



DIFFUSE LARGE B-CELL LYMPHOMA





Introduction

If you or a loved one has Diffuse Large B-Cell Lymphoma (DLBCL), 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 DLBCL diagnosis, treatment, and how to cope. We hope this will help you learn more about your options, know what questions to ask, and feel empowered to take control of your cancer journey.

TALKING ABOUT DLBCL

You may hear many words used to talk about DLBCL. 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 Diffuse Large B-Cell Lymphoma?

Diffuse Large B-Cell Lymphoma (DLBCL) is the most common form of non-Hodgkin lymphoma (NHL). NHL is the name of a group of blood cancers that develop in the white blood cells. Unlike Hodgkin lymphoma, NHL does not create an abnormal cell type as it develops. This abnormal cell is known as a Reed-Sternberg cell. NHL can be either indolent (slow growing) or aggressive (fast growing). There are about 60 different subtypes of NHL, but most subtypes fall into two main groups: B-cell lymphomas or T-cell lymphomas. These groups are named after the cell where the lymphoma starts. B-cell lymphomas make up most (about 85 percent) of the NHL cases in the United States.



Diffuse large B-cell lymphoma is an aggressive NHL. It accounts for around one-third of NHL cases and occurs mostly in people who are older. The average age at diagnosis is mid-60s to 70 years old. In rare cases, DLBCL can develop in children and younger adults.

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.

What are the types of DLBCL?

Within DLBCL, there are many subtypes. Some subtypes include:

- Primary mediastinal (thymic) B-cell lymphoma begins as a mass in the chest and can affect breathing. It occurs mostly in people in their 30s who were born female. It is fast-growing but often treatable.
- Primary DLBCL of the central nervous system begins in or near the brain, spinal cord, or eyes. It occurs more often in middle-aged people who were born male. It is also found in people with weakened immune systems.
- Cutaneous leg type DLBCL first appears as lesions on the legs. It is more common among older people who were born female.

Doctors sometimes use the germinal center (GC) to describe DLBCL. It can be GC or NGC (non-germinal center). The germinal center is an area where many B-cells are found and grow. Cancers that have germinal centers respond differently to treatment than those that do not.

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.

The following are risk factors for DLBCL. These are similar to those for other NHLs:

- **Age:** Although DLBCL can develop at any age, most people are diagnosed when they are 60 or older.
- **Sex at Birth:** DLBCL occurs more often in people who are born male than in people who are born female. Some subtypes are more common in people who are born female.
- **Geography:** DLBCL is more common in developed countries.
- Race and ethnicity: In the U.S., white people are more likely to develop DLBCL than African Americans or Asian Americans/ Pacific Islanders.



- Weakened Immune System: People who have a weakened 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, lupus, or for a solid organ transplant.
- Past Cancer Treatment: Past treatment with chemotherapy or radiation therapy may increase the risk of DLBCL.

For more information on DLBCL risk factors, visit www.CancerSupportCommunity.org/DLBCL.

SIGNS TO START TREATMENT & SYMPTOMS

Many of the signs and symptoms of DLBCL are similar to those for other lymphomas. Common signs and symptoms for DLBCL 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.
- Central Nervous System Changes: DLBCL may cause severe headaches, changes in personality, difficulty moving parts of the body, or seizures.
- Coughing and Breathing Issues: Certain types of DLBCL 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.

DIFFUSE LARGE B-CELL LYMPHOMA DIAGNOSIS

Lymphoma can be hard to diagnose. A complete diagnosis often takes more than one doctor's visit. It may involve a physical exam, blood tests, scans, and a biopsy. These tests will confirm the exact type and stage of disease. Your health care team will first determine if you have non-Hodgkin lymphoma (NHL), then if it is DLBCL.

A biopsy will be needed to confirm that you have DLBCL. In a biopsy, tissue is removed and sent to a lab for study. Doctors diagnose DLBCL based on:

- 1. How the cells look under a microscope
- 2. Any genetic changes in the lymphoma cells
- 3. The presence of certain markers on the surface of the cells



In DLBCL, the cells are large and spread apart. Around 5% of DLBCLs are "double hit." This means that two genes (MYC, BCL2, or BCL6) in the cell have switched places. Triple hit, which is even rarer, involves all three genes.

Two kinds of biopsies are used to diagnose DLBCL:

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 the swelling is caused by cancer. The doctor will get as large of a sample as possible to determine if the specific type of non-Hodgkin lymphoma is DLBCL. This sometimes requires surgery, or the removal of the entire lymph node. Surgery is also used if the lymph node is in a location that is more difficult to reach.

Bone Marrow Aspiration and Biopsy - The doctor will insert a needle into your hipbone to get a sample of liquid or tissue from the bone marrow. The removal of liquid is an aspiration. The removal of tissue is a biopsy. This helps to see if lymphoma cells are present. Sometimes the doctor may use the sternum bone in the chest to check instead.

If a biopsy confirms a DLBCL diagnosis, your doctor may recommend more 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 DLBCL 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.

Doctors use the Lugano Staging System to describe DLBCL. It is based on a similar system called Ann Arbor. Stages are assigned Roman numerals I-IV (1-4). A higher number means the disease is more advanced. Although most lymphomas are stage III or IV when diagnosed, they are often treatable and possibly curable.

- Stage I: Cancer is found in only one lymph node area or organ in the lymphatic system, such as the thymus gland (I). The letters IE (extranodal) are used when the cancer is found in one area of an organ outside the lymph system (such as the lung, liver, or bone).
- **Stage II:** Cancer is found in two or more lymph node areas on the same side of the diaphragm (IIE). The diaphragm is the muscle below the lungs. It separates the chest and abdomen. When the cancer has spread to a nearby organ, it is considered IIE.
- **Stage III:** Cancer is found in lymph nodes both above and below the diaphragm (III). It has also spread to nearby organs (IIIE), the spleen (IIIS), or both (IIIES).
- **Stage IV:** The cancer has spread to one or more organs outside of the lymph system. For example, it may have spread to the liver, bone marrow, or lung.



Letters can be added to the stages to provide more information about the cancer:

- Letter "A": Added if the "B" symptoms (listed below) are not present.
- **Letter "B":** Added if 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
 - Drenching night sweats
- Letter "E": Added if DLBCL is affecting an organ outside of the lymph system.
- **Letter "S":** Added if DLBCL is affecting the spleen.
- Letter "X": Added if the tumor measures at least 10 centimeters across (about 4 inches). This may require more intense treatment. Adding the letter "X" indicates that the tumor is "bulky."

Doctors also use the revised International Prognostic Index score (R-IPI) to describe DLBCL. This score helps the doctor see how well a patient may respond to treatment. Points are assigned for each item. The total number of points helps predict the risk of disease relapse.

The index score is based on five factors:

- 1. The person's age
- 2. The stage of DLBCL
- 3. Whether the cancer is in organs outside the lymphatic system

- 4. The patient's overall health and ability to perform normal activities of daily living
- 5. The level of the enzyme lactate dehydrogenase (LDH) in the person's blood

Choosing Your Treatment Team

The best cancer treatments can be 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 DLBCL? If not, you can ask for a "second opinion" with a "hematologist-oncologist" who specializes in your cancer.

If your doctor treats all cancers, ask about how many DLBCL patients they treat each year and if they stay current on the newest DLBCL 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 DLBCL, your overall health, and 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.

DLBCL is an aggressive or fast-growing cancer, so it usually needs to be treated right away. 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.

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 DLBCL. This can help you better understand your test results and treatment options.

When you talk to your doctor about your treatment options, 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? Think about any concerns you might have about suggested treatment options.

Treatment Options

DLBCL is an aggressive or fast-growing cancer, so it usually needs to be treated right away. Treatment is often effective, and some patients are considered cured. The most common treatment involves chemotherapy combined with immunotherapy.

CHEMOTHERAPY

Chemotherapy uses drugs to destroy cancer cells. It is a systemic (whole body) treatment. This means it can destroy cancer cells almost anywhere in your body. It may be given by IV (through a vein), in pill form (by mouth), as an injection (a shot), applied directly on the skin into the area around the tumor, or placed directly into the tumor site. Most often, chemotherapy is given in an outpatient clinic. You will have a regular schedule of treatments for a set period of time.

Chemotherapy is most effective against fast growing cells, like cancer. But some healthy, normal cells may also be damaged by this treatment. The side effects will vary depending on the drug(s) you take,



the dose of your drugs, and how often you get treatments. 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). It is not a surgery. The procedure has two parts. First, you will receive high doses of chemotherapy. This destroys blood cells.

Next, stem cells are introduced into the bloodstream to replace blood cells. Bone marrow transplant is one kind of stem cell transplant. Sometimes patients serve as their own donors (autologous stem cell transplant). Other times, patients get stem cells from donors (allogeneic stem cell transplant).

A SCT is not the primary treatment for DLBCL. Your doctor may recommend a SCT after initial treatment. This can help reduce the chance of the cancer returning. Before you go through a stem cell transplant, there are many things to consider. Learn the risks and benefits of a SCT if it 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/SCT.

IMMUNOTHERAPY

Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells. One type of immunotherapy, monoclonal antibodies, may be used in combination with chemotherapy to treat DLBCL. Some immunotherapy treatments are available only through clinical trials.

To learn more, visit www.

CancerSupportCommunity.org/
immunotherapy.

TARGETED THERAPY

Targeted therapy aims to attack cancer cells more precisely. These drugs target changes in the genes or proteins of cancer cells that help them grow, divide, and spread. They treat the cancer cells with less harm to normal cells. There are different types of targeted therapy. It may be given as a pill, as an IV through a vein, or as an injection (shot).

In the past, targeted therapies were used mostly for lymphomas that returned after initial treatment. Today these new therapies are more often being used as part of initial treatment. You may get targeted therapy alone or in combination with other treatments, like chemotherapy or immunotherapy. Some targeted therapies may only be available through clinical trials.



RADIATION THERAPY

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. It is given before, during, or after other treatments. The goal is to damage as many cancer cells as possible without harming healthy tissue. To lessen damage, doses are very precise, and treatment is often spaced out.

Radiation therapy for DLBCL uses a focused beam of radiation from a machine outside of the body. External beam radiation is a painless procedure. It may be used after drug therapy or a stem cell transplant.

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, clinical trials provide new treatments for many types of lymphoma, including DLBCL. To learn more, be sure to ask your health care team about clinical trials that may be relevant to you.



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KEY THINGS TO KNOW ABOUT CLINICAL TRIALS

- Clinical trials for DLBCL are done to test new treatments, combinations of treatments, or different ways of doing stem cell transplant.
- A doctor experienced in treating DLBCL 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.
- Not every doctor offers the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health care plan 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. It is important to let your health care team know if you have any side effects. 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 common side effects:

- Hair Loss
- Mouth sores or dry mouth
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Skin changes
- Increased chance of infections (from having too few white blood cells)
- Easy bruising or bleeding (from having too few blood platelets)
- Fatigue (from having too few red blood cells)

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 of Care

The treatment for DLBCL 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 for more information on managing health care costs.



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QUESTIONS TO ASK YOUR HEALTH CARE TEAM:

What stage is my DLBCL?
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 DLBCL

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 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 if 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 DLBCL.
- 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 list 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. For more resources for caregivers, visit www. CancerSupportCommunity.org/Caregivers.



Support for DLBCL Caregivers

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

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 DLBCL. 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 DLBCL 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.

DLBCL RESOURCES

Cancer Support Community · 1-888-793-9355 · www.CancerSupportCommunity.org

American Cancer Society · 800-227-2345 · www.Cancer.org

American Cancer Society Clinical Oncology (ASCO) · 800-227-2345 · www.Cancer.net/nhl

CancerCare · 800-813-4673 · www.CancerCare.org

Imerman Angels · 866-463-7626 · www.ImermanAngels.org

Leukemia & Lymphoma Society · 800-955-4572 · www.lls.org

Lymphoma Research Foundation · www.Lymphoma.org/aboutlymphoma/nhl

Patient Empowerment Network · www.PowerfulPatients.org/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.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **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**.

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**.

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/DLBCL.

For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

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