

Lymphoma Facts

You can better manage lymphoma when you know the basic facts. This sheet has information to help—with facts about lymphoma and its tests, plus questions to ask your doctor or nurse and ways to learn more.

Lymphoma is a cancer of the lymphatic system.

Your lymphatic system includes tissues and organs such as your spleen and tonsils. It also includes lymphocytes (a type of white blood cell) and small bean-shaped organs called lymph nodes, which help your body fight infection and disease.

The Lymphatic System

This picture shows your lymphatic system, lymph nodes, and organs.

Lymph nodes are drawn as small circles.

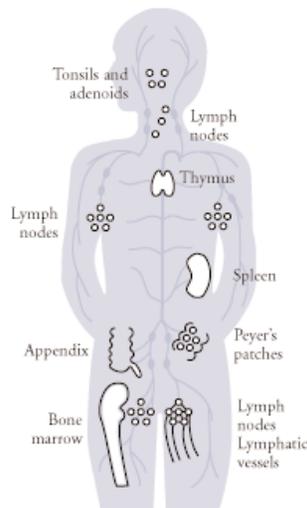
There are two types of lymphoma:

- **Non-Hodgkin's Lymphoma (NHL):**

There are two types of NHL, "B-cell lymphoma" and "T-cell lymphoma." The two types are again divided into:

"Indolent lymphoma" grows slowly.

"Aggressive lymphoma" grows quickly.



When doctors describe lymphoma, they will often use both terms.

- **Hodgkin's Lymphoma (HL):** This type of lymphoma looks a lot like NHL, but there are some differences. People with HL have abnormal cells called Reed-Sternberg (R-S cells). HL is also different because it spreads in a more orderly manner than NHL.

Stages of Lymphoma

Your doctor or nurse will talk about lymphoma in terms of stages. This is a way of saying where your cancer is and if it has spread. Do not get overly alarmed if your doctor tells you that you have widespread disease, because this is common in NHL and not considered unusual. Here is what the stages mean:

- **Stage I:** Cancer cells are in just one lymph node or region (part of your body). This is called "early disease."
- **Stage II:** Cancer cells are in two or more lymph nodes or regions AND either above or below your diaphragm (muscle between your abdomen and chest). This is called "locally advanced disease."

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To learn more, contact:

LYMPHOMA
RESEARCH • FOUNDATION

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Lymphoma Facts (continued)

- **Stage III:** Cancer cells are on both sides of your diaphragm (above and below). This is called “advanced disease.”
- **Stage IV:** Cancer cells have spread to one or more of your body organs (bone, bone marrow, skin, liver, or lungs). This is called “widespread disease.”

Categories of Lymphoma

After the stage, lymphoma is again divided into “A,” “B,” or “E” categories depending on the type of symptoms you have:

- **A:** no symptoms.
- **B:** symptoms may include: fever, chills, night sweats, itching, and weight loss.
- **E:** your lymphoma has spread from a lymph node directly to an organ.

Tests for Lymphoma

You are likely to have many tests throughout your course of treatment. These help doctors diagnose lymphoma and see if it has spread. Here are some of the tests:

Biopsy

Tissue cells are taken out with a needle or by surgery.

Blood Tests

Blood is taken from your arm through a thin needle. Doctors then look at your red blood cells, white blood cells, and blood platelets under a microscope.

Tissue Biopsy

A sample of bone marrow (the spongy material inside your bones) is taken from your hip using a thin needle.

Spinal Tap (lumbar puncture)

Fluid is taken from your spine (lower part of your back) using a thin needle. This is done only in certain situations.

CT Scan

A large machine (like an x-ray) takes pictures of your body from many angles. This shows doctors where the lymphoma tumors are in your body.

MRI

This test uses magnets and radio waves to show whether lymphoma has spread to your nervous system or other body organs.

MUGA Scan

This type of scan shows how well your heart muscle is working.

PET Scan

This type of scan shows doctors if certain lymph nodes still have the disease.

X-Rays

This test uses radiation to take pictures of the inside of your body.

Lymphoma Treatments

Your doctor or nurse may ask you to help make a choice about your lymphoma treatment. Use this sheet to help you learn the basic facts.

Lymphoma Basics

Lymphoma is a cancer of the lymphatic system.

Your lymphatic system is made up of a type of white blood cell. This is called a lymphocyte. It is located in your lymph nodes, spleen, tonsils and bone marrow (where blood cells are manufactured). The lymphatic system helps your body fight infection and disease.

There are two main types of lymphoma:

Non-Hodgkin's Lymphoma (NHL)

This type of lymphoma is most common in middle aged or elderly people. NHL can occur in lymph nodes and/or other organs that contain lymph tissue. The cancer may be located in one place in your body, but often, it is located in multiple areas throughout the body. This is because cancerous ("malignant") lymphocytes often circulate throughout your body, just like normal lymphocytes. NHL can be either "B-cell lymphoma" or "T-cell lymphoma," depending on which type of lymphocyte becomes cancerous. There are over 40 different types of NHL. Some types of NHL grow very quickly. Other types grow more slowly.

Hodgkin's Lymphoma (HL)

This type of lymphoma is most common in young adults. The cancerous ("malignant") lymph nodes contain a particular type of malignant lymphocyte, which is known as a Reed-Sternberg cell.

How to Choose a Treatment

There are many types of treatment for lymphoma. Your treatment choices depend on three main things:

- 1) What type of lymphoma you have.
- 2) The stage of the lymphoma (this means how many areas are affected by the lymphoma).
- 3) Your general health.

You should ask the following questions when you are making a decision about your treatment:

- **What type of treatment** is best for me (chemotherapy, radiation therapy, biologic therapy, transplant)?
- **When should I begin** treatment?
- **Benefits** (how can treatment help me)?
- **Side effects** of treatment (what other minor problems are caused by treatment)?

Together, you and your health care team will make a choice about which treatment (or treatments) is best for you. You should talk with your doctor, nurse, and other members of your health care team. You may ask a lot of questions about your treatment choices before making a choice.

The Lymphoma treatments include:

Biologic Therapy

This treatment increases your body's natural ability to fight cancer. It does this by giving a boost to your immune system. There are several kinds of biologic therapy:

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Lymphoma Treatments (continued)

How to Choose a Treatment (continued)

- **Monoclonal Antibodies:** These are drugs like Rituxan®, which directly target lymphoma cells and do not harm normal cells. These drugs are sometimes called “smart drugs” or “guided missiles” because they know exactly where to go in your body.
- **Radioimmunotherapy:** These are therapies like Rituxan®, which have a radioisotope attached to them. These “guided missiles” are able to destroy cancer cells because they attach to the lymphoma and deliver small doses of medicine to the cells.
- **Interleukin 2:** This is a medicine that activates the immune system so that it can kill cancer cells.
- **Vaccines:** These are treatments that help the body protect itself against the lymphoma.

Chemotherapy (“Chemo”)

This treatment uses drugs to kill cancer cells and reduce the size of cancer tumors. Chemotherapy drugs may also affect healthy cells and cause side effects like hair loss or mouth sores. There are many types of chemotherapy drugs. Many drugs are often used together for chemotherapy.

Radiation Therapy

This treatment uses radiation (high energy x-rays) to kill cancer cells. The treatment often only takes place in the part of your body where the lymphoma is located.

Transplants

Sometimes high doses of chemotherapy destroy the lymphoma cells and your bone marrow, which is the “factory” for blood cells. To help your bone marrow make new healthy blood cells, some stem cells (immature cells that will grow up into red blood cells, white blood cells, and platelets) may be taken with a special machine before chemotherapy is given. These

cells are then transplanted (put back) into the body. These transplanted cells will then find their way to the bone marrow and restore it, so that it can build healthy new blood cells.

There are two types of transplants:

- 1) **Autologous transplants**—this uses your own bone marrow or stem cells.
- 2) **Allogeneic transplants**—this uses bone marrow or stem cells from a donor (someone else, often a brother or sister).

Watchful Waiting

This means that you do not have to get any active treatment now. But, you may need to get treatments later, if tests show that your cancer is growing. Watchful waiting is usually recommended only for people with slow-growing lymphomas.

Clinical Trials

These are research studies that help doctors learn more about lymphoma treatment. They can also help people with cancer, because it allows them to receive the treatment. Often, clinical trials are the only way patients can receive new treatments, which are not otherwise available. Clinical trials can help doctors learn about:

- New types of treatments.
- Ways to prevent cancer.

While clinical trials can provide many benefits, they can also be harmful for some patients. You should speak with your doctor, nurse, or health care team about clinical trials.

Lymphoma Side Effects and Toxicity

Lymphoma and its treatments can cause pain and toxicity (side effects in your body caused by treatment). You can better manage these problems when you know what to expect and what to do. This sheet can help. It has facts about pain and side effects from chemotherapy and radiation therapy. It also has a list of symptoms and side effects you should call about, questions to ask your doctor or nurse, and ways to learn more.

Chemotherapy Side Effects

Chemotherapy uses drugs to kill cancer cells or keep them from growing. But these drugs also kill healthy cells, which can cause side effects. Side effects vary by the type of chemotherapy drugs used. They include:

- **Decreased Blood Cell Production:** This means that your body has less than normal red blood cells (anemia), white blood cells (leukopenia), and platelets (thrombocytopenia).
- **Diarrhea:** This is when you have runny bowel movements more than several times a day.
- **Fatigue:** This is when you feel like you have no strength or energy, and you feel tired all of the time.
- **Hair Loss:** Chemotherapy may or may not cause hair loss (“alopecia”) anywhere on your body.
- **Mouth Sores** (mucositis): The inside of your mouth can become red or sore because of chemotherapy. Most mouth sores can be treated with medication.
- **Nausea or Vomiting:** You may have nausea (feel like you want to throw up) or vomiting (when you throw up). There are medicines that can stop nausea and vomiting. You should tell your doctor if you have nausea. If the doctor gives you nausea medicine, you should tell him/her whether it is working.

- **Sterility:** Chemotherapy can sometimes produce either temporary or permanent sterility (the inability to have children). This is because some chemotherapy can harm sperm and egg cells. You should talk to your doctor about whether you can store your sperm or eggs before you undergo chemotherapy.
- **Libido:** Chemotherapy can often cause a lower libido (sex drive). Usually a normal libido will return after you finish your chemotherapy treatment.

Radiation Side Effects

Radiation uses high energy x-rays to kill cancer cells. Radiation can cause side effects. These side effects will appear in the part of your body that is being treated with radiation. They may include:

- **Fatigue:** This is when you feel like you have no strength or energy, and you feel tired all of the time.
- **Hair Loss:** Sometimes radiation causes hair loss, but only in that part of your body getting treated. This means that if you get radiation to your stomach and bowels, you will not have hair loss on your head. This is not the same as hair loss from chemotherapy.

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Lymphoma Side Effects and Toxicity (continued)

- **Nausea:** You may have nausea (feel like you want to throw up) after radiation treatments. This often happens to people who have radiation to their abdomen (stomach and bowels).
- **Skin Changes:** Your skin might get red and itch or hurt. Skin changes almost always go away after radiation therapy is finished.

Steroid Side Effects

Very often patients will receive steroids (cortisone, prednisone, dexamethasone, glucocorticoid). These medicines may have side effects, including:

- **Insomnia:** This is when you are not able to fall asleep.
- **Increased Appetite:** This is when you feel hungry all of the time.
- **Mood/Personality Changes:** This is when you feel more angry, sad, or anxious than normal. You may also feel that you are more emotional than before.
- **Weight Gain:** This is when you gain a lot of weight in a short period of time.

Steroids are often used for short periods of time, so you may not experience any of these side effects.

Important Treatment Matters: Things to Help Yourself

There are some things that you can do to lessen the side effects of chemotherapy or radiation:

- You should drink a lot of liquids before chemotherapy. These can include water, non-caffeine soft drinks, and clear broth.
- You should avoid citrus or tomato juice if your mouth is sore. Milk and cream can be soothing to drink.
- You should eat smaller meals more often, rather than a few large meals each day.
- You may be able to take medicines to prevent nausea before chemotherapy. You should speak with your doctor about this.

- If you experience vomiting or diarrhea, you should speak with your doctor about how you can avoid dehydration (losing too many body fluids).
- You should avoid crowds or people who may have a cold or flu if your blood counts are low.
- If you are taking steroids, you may want to avoid making important decisions. This is because you may not be able to think clearly.

Important Information to Tell Your Doctor

You should tell your doctor and health care team about any other medications you are taking. This includes any herbs, vitamins, herbal supplements, large amounts of foods/drinks (such as tea), or medicine given to you by another doctor. This is because they may affect your lymphoma treatment.

When to Call Your Doctor

You should speak with your doctor or members of your health care team about any matter that seems different or is bothering you during your treatment. If you experience any of these issues, you should contact your doctor immediately:

- **Fever of 100.5 F (38.6 C) or higher** (you may have chills before the fever).
- **Constipation or diarrhea** that lasts for more than 48 hours.
- **Dizziness** (feeling unbalanced or lightheaded)
- **Severe shortness of breath** (feeling like you cannot breathe)
- **Bleeding** that does not stop quickly.
- **Unusual bruising** that does not go away.
- **Constant nausea or vomiting**, even though you are taking nausea medication.
- **Not being able to eat, drink, or swallow** for more than 24 hours.

Communication with Your Health Care Team

You may feel scared or upset because you have lymphoma. This can be very common. However, you should know that there is a team of health care providers who can help you. This fact sheet is about the people on your healthcare team and how you can work with them. It also has some sample questions plus ways to learn more.

People on Your Health Care Team

Your health care team may include many different people who can help with your lymphoma care. This team works together, although you might not meet all of them. Here are some of the people who may be on your health care team:

- **Doctors:** You are likely to meet many doctors. Some of them you may only meet one time. Other doctors will work with you throughout your treatment and care. These doctors can include:

Hematologist: Treats people with cancers of the blood (lymphoma, leukemia, and myeloma).

Oncologist: Treats people with all types of cancer.

Pain and Palliative Care Specialist: Helps reduce or ease pain or other symptoms through medication and other ways.

Radiation Oncologist: Uses radiation to treat and manage cancer.

Radiologist: Looks at x-rays and other types of high-energy scans.

- **Financial Counselor:** Can answer questions about hospital bills and other costs.
- **Nurse:** Works with all the health care providers on your health care team. Nurses provide cancer treatment and can teach patients and their families ways to manage pain and treatment side effects.
- **Nutritionist:** Teaches about which foods and drinks to have during lymphoma treatment.
- **Pharmacist:** Prepares and gives out prescription medications.
- **Radiation Technician:** Operates (uses) radiation therapy equipment.
- **Social Worker:** A licensed professional who provides emotional support. Social workers can also provide referrals to support groups, and assist with transportation issues and financial matters.
- **Psychologist or Psychiatrist:** Mental health workers who can provide counseling, treat anxiety or depression, and help you with coping with your illness.

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Working with Your Health Care Team

There are many ways you can work together with your health care team. Here is what you can do:

- ***Build a Relationship***

You should try to be open and honest with your health care team regarding your diagnosis. You can also discuss your treatment plan, as well as the possible side effects.

- ***Staying in Touch***

You are welcome to make additional appointments or contact your health care team if you have additional questions.

- ***Bring Someone with You***

You should ask a family member or close friend to go with you to appointments. This person can help ask questions, take notes, and remember what was said.

- ***Keep a Notebook***

You should write down your questions in a notebook or diary. Then, you should bring the notebook or diary with you to your appointments. This is a good way to remember all of your questions.

- ***Ask Questions***

You should ask questions until you feel like you know everything you want to know about your diagnosis and treatment. You can ask any of the people in your health care team. You should make sure understand the answers. If you don't understand the answers, you should ask the doctor to explain it in another way.

Questions to Ask Your Healthcare Team

About lymphoma, in general...

- What type of lymphoma do I have?
- What stage is my lymphoma?
- What tests do I need?

About lymphoma treatment...

- What are my treatment choices?
- How can this treatment help me?
- How is this treatment given?
- How long with the treatment last?
- What are the side effects of this treatment?

About pain and side effects...

- Which side effects am I likely to get?
- How can you or I manage these side effects?
- When do I need to call you about my symptoms or side effects?

About getting the help you need...

- How do I contact my doctor, nurse, or social worker?
- Why is it important to bring someone with me to an appointment?
- How can the financial counselor help me?

Coping with Lymphoma

Being diagnosed with lymphoma and receiving treatment can present many emotional and psychological challenges. You may experience a wide range of emotions including fear, anxiety, shock, and disbelief, when you learned you have lymphoma. Often, when people are able to learn more about the disease and gain knowledge about the different options they have, they are better able to manage their feelings and the challenges they face.

This fact sheet will provide you with information about areas of your life that may be affected by your lymphoma and your feelings. It will also list resources that may help you throughout

Common Areas Affected by Lymphoma

- Finances
- Work/School
- Sexual Intimacy
- Social Support
- Emotional Reactions

Finances

Lymphoma diagnosis and treatment can be expensive. Depending on the type of insurance coverage you have, you may need to pay for medical bills, hospital bills and medications. You also have to pay for transportation to and from the treatment center, childcare, home care services, and other necessary items such as wigs/equipment. You should speak with your health care team about your concerns. Your health care team can help you during this difficult time by providing valuable information to help meet your financial needs at any stage of your diagnosis and treatment.

Work/School

Some people can continue going to work or school during their lymphoma treatment. Other people may decide that it is best to return to work or school

after they have finished their treatment. You should decide which option is best for you. Regardless of what you choose, you need to know that lymphoma treatments can make people feel tired and weak. This can affect your ability to concentrate. It is important to talk with your health care team when deciding what is best for you. Many people are affected financially by their inability to work. It may be helpful to speak with your social worker regarding specific resources available to you.

Sexual Intimacy

Sexual intimacy is an important part of life. Side effects from treatment, as well as your feelings of fatigue, anxiety, and sadness may temporarily change your level of sexual interest and ability to be sexually intimate. Although it may be difficult to talk to your doctor or partner, this is the first step you should take to feel comfortable and get the help you need. Remember, there are many ways to be intimate that can make you feel more connected to your partner. One way to feel closer to your partner is to take a shower or bath together. Another way you can feel close to one another is to give each other foot massages.

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Coping with Lymphoma (continued)

Social Support

Social support can play an important role for you. Finding out about available resources and information to turn to in times of need can provide you with a sense of connection to others and decrease feelings of loneliness, sadness and anxiety, while enhancing your quality of life. Social support can come from many sources including: your health care team, family and friends, support groups, mental health professionals (social workers, psychologists, psychiatrists), and places of worship where you practice your religious and spiritual beliefs (church, synagogue, mosque, temple).

Emotional Reactions

You may experience many different feelings as a result of your lymphoma diagnosis and treatment. Some common feelings may include:

- Loneliness
- Fear
- Anxiety
- Depression
- Anger
- Feeling uncertain about the future

Please know that all people manage their feelings differently. Some people prefer to connect with others at a support group or via a lymphoma buddy program. These may help you to feel more connected and secure.

You may feel overwhelmed or anxious about your situation. You may also feel depressed. Crying, feeling very sad, and not wanting to be around others may be signs that you are depressed. You should try to be open and honest about your feelings. It can be helpful to discuss your feelings with your doctor, nurse, social worker, psychologist or psychiatrist. They may be able to help you manage your feelings and ease your symptoms.

Here are Some Questions to Ask:

- What can I do if I can't afford to pay for my treatment?
- Should I tell my employer that I have lymphoma?
- How much time will I need to take off work?
- What do I tell my partner and family?
- Will I ever be able to be sexually intimate with my partner?
- What should I do if my feelings of sadness and worry continue to bother me?
- Where else can I go for help?

Other Resources

There are many other resources and organizations to help you deal with your lymphoma. Some of these are:

Asian American Donor Program

7700 Edgewater Drive, #265, Oakland, CA 94621

1-800-568-3700

Email: asamdonors@aadp.org

Web: www.aadp.org

Asians for Miracle Marrow Matches

231 E. Third Street, Suite G107,
Los Angeles, California 90013

213-473-1663/800-A3M-HOPE

Web: www.AsianMarrow.org

Cancer Care Inc.

National Office

275 Seventh Avenue, New York, N.Y. 10001

212-712-8400/1-800-813-4673

Email: info@cancercare.org

Web: www.cancercare.org

Intercultural Cancer Council

6655 Travis, Suite 322, Houston, TX 77030

713-798-4617

Email: info@iccnetwork.org