

# FRANKLY SPEAKING ABOUT CANCER

# Lymphoma

## Diagnosed with Lymphoma?

It's important to understand everything you can about your diagnosis, treatment options, and places to go for support. This will help you make treatment decisions that you feel satisfied with, and it will help you feel better. Ask questions. Cancer is serious; but, the more you know, the more you can do to manage the disease. Here are some **essential actions** you can take.

## Starting Point

*Learn facts about lymphoma and your diagnosis.*

- Lymphoma is a blood cancer that begins in the cells of the immune system., specifically white blood cells (the lymphocytes of the lymphatic system). This is a system of cells that protect your body from infection and disease. Your lymphatic system includes organs such as your spleen and tonsils as well as lymph nodes. The Lymphatic system is located throughout your body (in your neck, armpits, chest, and groin).
- When lymphocytes don't function normally and grow without control, they can cause symptoms such as low energy, night sweats, headaches, weight loss, itching or coughing, and sometimes tumors. Because lymph tissue is so essential to your body, lymphoma can start almost anywhere and spread to almost any organ or tissue.
- There are two main types of lymphoma: Hodgkin and non-Hodgkin lymphoma; both of which have many sub-types. Your doctor will look at tissue cells from a biopsy to determine exactly what type and sub-type of lymphoma you have and the stage of your lymphoma.
- It's important to talk with experts in lymphoma to properly diagnose and treat this disease. It helps to do your own research with credible sources and to learn as much as you can about your diagnosis so you can ask questions that will help you receive the best possible treatment and care.

### LYMPHOMA SPECIFIC SUPPORT AND INFORMATION

Leukemia & Lymphoma Society (LLS)	1-800-955-4572	<a href="http://www.lls.org">www.lls.org</a>
Lymphoma Research Foundation (LRF)	1-800-500-9976	<a href="http://www.lymphoma.org">www.lymphoma.org</a>
National Cancer Institute (NCI)	1-800-422-6237	<a href="http://www.cancer.gov">www.cancer.gov</a>
American Cancer Society (ACS)	1-800-227-2345	<a href="http://www.cancer.org">www.cancer.org</a>



*You matter. Your wants, your goals and your needs  
are the MOST important things you should consider.*

— Dr. Mitch Golant

# Double Check

*Make sure that your diagnosis is accurate and that you trust your treatment team.*

After a physical exam, diagnostic tests, are done to help doctors accurately diagnose lymphoma. These can include:

- **Blood tests** - blood is removed to determine a complete blood count and to check for abnormal cells and substances associated with lymphoma
- **Biopsy** - tissue cells are removed with a needle or surgery and viewed under a microscope – sometimes an entire lymph node or bone marrow is removed and studied.
- **Bone Marrow Biopsy (spongy material in your hip bone)** - removes cells from the bone marrow to determine if the bone marrow has been affected by the cancer.
- **Immunophenotyping** is the term used when cells from a lymph node, blood or bone marrow are examined to determine the type of lymphoma cells found.
- **Imaging tests** such as the **CT (computed tomography) Scan** which, like an x-ray looks for tumors in your body, **MUGA Scan** (showing your heart muscle health), **PET (positron emissions test) Scan** which shows if lymph nodes are affected, and **X-Rays** which are pictures made with radiation to view the inside of your body
- **Lumbar Puncture (also called spinal tap)** where fluid is taken from your spine – only in certain situations)
- **Pulmonary (lung) function tests** and **cardiac (heart) tests** such as an **EKG** or **ECHO Cardiogram function tests**

## QUESTIONS TO ASK BEFORE HAVING DIAGNOSTIC TESTS

- Which diagnostic tests will I have? How will these be useful in understanding my diagnosis and treatment if I have cancer?
  - Can I have the biopsy or imaging tests in your office?
  - Will I have to do anything to prepare?
  - How long will it take? Will I be awake?
  - Are there risks or side effects?
  - How soon will I know the results? Who will explain them to me? Will I hear from the doctor over the phone or will I get the results at my next clinic appointment?
  - If I do have cancer, who will talk to me about next steps?
- Your cancer treatment will be led by a hematologist/oncologist, these are doctors that specialize in blood cancers such as Hodgkin and non-Hodgkin lymphoma.
  - Seeking a second or third opinion about you diagnosis and treatment plan from another lymphoma expert can make you feel more confident in your doctor and course of treatment. Doctors are not insulted when you ask for referrals, and often insurance companies encourage more than one opinion. Consider a lymphoma expert from a National Cancer Institute (NCI) Comprehensive Cancer Center near you. Call 1-800-422-6237 for more information. Hematologist/Oncologists who work in these federally funded centers are very specialized in the diseases they treat.

**WHO WOULD YOU LIKE TO WORK WITH FOR TREATMENT?**

It is important to feel able to trust the doctor(s) and health care providers on your team with open communication. Ask yourself:

- Do I trust and like these professionals?
- Who is on my "team"? In addition to the doctor, will there be an oncology nurse, social worker, case manager? Are there others that can help me?
- Do I feel that they are "expert" in treating my lymphoma and can address my needs?
- Does my doctor let me ask questions without rushing me – and give me answers that I understand?
- Who on my medical team help me sort through insurance questions and coverage?

- Lymphoma can be treated and even cured. It is important to work in partnership with your treatment team, seek information, ask questions and get support.

## Take Time

*Learn everything you can.*

- Unless your disease is at a very advanced stage, you typically have some time to make treatment decisions. Bring someone who can help you sort through information at medical appointments, take notes and ask questions. You will receive a lot of information and it can feel overwhelming and confusing.
- If you spend time and talking through your options with loved ones and professionals who understand your needs, you can make more thoughtful decisions and feel a greater sense of control.
- Cancer can cause sterility, if you are concerned about preserving your fertility, talk to your team about egg preservation and sperm storage.

**QUESTIONS TO ASK BEFORE HAVING DIAGNOSTIC TESTS**

- What is the stage, type and spread of my cancer and what does this mean for me?
- What treatments are best for me and why?
- What are the risks and benefits of each treatment option you have suggested for me?
- Is there a clinical trial that I should consider, and why?
- What is the goal for treatment? Will I be on treatment to cure the cancer, control the cancer, or something else?
- What side effects should I expect from treatment and from the cancer?
- What can I do to feel better? Can I call or email my doctor if I have questions along the way?  
Can I speak with another patient with a diagnosis similar to mine regarding their experience?

# Treatment Options

- Treatment for lymphoma commonly includes chemotherapy, radiation, targeted therapy, sometimes bone marrow/stem cell transplants (involving either your own stem cells or matched donor cells), clinical trials, or a combination of these. Treatment depends upon the sub-type of lymphoma, the stage of lymphoma (how many areas of your body are affected), how the cancer has grown (slowly or quickly), and your overall health. It is important to ask about ALL of your treatment options before starting a treatment plan.
- Targeted treatment options depend on the types of lymphocytes found in the cancer cells in your body, whether they are B cells, T cells, Natural Killer cells or something else. Targeted treatment options are not recommended in every case and they are dependent on the specific type of lymphoma one has.
- Before you choose a treatment plan, it's important to ask your doctor(s) about the length of the treatment plan, the expected and unexpected side effects that can occur, and for tips to manage them up front.

## Chemotherapy

Chemical drug treatment prescribed by a hematologist or oncologist is the main therapy for Hodgkin lymphoma and non-Hodgkin lymphoma. Combination chemotherapy, a mixture of drugs with different properties, is often used. Since chemotherapy may lower certain types of blood cells, it may be common to need a red blood cell transfusion, platelet transfusion or an injection that is a growth factor that helps the white cells reproduce. Chemotherapy treatment can take several months, and is known to cause side effects such as hair loss, nausea, a loss of appetite, gastro-intestinal problems, and fatigue.

## Radiation Therapy

Radiation therapy techniques allow skilled radiologists to target tumors more precisely, delivering the maximum amount of radiation to a cancer with limited damage to healthy cells. Radiation therapy may be used in early-stage lymphoma or to help symptoms such as pain or to reduce the size of tumors. It is rarely the only treatment given. Side effects include skin irritation at the site of radiation and fatigue.

## Targeted Treatment and Immunotherapy

Examples of possible targeted drug treatment for lymphoma include:

- Monoclonal antibodies, including Rituxan® for non-Hodgkin lymphoma and SGN-35 for Hodgkin lymphoma
- Radioimmunotherapy, connecting a monoclonal antibody with a radioactive substance to target cancer cells, such as Zevalin® or Bexxar®
- Immune modulators that modify the tumor cell's environment and allow it to die, such as thalidomide and lenalidomide
- Small molecule therapies that block the ability of a cancer cell to survive and multiply, such as panobinostat for Hodgkin lymphoma

## Stem cell transplantation

If chemotherapy does not stop cancer cells from growing or if lymphoma returns, a stem cell or bone marrow transplant may be recommended. Stem cell transplants can also help repair blood and bone marrow harmed by chemotherapy. One of the most common and serious side effects from bone marrow or stem cell transplantation is infection.

## Watchful waiting

This approach is used in slow growing lymphomas and involves closely monitoring lymphoma with diagnostic imaging at a specified time period without active treatment.

### Lymphoma Clinical Trials

At leading cancer centers, Hodgkin and non-Hodgkin lymphoma clinical trials (research studies) enable patients to utilize new treatments for many types of lymphoma, including recurrent disease. To find out more about clinical trials, speak to your treatment team about the clinical trials that are relevant to you.

### Proton Therapy

Comprehensive Cancer Centers may offer proton therapy which delivers high radiation directly to the tumor site, with limited damage to nearby healthy tissue. For some patients, this therapy can result in better cancer control with fewer side effects.

## You're Not Alone

*Help is available — and important.*

- Professionals, such as oncology social workers and counselors are available to provide guidance and support. There are places to go for free support groups, education and information. It's never too late to get support. No one can do it alone, and no one has to.

### QUESTIONS TO ASK YOURSELF

- What type of help do I want and need? (Help at home? Help with driving, childcare, or medical decisions?)
  - Who would you like to talk with about treatment decisions? Or join you at medical appointments?
  - Does your doctor recommend an oncology social worker to talk with? Or a support group?
  - Who would be able to help you with practical support, such as with meals or babysitting or driving?
  - Can a website scheduler help? (try [www.mylifeline.org](http://www.mylifeline.org))
  - Can a cancer support organization provide you with useful services or information?
  - Who can help you sort through insurance or financial questions?
- People you feel close with want to help. Think about the things that each of them can do based on their availability and skills, and let them know what would help. Try to be patient when they can't help—and seek “back up” support. Many cancer support organizations, spiritual organizations, and local hospitals can link you with supportive people and services.
  - Cancer is stressful and it causes many strong emotions. Find ways to express your feelings. Don't underestimate the importance of seeking help if you feel overwhelmed, stressed, anxious or depressed about a lymphoma diagnosis. With education and support, you can be assured that you will be able to deal with the many issues and emotions that cancer brings.
  - People diagnosed with cancer often learn a lot from other people who've had similar experiences. A cancer survivor might understand, more personally, what you're going through. Contact organizations that specialize in lymphoma (see the resources we list). They can provide information and connect you with a lymphoma survivor who has had similar experiences.

**OTHER CANCER SURVIVORS CAN**

- Talk with you about questions you can't easily ask your doctor or friends.
- Share information about where to go for support, hope and services.
- Give you tips to help you stay on track with difficult medical appointments and treatment schedules.
- Help you explore what a survivor has experienced and what has helped them.

## Maintain Hope

*You may have cancer, but cancer doesn't have you.*

- Many people with cancer find new ways to think about their lives and priorities. You can find meaning in your cancer experience that is inspiring for you and for those around you.
- It's important to appreciate the hopeful details in every moment. Try to do what you can to feel healthy and gain energy. Try to spend time with people who make you feel good.

**TRY TO BE PRO-ACTIVE AND ASK YOURSELF**

- What is important to me?
- What can I do to improve my health? Can I try to do more exercise and eat more healthful foods?  
There is often a nutritionist on staff at the hospital
- Do I get enough rest? Talk to your physician or medical team about this.
- Can I spend more time with people I enjoy?
- Can I make plans to do something I'll look forward to?
- Can I do things that will give me a hopeful sense of peace?

**VALUABLE RESOURCES**

**Lymphoma Specific Information & Support**

<b>Leukemia &amp; Lymphoma Society (LLS)</b>	800-955-4572	<a href="http://www.lls.org">www.lls.org</a>
<b>Lymphoma Research Foundation (LRF)</b>	800-500-9976	<a href="http://www.lymphoma.org">www.lymphoma.org</a>
<b>National Cancer Institute (NCI)</b>	800-422-6237	<a href="http://www.cancer.gov">www.cancer.gov</a>
<b>American Cancer Society (ACS)</b>	800-227-2345	<a href="http://www.cancer.org">www.cancer.org</a>

**General Cancer Information, Survivorship & Support**

<b>Cancer Support Community (CSC)</b>	888-793-9355	<a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a>
<b>Cancer.net</b>	800-653038	<a href="http://www.cancer.net">www.cancer.net</a>
<b>CancerCare</b>	800-813-4673	<a href="http://www.cancercare.org">www.cancercare.org</a>
<b>LIVESTRONG</b>	855-220-7777	<a href="http://www.livestrong.org">www.livestrong.org</a>

**Financial & Legal Support**

<b>Patient Advocate Foundation (PAF)</b>	800-532-5274	<a href="http://www.patientadvocate.org">www.patientadvocate.org</a> (PAF's co-pay relief program is at <a href="http://www.copays.org">www.copays.org</a> ).
<b>Cancer Legal Resources Center</b>	866-843-2572	<a href="http://www.cancerlegalresourcescenter.org">www.cancerlegalresourcescenter.org</a>

**Bone Marrow and Peripheral Blood Stem Cell Transplant Information**

<b>National Bone Marrow Transplant Link</b>	800-546-5268	<a href="http://www.nbmtlink.org">www.nbmtlink.org</a>
<b>National Marrow Donor Program</b>	800-627-7692	<a href="http://www.marrow.org">www.marrow.org</a>

**Clinical Trials and New Treatment Developments**

<b>Food and Drug Administration (FDA)</b>	888-463-6334	<a href="http://www.fda.gov">www.fda.gov</a>
<b>NCI's Clinical Trials Registry</b>	888-422-6237	<a href="http://www.cancer.gov/clinicaltrials">www.cancer.gov/clinicaltrials</a>
<b>CSC's Emerging Med Search</b>	800-814-8927	<a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a>

**Caregiver Support, Complementary Support**

<b>National Family Caregivers Association</b>	800-896-3650	<a href="http://www.nfcares.org">www.nfcares.org</a>
<b>National Center for Complementary and Alternative Medicine</b>	888-644-6226	<a href="http://nccam.nih.gov">http://nccam.nih.gov</a>



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