



# FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



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## NON-HODGKIN LYMPHOMA

## Introduction

If you or a loved one has Non-Hodgkin Lymphoma (NHL), you may feel overwhelmed. There may be a lot to process and many upcoming doctor visits. Whether you have decisions to make about treatments or not, knowing what to expect with this diagnosis can help. This booklet gives an overview of a NHL diagnosis, treatment, and how to cope. We hope this will help you learn more about your options, know what questions to ask, and help you feel empowered to take control of your cancer journey.

### TALKING ABOUT NHL

You may hear many words used to talk about NHL. Some key ones to know are:

- **Blood Cancer (blud KAN-ser):** Cancer that begins in blood-forming tissue, such as bone marrow, or in the cells of the immune system
- **Lymphocytes (LIM-foh-sites):** A type of white blood cell that is a part of the body's immune system
- **Lymphoma (LIM-foh-ma):** A cancer that begins in the white blood cells. It causes these cells to stop working properly and grow out of control
- **Marrow (MAYR-oh):** The soft substance in the middle of many large bones. Blood cells are made in the bone marrow

## What is Lymphoma?

Lymphoma is a blood cancer that begins in the cells of the immune system, specifically in white blood cells. White blood cells are also known as lymphocytes and are a part of the lymphatic system. This system of cells protects your body from infection and disease. When lymphocytes don't function properly and grow without control, they can lead to symptoms related to lymphoma. Some symptoms include low energy, headaches, weight loss, and sometimes tumors. Lymphoma can start almost anywhere and spread to almost any organ or tissue in the body. There are two main types of lymphoma: Hodgkin and non-Hodgkin lymphoma; both of which have many subtypes.

## What is NHL?

Non-Hodgkin lymphoma (NHL) is one of the most common cancers in the United States. It accounts for about 4 percent of all cancer cases. More than 95 percent of cases occur in adults, but certain types are common among children.

NHL is the name of a group of blood cancers that develop in the white blood cells. NHL usually begins in the lymph nodes or other lymph tissue in the body. It can be either indolent (slow growing) or aggressive (fast growing). There are some indolent NHL that may not need treatment right away. Doctors may just watch them very closely instead. Aggressive NHL usually needs to be treated quickly.



# Types of NHL

There are about 60 different subtypes of non-Hodgkin lymphoma. Most subtypes fall into two main groups named for the cell where the lymphoma starts: B-cell lymphomas or T-cell lymphomas.

## B-CELL LYMPHOMAS

B-Cell lymphomas make up most (about 85 percent) of the NHL cases in the United States. The majority of these lymphomas are either diffuse large B-cell lymphoma (DLBCL) or follicular lymphoma (FL).

- **Diffuse large B cell lymphoma (DLBCL)** is the most common form of non-Hodgkin lymphoma. It is considered an aggressive NHL and occurs mostly in people who are older. In rare cases it occurs in children and younger adults. The average age at diagnosis is mid-60s to 70 years old.

- DLBCL usually starts as a quickly growing mass in a lymph node in the chest or abdomen. It can also start in a lymph node you can feel, such as the neck or armpit. It can grow in other areas such as the intestines, bone, or even the brain or spinal cord. While this is a fast-growing lymphoma, DLBCL usually responds well to treatment. It can sometimes be cured entirely with chemotherapy.

- **Follicular lymphoma (FL)** accounts for nearly 20 percent of lymphomas in the United States. The average age for people with this lymphoma is about 60 years old. FL rarely occurs in very young people. This lymphoma usually appears in many lymph nodes throughout the body and in the bone marrow.

- FL is often slow-growing. It can be treated but is difficult to cure. This type of lymphoma may not require any treatment at first. Many people with FL live for a decade or more with this disease. Depending on certain factors, treatment may be delayed until the disease grows or the person begins to have symptoms. When needed, treatment is often effective. It may lead to a period of remission (when all signs of your cancer are gone) after which the cancer returns. In 25-60 percent of people with FL, their disease eventually turns into a more aggressive large cell lymphoma. This usually does not happen until quite some time after diagnosis, often years later.

- **Other subtypes** of B-cell lymphomas include:

- Mucosa-associated lymphatic tissue (MALT) lymphoma
- Small cell lymphocytic lymphoma/chronic lymphocytic leukemia (SLL/CLL)
- Mantle cell lymphoma (MCL)
- Mediastinal (thymic) large B-cell lymphoma
- Lymphoplasmacytic lymphoma and Waldenstrom macroglobulinemia
- Nodal marginal zone B-cell lymphoma
- Splenic marginal zone lymphoma
- Extranodal marginal zone B-cell lymphoma
- Intravascular large B-cell lymphoma
- Primary effusion lymphoma
- Burkitt lymphoma
- Primary central nervous system lymphoma



## T-CELL LYMPHOMAS

T-cell lymphomas make up less than 15 percent of NHL cases in the United States. They can be aggressive (fast growing) or indolent (slow growing). Common subtypes of T-cell lymphomas include:

- Peripheral T-cell lymphoma, not otherwise specified (PTCL-NOS)
- Cutaneous T-cell lymphoma (Sézary syndrome and mycosis fungoides)
- Anaplastic large cell lymphoma
- Angioimmunoblastic T-cell lymphoma

## Diagnosis & Staging

### RISK FACTORS

Risk factors are things that can increase the chance of developing a disease. Certain cancer risk factors, such as smoking, can be changed. Other cancer risk factors, like a person's age or family history, cannot be changed. Having one or even many risk factors does not mean that a person will get the disease.

These are risk factors for non-Hodgkin lymphoma (NHL):

- Age: Although NHL can be diagnosed at any age, people are often diagnosed when they are 60 or older.
- Biological sex: NHL occurs more often in men than in women. There are certain types that are more common in women. Reasons for this are not known.
- Geography: NHL is more common in North America and northern Europe. It is least common in Asian countries. Worldwide, NHL is more common in developed countries.

- Race and ethnicity: In the U.S., whites are more likely to develop NHL than African Americans or Asian Americans/ Pacific Islanders.
- Immune suppression: People who have a suppressed immune system are at increased risk. This includes those with the human immunodeficiency virus (HIV). It also includes anyone who takes immune suppression treatment for conditions like rheumatoid arthritis or lupus.

There are also some specific infections that increase your risk of developing NHL:

- Infections that weaken the immune system
- Infections that affect lymphocytes
- Infections that activate the immune system

For more information on NHL risk factors, visit [www.CancerSupportCommunity.org/non-hodgkin-lymphoma](http://www.CancerSupportCommunity.org/non-hodgkin-lymphoma)

### SIGNS TO START

### TREATMENT & SYMPTOMS

Common signs and symptoms of non-Hodgkin lymphoma (NHL) may include:

- Abdominal Swelling: A tumor or large collection of fluid may cause the abdomen to become swollen and tender. Swelling may block the passage of feces. This causes abdominal pain, nausea, or vomiting.
- Coughing and Breathing Issues: Certain types of lymphoma can develop into large tumors in the chest. If the tumor presses on the windpipe, it causes trouble breathing.



- **Fatigue and Loss of Appetite:** Sometimes the only signs of the disease are constant tiredness and not feeling hungry.
- **Fever:** A high temperature may occur over several days or weeks.
- **Lumps:** Painless lumps or swollen lymph nodes may develop in the neck, underarm, or groin area.
- **Night Sweats:** You may wake up drenched in sweat.
- **Weight Loss:** You may lose weight without dieting or attempting weight loss.
- **Central Nervous System Changes:** NHL may cause severe headaches, changes in personality, difficulty moving parts of the body, or seizures.

## NON-HODGKIN LYMPHOMA DIAGNOSIS

A lymphoma diagnosis is based on 3 factors:

- How the cells look under a microscope
- Genetic changes in lymphoma cells
- The presence of certain markers on the surface of the cells

To diagnose NHL, your doctor will order several tests. This includes a physical exam, blood tests, biopsies, and imaging tests. These tests will confirm the exact type and stage of your disease. This will help the doctor decide the best treatment options for you.

There are different kinds of biopsies used to diagnose NHL:

- **Lymph Node Biopsy** - The doctor will remove a piece of the lymph node and examine it under a microscope. This is the only way to know for sure if any swelling is caused by cancer. The doctor will get as large of a sample as possible to determine the specific type of NHL. This can help the doctor decide on the best treatment

for you. This may require surgery to get a large enough sample or if the lymph node is in a location that is more difficult to get to. Sometimes the entire lymph node may need to be removed for an accurate diagnosis.

- **Incisional Biopsy** - When the entire lymph node cannot be removed, a piece of tissue will be taken to confirm the diagnosis.
- **Bone Marrow Biopsy** - The doctor will insert a needle into your hip bone to see if lymphoma cells are present in your bone marrow. Sometimes the doctor may use the sternum bone in the chest to check instead.

NHL can be difficult to diagnose and may require multiple tests. If a biopsy confirms an NHL diagnosis, your doctor may recommend additional tests to find out how far the disease has spread. These other tests could include a chest x-ray, CT scan, MRI, PET scan, or blood tests.

## STAGING

After confirming a NHL diagnosis, the doctor needs to know the stage, or extent, of the disease to plan the best treatment. Staging is used to find out whether the cancer has spread, and if so, to which parts of the body.

The Ann Arbor Staging System is most commonly used to describe the extent of non-Hodgkin lymphoma in adults. Stages are classified as Roman numerals I-IV (1-4). A higher number indicates a more advanced disease. Although most lymphomas are stage III or IV when diagnosed, they are often still very treatable and possibly curable, even though they have spread across the body.





- **Stage I:** The disease is found in only one lymph node or in an organ that is part of the lymphatic system, such as the thymus gland (I). A lymphoma can be classified as stage IE (extranodal) when it is found in one area of a single organ that is not part of the lymph system (such as lung, liver, or bone).
- **Stage II:** The disease is found in two or more lymph node areas on the same side of the diaphragm (the sheet of muscle underneath the lungs) (IIE). Or the cancer has spread to a nearby organ next to the lymph nodes (IIE).
- **Stage III:** The disease is found in lymph nodes on both sides of the diaphragm (above and below it) (III) and has also spread to nearby organs (IIIE), to the spleen (IIIS), or to both (IIIES).
- **Stage IV:** The disease has spread widely through one or more organs outside of the lymph system, such as the liver, bone marrow, or lung; it is found in organs in two distant parts of the body and not in nearby lymph nodes; or it is diagnosed in the liver, bone marrow, lungs, or cerebrospinal fluid (the liquid that surrounds the brain and spinal cord).

In addition, letters can be assigned to the stages to provide more information about the disease:

- **Letter “A”:** The symptoms known as “B” symptoms (listed below) caused by NHL are not present.
- **Letter “B”:** The following symptoms are present:
  - A loss of more than 10 percent of body weight over six months (without

diETING or over-exercising)

- A fever of 100.4°F (38 degrees Celsius) or greater without any known cause, and/or
- Drenching night sweats
- **Letter “E”:** NHL has affected an organ outside of the lymph system but is present next to an affected lymph node.
- **Letter “S”:** NHL is affecting the spleen.
- **Letter “X”:** The tumor measures at least 10 centimeters across (about 4 inches), which may require more intense treatment. The addition of the letter “X” indicates that the tumor is “bulky.”

Doctors also use the International Prognostic Index (IPI) score to help them better estimate a patient’s outcome. The index was developed to determine the outlook for people with fast-growing (aggressive) lymphomas. There are even some different versions of this index for various types of NHL, such as FL-IPI for follicular lymphoma, MIPI for mantle cell lymphoma, and the revised IPI (R-IPI) for diffuse large B-cell lymphoma. The total number of points helps predict the risk of disease relapse.

The index includes 5 factors:

1. The person’s age
2. The stage of lymphoma
3. Whether there is involvement of non-lymph system organs
4. The patient’s overall health and ability to perform normal activities of daily living
5. The level of the enzyme LDH in the person’s blood. LDH levels are often higher in patients with lymphomas.



# Choosing Your Treatment Team

The best cancer treatments can be very complicated and change all the time with new discoveries. You want a health care team you can trust to take the best care of you. You also want a doctor and team that you can communicate with well. Your team may include many people including:

- **Medical oncologist/hematologist:** Look for a doctor who specializes in blood cancers.
- **Oncology nurses, oncology nurse practitioners, and physician assistants.**
- **Social worker:** Can help you and your family find resources to cope with cancer, cope with treatment, and pay for care.
- **Patient navigator/advocate:** A person who helps patients through the care system, from diagnosis through treatment and recovery.

## GETTING A 'SECOND OPINION'

Are your questions about treatment getting answered? Do you feel comfortable with your care team? Do you see a doctor who specializes in NHL? You can ask for a “second opinion” with a “hematologist-oncologist” who specializes in NHL.

If your doctor treats all cancers, ask about how many NHL patients they treat each year and if they stay current on the newest NHL treatments. Consider getting treatment or a second opinion at a major cancer center or university hospital. Talking with a second doctor can help you understand your disease and how to better treat it, or reassure you that the first treatment recommended is best.

Let your doctor know if you want a second opinion. It is your choice to continue with the first or second doctor.

## Treatment Planning

Your doctor will recommend treatment options based on the stage of your NHL and your overall health. They may ask about your treatment preferences. This is called treatment planning. You may make choices at the start of treatment and again along the way. Your treatment plan should be designed specifically for your cancer.

If your disease is diagnosed early, is indolent (slow growing), and you have no symptoms, your doctor may recommend a watchful waiting approach. This means your doctor may not recommend any treatment when you are diagnosed. Instead, you will be watched closely for any signs that treatment is needed.

If you need immediate treatment, talk with your doctors about developing a treatment plan that covers managing your cancer in the short term and long term. It is okay to seek a second opinion to discuss your diagnosis or treatment options.

When you talk to your doctor about your treatment options (including the option to wait to start treatment), ask about the goals of each option and how each option might affect the goals you have for your life. Think about what you want to be able to do. Do you want to continue working? How will your treatment affect your family and social relationships? Will you be able to do the things you enjoy? If the doctor recommends that the NHL does not need to be treated at this time, think about any concerns you might have about this option.



**OPEN TO OPTIONS®** If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. **Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.**



## TIPS FOR TREATMENT PLANNING

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.
- Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- If your health care team has recommended “watch and wait,” talk with them about what this means. Ask about next steps and treatment options.
- If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- Write down your questions before each doctor's visit. Keep a journal to track your side effects and results over time.
- Learn the words that doctors use to talk about NHL. This can help you better understand your test results and treatment options.

## Treatment Options

There are a number of treatments that work well for NHL. Though most current treatments do not cure NHL, they do help manage it. While some people with NHL can live for years without treatment, most people will need to be treated on and off for years.

### “WATCH & WAIT”

If you have indolent (slow-growing) NHL, you may not need treatment right away. Instead, watchful waiting (also called “active surveillance”) may be the safest approach for your care. With watchful waiting, you see a doctor regularly but don't begin treatment until needed. Studies have shown that when there is no indication to start treatment, watchful waiting allows the patient to continue their lifestyle without causing their disease to progress more rapidly. Studies do not show any benefit to starting treatment before there is a need. Watchful waiting delays treatment related side effects, while still allowing your treatment to begin when needed.

### CHEMOTHERAPY

Chemotherapy uses drugs to destroy cancer cells. It is a systemic (whole body) treatment. This treatment kills fast-growing cancer cells but can also harm fast-growing healthy cells. This can lead to side effects.





Each chemotherapy drug has its own set of side effects and ways of working. You may receive more than one drug for treatment. Comparing treatments and side effects with other lymphoma patients may be confusing. This is because each patient has a detailed treatment plan created just for them. Be sure to talk with your health care team about any side effects you may have.

## **STEM CELL TRANSPLANT**

A stem cell transplant (SCT) is an infusion of blood-forming cells (stem cells), not a surgery. Sometimes patients serve as their own donors (autologous stem cell transplant). Other times, patients get stem cells from donors (allogeneic stem cell transplant).

Not all patients are good candidates for a transplant. You must be in relatively good health. Previously, patients needed to be under age 65 to qualify for a SCT. However, new methods of doing SCT now allow some older patients to get a SCT. If your care team thinks a stem cell transplant may work for you, you will work with a new transplant team. This team will help you coordinate the treatment and find a donor. You should meet with your transplant team early on so they can identify a matching donor as soon as possible.

Before you go through a stem cell transplant, there are many things to consider. Learn the risks and benefits of the SCT that is recommended for you. Learn what to expect from the procedure and how to prepare for it. You'll also want to know what to expect for recovery and beyond. Ask if your transplant will be done in the hospital or as an outpatient. To learn more about SCT, please visit [www.CancerSupportCommunity.org/article/stem-cell-transplant-cancer](http://www.CancerSupportCommunity.org/article/stem-cell-transplant-cancer).

## **IMMUNOTHERAPY**

Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells. Common categories of immunotherapy include:

- Monoclonal antibodies (man-made versions of antibodies)
- Antibodies that target the CD52 and CD30 antigens
- Immune checkpoint inhibitors
- Immunomodulating drugs
- Radioimmunotherapy

Many of these immunotherapy treatments are available only through clinical trials. To learn more, visit [www.CancerSupportCommunity.org/immunotherapy-cancer-it-right-you](http://www.CancerSupportCommunity.org/immunotherapy-cancer-it-right-you).

## **CELL THERAPY**

CAR T cell therapy is one way to use the body's natural defenses to fight cancer. It is called CAR T cell therapy because a lab-made protein, called chimeric antigen receptor (CAR), is added to the patient's own T cells. T cells are a type of white blood cell. The CAR protein helps the T cells target cancer cells to be killed and helps train your immune system to attack the cancer.

CAR T cell therapy is a new type of immunotherapy. It can only be given at approved centers with very close monitoring. It is not used as a first-line treatment. CAR T cell therapy is used in cases where a patient has suffered a relapse of their NHL after two prior lines of treatment. To learn more, visit [www.CancerSupportCommunity.org/car-t-cell-therapy](http://www.CancerSupportCommunity.org/car-t-cell-therapy).



## TARGET THERAPY

Targeted therapy aims to more precisely attack cancer cells. These drugs target changes in the genes or proteins of cancer cells that help them grow, divide, and spread. 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.

## RADIATION THERAPY

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. Radiation therapy for NHL uses a focused beam of radiation from a machine outside of the body. External beam radiation is a painless procedure. However, it may cause some side effects to the skin near the radiation area.

Radiation may be the main treatment for some stage I and II lymphomas. It may be used with chemotherapy for more advanced lymphomas. This is used to kill lymphoma cells throughout the body and to help prepare the body to receive any stem cells. Radiation therapy is also sometimes used to treat symptoms of lymphoma. Some radiation is available in drug form.

## CLINICAL TRIALS

Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments.

At leading cancer centers, non-Hodgkin lymphoma clinical trials enable patients to utilize new treatments for many types of lymphoma, including recurrent disease. To learn more, be sure to ask your health care team about clinical trials that may be relevant to you.

### KEY THINGS TO KNOW ABOUT CLINICAL TRIALS

- Clinical trials for NHL are done to test new treatments, combinations of treatments, or different ways of doing stem cell transplant.
- A doctor experienced in treating NHL should be able to recommend specific trials.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover “standard” treatment costs. Be sure to ask what costs you may incur.

*See the resources on the back page for help finding clinical trials that might be right for you.*



## Managing Side Effects

It helps to learn more about the side effects of treatment before you begin so you will know what to expect. When you know more, you can work with your health care team to manage your quality of life during and after treatment.

There are many medications available to address side effects from cancer treatment. Everyone reacts differently to treatment and experiences side effects differently. After you start treatment, keep track of how you feel. Write down when you notice a problem, how long it lasts, and if there is anything that makes it better. It is important to let your health care team know. Your doctor may discuss options such as lowering the dose of your treatment if side effects persist and are not easy to manage. You may want to consult a palliative and supportive care specialist to help manage symptoms from cancer treatment.

The following are examples of important side effects reported by NHL patients:

- **Increased chances of infection** from having too few healthy white blood cells. Antibiotics are often used to treat infections. If you keep getting them, injections of immunoglobulin (gamma globulin) or drugs to increase your white blood cell count may help. Be sure you are up to date with flu, pneumococcal, and VZV vaccines. Avoid “live” vaccines.
- **Fatigue** is a feeling of tiredness that doesn’t go away. Some people also have muscle weakness or difficulty concentrating. It may be caused by the cancer, by treatment, or other health problems. Fatigue in NHL patients can

be the result of having too few red blood cells. If you have cancer- related fatigue, your doctor will try to find and treat what is causing it.

You may also experience treatment side effects well after your treatment has ended. It is important to talk to your doctor about the long-term effects of treatment as part of your post-treatment plan.

## Cost

The treatment for NHL and follow-up appointments can be costly. Keeping up with these costs might be overwhelming. Many families facing cancer say that financial worries about cancer costs are a big source of stress, and they don’t know where to turn.

There are resources that can help. Visit [www.CancerSupportCommunity.org/Cost](http://www.CancerSupportCommunity.org/Cost) for more information on managing health care costs.



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## QUESTIONS TO ASK YOUR HEALTH CARE TEAM:

What stage is my NHL?

What type of NHL do I have?

What type of treatment do you recommend?

How often and where will the treatment take place? Will I have to stay overnight in the hospital for any part of the treatment?

What are the goals of my treatment?

What are the side effects of treatment?

Will I need someone to take care of me at any point during this treatment?

Do you recommend a clinical trial?

How will my cancer affect my quality of life?

What will my treatment cost and how much will my insurance cover?



# Coping with NHL

Cancer stirs up many feelings. It affects people who have it, their families, and loved ones. It is normal to feel sad, worried, shocked, stressed, or even panicked. The feelings may be mild or more serious. Remember that cancer can affect anyone. No one deserves cancer. And everyone with cancer deserves good care.

## TIPS FOR COPING

- Ask your health care team questions until you understand why watchful waiting or your current treatment is a good choice for you.
- Know if there are signs or symptoms that you should tell your care team about right away.
- Control what you can. If you smoke, get help to stop. Exercise regularly, as long as it is approved by your care team. Eat healthy foods and maintain a healthy weight.
- Know that you will be more anxious when it gets close to your doctor's appointments. Be gentle with yourself when you are feeling stressed.

## FINDING SUPPORT YOU NEED

- Share your feelings with friends, family members, a counselor, or a clergyperson.
- A counselor or a therapist can help you cope with anxiety. Other things that can help are yoga, breathing, and relaxation exercises.
- Ask for help from friends and your community. The Cancer Support Community's **MyLifeLine.org** is a great way to coordinate this online.
- Contact the patient groups on the back page to find local and online support groups, helplines, and other ways to seek support from people who have NHL.
- Ask your health care team about resources for social, emotional, and practical support. Let them know about your concerns.
- If you search for information online, make sure you are using trusted websites. Turn to the back page to see a listing of trusted resources.



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## CAREGIVERS

Caregivers help or arrange help for people who are ill or disabled. This can take different forms. It might involve physical care or emotional support. Some caregivers assist with money matters, insurance, household chores, rides, or making appointments. Caregivers may or may not live with the person. Caring for someone who has cancer is not easy. People who do so need support and help from their family, friends, and health care team.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down

promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time.

Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit [www.CancerSupportCommunity.org/Caregivers](http://www.CancerSupportCommunity.org/Caregivers).



# Support for NHL Caregivers

NHL affects not only those with the disease, but also the people who care for them. Caregiving for a person with NHL can be stressful and frustrating. You may feel angry, guilty, alone, afraid, or sad. If you are caring for a person with NHL:

## FIND SUPPORT

Share your feelings with others. Look for caregiver support groups, either in person or online. Ask the patient's cancer center if they have a support program for caregivers.

## LOOK FOR EXTRA HELP

Ask friends and family if they can help. If they offer, give them specific tasks. If you can afford it, consider hiring people to help care for the person with NHL. Or have them help with chores, childcare, or errands.

## TAKE BREAKS

Carve out time for yourself. Spend time with people important to you, and take time for activities you enjoy. Don't feel guilty about making time for yourself—it is important for your own health.

## TAKE CARE OF YOURSELF

Just as the person with NHL needs to pay attention to their diet, exercise, and sleep, so do you. If you smoke, find a smoking cessation program. Limit alcohol.

## LEARN ABOUT THE FAMILY AND MEDICAL LEAVE ACT (FMLA)

You may qualify to take up to 12 weeks of unpaid, job-protected leave to care for a seriously ill family member.

## LEARN ABOUT FINANCIAL ASSISTANCE

You may have high out-of-pocket costs from parking, transportation, and food as part of your caregiving duties. Ask the hospital where the person with cancer is receiving treatment if they can provide help with financial counseling for caregivers.



## NHL RESOURCES

**Cancer Support Community** · 1-888-793-9355 · [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**American Cancer Society** · 800-227-2345 · [www.Cancer.org](http://www.Cancer.org)

**American Cancer Society Clinical Oncology (ASCO)** · 800-227-2345 · [www.Cancer.net/nhl](http://www.Cancer.net/nhl)

**CancerCare** · 800-813-4673 · [www.CancerCare.org](http://www.CancerCare.org)

**Imerman Angels** · 866-463-7626 · [www.ImermanAngels.org](http://www.ImermanAngels.org)

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

**Lymphoma Research Foundation** · [www.Lymphoma.org/aboutlymphoma/nhl/](http://www.Lymphoma.org/aboutlymphoma/nhl/)

**Patient Empowerment Network** · [www.PowerfulPatients.org/help-by-cancer-diagnosis/non-hodgkin-lymphoma-nhl/](http://www.PowerfulPatients.org/help-by-cancer-diagnosis/non-hodgkin-lymphoma-nhl/)

## 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 and Sat-Sun 9am-5pm 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.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**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 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).

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/Non-Hodgkin-Lymphoma](http://www.CancerSupportCommunity.org/Non-Hodgkin-Lymphoma). 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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