



If you or a loved one has been diagnosed with lymphoma, you may be feeling overwhelmed. You may have a lot to process and a lot of doctor visits. It can seem sometimes like your health care team is speaking another language. Whether you have decisions to make about your treatment or not, it helps to know what to expect from treatments.

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.

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

## Double Check

### MAKE SURE YOUR DIAGNOSIS IS ACCURATE AND 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:** Cells are removed from the bone marrow (spongy material in your hip bone) to determine if the bone marrow has been affected by the cancer.

**Immunophenotyping:** Cells from a lymph node, blood, or bone marrow are examined to determine the type of lymphoma cells found.

#### Imaging tests:

- **CT Scan** (computed tomography scan): A series of images, like an x-ray, are combined to look for tumors in your body.
- **MUGA Scan:** (multigated acquisition scan): Images are created to show your heart muscle health.

— Dr. Mitch Golant

- **PET Scan** (positron emissions test scan): An imaging technique is used to show if lymph nodes are affected.
- **X-Rays**: Pictures are made with radiation to view the inside of your body.

**Lumbar Puncture** (also called spinal tap): Fluid is taken from your spine (only done in certain situations).

**Pulmonary tests**: Tests measure lung function and how well your lungs work.

**Cardiac tests**: The condition of the heart is checked by tests such as an **EKG** (electrocardiogram) or **ECHO Cardiogram**.

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 your 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.

Lymphoma can be treated and sometimes even cured, depending on the type of lymphoma and your overall health situation. It is important to work in partnership with your treatment team, seek information, ask questions and get support.

## 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 can help me sort through insurance questions and coverage?

## 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 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 YOUR HEALTH CARE TEAM

## BEFORE HAVING DIAGNOSTIC TESTS

1. Which diagnostic tests will I have? How will these be useful in understanding my diagnosis and treatment if I have cancer?
2. Can I have the biopsy or imaging tests in your office?
3. Will I have to do anything to prepare?
4. How long will it take? Will I be awake?
5. Are there risks or side effects?
6. 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?
7. If I do have cancer, who will talk to me about next steps?

## AFTER YOUR DIAGNOSTIC TESTS

8. What is the stage, type and spread of my cancer and what does this mean for me?
9. What treatments are best for me and why?
10. What are the risks and benefits of each treatment option suggested for me?
11. Is there a clinical trial that I should consider, and why?
12. What is the goal for treatment? Will I be on treatment to cure the cancer, control the cancer, or something else?
13. What side effects should I expect from treatment and from the cancer?
14. 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, immunotherapy, targeted therapy, sometimes bone marrow/stem cell transplants (involving either your own stem cells or matched donor cells), CAR T cell therapy, 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.

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 while 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, among other issues. The side effects from lymphoma treatment can vary a great deal. They can depend on the type of chemotherapy drug(s), the dose, and how often it is given. Ask about possible side effects before you start treatment and how to manage them. Chemotherapy is often combined with a steroid, which can have helpful anti-lymphoma effects.

### 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.

### IMMUNOTHERAPY



Immunotherapy is any treatment that boosts the patient's own immune system to fight cancer or uses man-made versions of the normal parts of the immune system to kill lymphoma cells or slow their growth. Some types of immunotherapy in use today include monoclonal antibodies, immune checkpoint inhibitors, immune modulators, and CAR T cell therapy (see Cellular Therapy section, below).

## TARGETED THERAPY



Targeted therapy uses new kinds of drugs to identify and target cancer cells, causing less harm to normal cells.

There are several types of targeted therapy in use today, including: proteasome inhibitors, histone deacetylase (HDAC) inhibitors, kinase inhibitors, and antibody drug conjugates. Some work by interfering with a tumor's ability to grow its own blood supply. Others interrupt the signaling system within the cancer cell to stop it from growing and dividing. Still others act by delivering a small dose of radiation or other toxins to the cancer cells.

Targeted therapy is given either by mouth in pill form, through a vein, or as an injection. In the past, targeted therapies were used mostly for lymphomas that had returned after initial treatment. Today these new therapies are more often being used as part of initial treatment. Sometimes targeted therapy is used in combination with other treatments. Other targeted therapies may be available through clinical trials.

## STEM CELL TRANSPLANT AND CELLULAR THERAPY



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. A new type of cellular therapy is available for certain types of lymphomas in patients who have tried multiple prior treatments: CAR-T cell therapy. This involves removing and reprogramming one's own white blood cells to

attack the lymphoma. Visit our page on CAR T cell therapy to learn more about this treatment: [www.cancersupportcommunity.org/car-t-cell-immunotherapy](http://www.cancersupportcommunity.org/car-t-cell-immunotherapy).

## ACTIVE SURVEILLANCE (WATCHFUL WAITING)

This approach is used in slow growing lymphomas and involves closely monitoring the lymphoma with bloodwork, regular clinic visits, and sometimes 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.

## 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.

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.



## 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?

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—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?

# Lymphoma Information & Support

**Be The Match** — 888-999-6743 • [www.bethematch.org](http://www.bethematch.org)

**Cancer Support Community (CSC)** — 888-793-9355 • [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**Cancer.net** — 888-651-3038 • [www.cancer.net](http://www.cancer.net)

**Caregiver Action Network** — 855-227-3640 • [www.caregiveraction.org](http://www.caregiveraction.org)

**Leukemia & Lymphoma Society (LLS)** — 800-955-4572 • [www.lls.org](http://www.lls.org)

**Lymphoma Research Foundation (LRF)** — 800-500-9976 • [www.lymphoma.org](http://www.lymphoma.org)

**National Bone Marrow Transplant Link** — 800-546-5268 • [www.nbmtlink.org](http://www.nbmtlink.org)

**National Cancer Institute (NCI) Clinical Trials Registry** — 888-422-6237 • [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

**National Center for Complementary and Alternative Medicine** — 888-644-6226 • [www.nccam.nih.gov](http://www.nccam.nih.gov)

**Patient Advocate Foundation (PAF)** — 800-532-5274 • [www.patientadvocate.org](http://www.patientadvocate.org) • (PAF's co-pay relief program is at [www.copays.org](http://www.copays.org))

## Cancer Support Community Resources

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club at [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs at [www.CancerSupportCommunity.org/FSAC](http://www.CancerSupportCommunity.org/FSAC).

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community platform allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

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This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/biosimilars](http://www.CancerSupportCommunity.org/biosimilars). For print copies of this booklet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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