neck and chest and abdomen.

**Stage 4:** The lymphoma is widespread in the lymph nodes and other parts of the body, such as the lungs, liver or bone.

## Treatment for Non-Hodgkin Lymphoma

The doctor has to take into account many factors to make a treatment plan for non-Hodgkin lymphoma:

- The type of non-Hodgkin lymphoma
- How fast the lymphoma is growing
- The stage of the disease
- The type of lymphocyte affected (such as T cells or B cells)
- Whether parts of the body besides the lymph nodes are involved – such as the lungs, liver or bones
- The patient's age and overall health
- The patient's symptoms – such as fever, sweating and weight loss.

## Treatment for Slow-Growing Lymphoma

In most cases, a patient begins treatment for non-Hodgkin lymphoma right away. But when a patient has non-Hodgkin lymphoma 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.

If there are signs the lymphoma is starting to grow, then treatment will begin.

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.

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## **Relapsed or Refractory Disease**

Slow-growing lymphoma may return after a period of remission (called a “relapse”). Patients can have more treatment and return to remission.

Some patients may not respond to treatment for newly diagnosed or relapsed lymphoma. This is called “refractory” lymphoma. Doctors can change the patient’s treatment and use a different drug or drug combination.

## **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 Lymphoma**

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

## **Relapsed or Refractory Disease**

Patients may have a return (relapse) of lymphoma months or years after treatment. Additional treatment restores remission for many patients. In these cases, 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 disease should talk with the doctor about the risks and benefits of participating in a clinical trial.

## Drugs Used to Treat Non-Hodgkin Lymphoma

Many drug combinations are used to treat non-Hodgkin lymphoma. The drug choice depends on the type of non-Hodgkin lymphoma and the stage of treatment.

### Examples of Drugs Used to Treat Non-Hodgkin Lymphoma

Bleomycin (Blenoxane®)  
Carboplatin (Paraplatin®)  
Chlorambucil (Leukeran®)  
Cyclophosphamide (Cytosan®)  
Cytarabine (Cytosar-U®)  
Dacarbazine (DTIC-Dome®)  
Dexamethasone (Decadron®)  
Doxorubicin (Adriamycin®)  
Etoposide (Etopophos®)  
Fludarabine (Fludara®)  
Ifosfamide (Ifex®)  
Methotrexate  
Prednisone  
Rituximab (Rituxan®)  
Vincristine (Oncovin®)

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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 non-Hodgkin lymphoma.

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 one 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.



Rituxan® is one monoclonal antibody therapy for non-Hodgkin lymphoma. It is used alone or with chemotherapy to treat some types and treatment stages of non-Hodgkin lymphoma. 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®.

Bexxar® and Zevalin® are two other monoclonal antibodies that are used to treat non-Hodgkin lymphoma. 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.

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

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## 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

## 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 non-Hodgkin lymphoma 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 non-Hodgkin lymphoma. 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 Society's free booklet, *Blood and Marrow Stem Cell Transplantation*, has more details on this topic.**

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## 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. About one out of four brothers or sisters has stem cells that “match” the patient's. 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

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.

**A**llogeneic 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 **mini-transplant**. It may be helpful for older patients. See page 33 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.

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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 in patients (this is called anemia) 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.

Some common side effects from treatment for Hodgkin and non-Hodgkin lymphoma are:

- 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 may want to talk to their doctors about this 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.

**P**atients 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 Society's free booklet, *Understanding Drug Therapy and Managing Side Effects*, and the free fact sheet, *Fatigue*.





## 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 Leukemia & Lymphoma Society's 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 profiling will be used more in the future 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 non-Hodgkin lymphoma. These types of vaccines would not prevent non-Hodgkin lymphoma. One type of vaccine being studied might be used to help a patient stay in remission.

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

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## Stem Cell Transplants Under Study

A type of transplant called a mini-transplant is under study. A mini-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?
- Will the treatment be paid for by my health plan (or Medicare)?
- Should I (or my child) be treated in a cancer clinical trial?
- How will my treatment affect fertility, pregnancy or breastfeeding?

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- 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 Society's free 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.**

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

# Call Our Information Resource Center

The Society's Information Resource Center (IRC) provides patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our information specialists – master's level oncology professionals – are available by phone (800.955.4572) Monday through Friday, 9 am to 6 pm (ET); via email ([infocenter@LLS.org](mailto:infocenter@LLS.org)); or chat online at [www.LLS.org](http://www.LLS.org) (click on "Live Help").

Call 800.955.4572 for a complete directory of our patient services programs.



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

LEUKEMIA

LYMPHOMA

MYELOMA

## **The Society has free booklets and fact sheets.**

*Blood and Marrow Stem Cell Transplantation*

*Coping: Support for People Living with Leukemia, Lymphoma or Myeloma*

*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

*The Lymphomas: Hodgkin Lymphoma and Non-Hodgkin Lymphomas*

*Understanding Blood Counts* fact sheet

*Understanding Clinical Trials for Blood Cancers*

*Understanding Drug Therapy and Managing Side Effects*

*Vaccine Therapy Facts*

*Waldenstrom Macroglobulinemia* fact sheet

## **About or For Children**

*Emotional Aspects of Childhood Blood Cancers*

*Learning & Living with Cancer: Advocating for Your Child's Educational Needs*

*The Stem Cell Transplant Coloring Book*

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

# 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.

Join us for the latest information on lymphoma during our free teleconferences. Go to [www.LLS.org](http://www.LLS.org) or call (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.

# We're Here to Help

The Leukemia & Lymphoma Society has chapters around the nation.

The Society's chapters offer support groups and also can arrange for a lymphoma patient to talk with another person who has lymphoma. To find the Society's chapter in your area, call (800) 955-4572. Or go to [www.LLS.org](http://www.LLS.org), the Society's Web site. The Leukemia & Lymphoma Society (LLS) has free materials.



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

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For more information, please contact:



or:

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White Plains, NY 10605

Information Resource Center (IRC) 800.955.4572

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

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

The Society is a nonprofit organization that relies on the generosity of corporate and individual contributions to advance its mission.



**The Leukemia &  
Lymphoma Society**  
*Fighting Blood Cancers*