

# When Diffuse Large B-Cell Lymphoma (DLBCL) Doesn't Respond to Treatment



## A GUIDE TO TALKING ABOUT TREATMENT OPTIONS WITH YOUR CANCER CARE TEAM

This guide can help you take control and have better discussions with your health care team when Diffuse Large B-Cell Lymphoma (DLBCL) returns or doesn't respond to treatment. Inside you'll find a quick overview of treatment options, questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.

Treatment of DLBCL can include chemotherapy, immunotherapy, targeted therapy, CAR T cell therapy, and stem cell/bone marrow transplants. Due to the aggressive nature of DLBCL, your cancer team may want to start treatment quickly. It is normal to feel anxious and overwhelmed. You can learn more about coping and living with DLBCL at [www.CancerSupportCommunity.org/DLBCL](http://www.CancerSupportCommunity.org/DLBCL) or by contacting our Cancer Support Helpline at 888-793-9355.

### TALKING ABOUT LYMPHOMA & DLBCL

You will hear many words used to describe DLBCL and lymphoma. Here are some key terms to know:

**Diffuse Large B-Cell Lymphoma:** A type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually fast-growing (aggressive). It is the most common type of non-Hodgkin lymphoma.

**“Double-hit” or “Triple-hit” DLBCL:** When the cancer has a rearrangement in 2 (double-hit) or 3 (triple-hit) different genes called MYC, BCL2, and BCL6. This subtype of DLBCL is treated differently than other subtypes. It is often treated in the hospital with a continuous infusion of chemotherapy or other more intensive treatments.

**Lymphoma:** Cancer that starts in the lymph system. The 2 main types are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL).

**Refractory:** When the cancer doesn't respond to treatment.

**Relapse:** When the cancer returns after treatment.

**Remission:** When signs and symptoms of cancer have disappeared (although you may still have some cancer cells in your body).

**“Transformed” Lymphoma:** When the cancer starts as a slow-growing lymphoma and evolves into an aggressive lymphoma. The most common is when Follicular Lymphoma evolves into DLBCL.

## Overview of Treatment

There are many treatments for DLBCL, even if other therapies haven't worked for you. The main factors that help your doctor recommend treatments are:

- Your age and your overall health
- How large your tumors are
- If you have “double-hit” or “triple-hit” DLBCL
- Whether your lymphoma is “transformed” from follicular lymphoma
- What other treatments you have had

### COMMON FIRST TREATMENTS:

**Chemotherapy:** Uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. In lymphoma, chemotherapy is most often given with immunotherapy. This is called chemoimmunotherapy.

**Immunotherapy:** Uses the body's natural defenses (immune system) to identify, attack, and kill cancer cells.

**Radiation Therapy:** Uses energy beams, such as very strong x-rays, electrons, or protons, to kill cancer cells and shrink tumors.

**Clinical trials:** Can be offered at any time. These studies are done to test new drugs, combinations of drugs, or different ways of offering treatment.

### COMMON 2ND- AND 3RD-LINE TREATMENTS:

**Targeted therapy drugs:** These drugs “target” changes in cells that cause cancers to grow, divide, or spread. They may be given in combination with chemotherapy or alone.

**Stem cell/bone marrow transplant:** Allows you to have high dose chemotherapy to kill any remaining cancer cells. Because high dose chemo also kills your normal blood-forming cells (stem cells), your cells are replaced with stem cells collected from the blood or bone marrow of a donor.

**CAR T Cell Therapy:** Uses a patient's own immune cells and “re-engineers” them to better fight cancer.

## IN ORDER TO GET THE TREATMENT THAT IS RIGHT FOR YOU, IT IS IMPORTANT THAT YOU:

- **See a hematologist/oncologist who specializes in DLBCL.** There are many very new treatments that only DLBCL specialists will know about and be able to offer you.
- **Be evaluated to see if an autologous “auto” stem cell transplant is right for you.** Auto stem cell transplants are less risky than allogenic “allo” stem cell transplants. But not everyone is healthy enough to get a stem cell transplant.
- **Be evaluated to see if CAR T is right for you.** CAR T is only offered at a limited number of specialty cancer centers. You need to get a consult at one of these CAR T centers to find out if it is a treatment option for you now or in the future.

**Below are some symptoms & side effects that people with lymphoma may have. Think about how often they affect you. Talk to your cancer care team about how to manage them.**

	Rarely	Sometimes	All the Time
Fatigue, tiredness, decreased strength			
Menopause symptoms (hot flashes, night sweats, vaginal problems, mood changes, sleep problems)			
Tingling, pain, or numbness in hands, arms, feet, or legs*			
Feeling anxious, overwhelmed, depressed, or irritable			
Fever or chills, headache, or getting sick often			
Problems eating, weight gain, weight loss, water retention, or bladder discomfort			
Mouth sores, nausea, vomiting			
Itching or skin problems			
Constipation or diarrhea			
Night sweats			
Others:			

\* If you have any of these signs of neuropathy, let your health care team know as soon as possible. This can become a long-term problem if not managed early.

**How often are cancer or side effects interfering with your life?**

	Rarely	Sometimes	All the Time
Work / school / home (unable to go to work/school or do daily tasks)			
Unable to do activities or hobbies I normally enjoy			
Confidence / self-image			
Difficulty thinking / brain fog / chemo brain			
Social relationships, relationships with loved ones, sexuality/intimacy			
Health insurance or other financial worries			
Exercise / being active or eating problems			
Difficulty sleeping / insomnia			
Others:			

## THINK ABOUT TREATMENT AND PERSONAL GOALS

It is important for your care team’s treatment goals to match up with your current personal goals. When you talk to your doctor about your treatment options, ask about the goals of treatment and how treatment can achieve your goals. Possible goals may be to live as long as possible, to live as normally as possible, to make it to a special event/milestone, or to contribute

to progress by taking part in research. Let your care team know your treatment and personal goals. Remember, your goals may change over time. Here’s a worksheet to help you think through what goals are most important to you now:

<b>Physical Health and Well-Being</b>	<i>What is most important for you to be able to do?</i>
<b>Family and Social Relationships</b>	<i>What’s going on in the lives of others that is important to you? Are there important milestones in your loved ones’ lives coming up?</i>
<b>Work/School</b>	<i>Do you want to continue working? Can you adjust your schedule or responsibilities? Do you want to explore retirement or disability?</i>
<b>Personal and Spiritual Growth</b>	<i>How is your confidence and self-esteem? Are you able to do things you enjoy?</i>
<b>Community/Involvement</b>	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
<b>Other</b>	<i>What else is important to you?</i>

### GETTING SUPPORT

- You and your primary caregiver are going to need support. Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).
- Make a list of things you need (child care, meal prep, transportation, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support. You can also ask to be matched with another person living with DLBCL.
- Have a caregiver take notes during medical visits.
- CSC and many other organizations have educational information, helplines, support groups, online discussion boards, and more ways to seek support from others who have DLBCL.

### FINANCIAL RESOURCES

- Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.
- Talk with your health care team, pharmacist, and treatment center about the cost of your treatment.
- Ask your team to refer you to an oncology social worker, financial counselor, or nonprofit organization for help managing finances and costs.
- Contact your health plan to find out what resources they have that could help you. Ask to see if you qualify for pharmaceutical assistance programs.
- If your treatment is far away, ask if there are assistance programs to help cover travel costs. Also ask about housing/lodging assistance during treatment.
- The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment or applying for disability, visit: **www.CancerSupportCommunity.org/cost** or call our Helpline at 888-793-9355.

## QUESTIONS FOR MY HEALTH CARE TEAM

You may start treatment very soon after diagnosis. You can always ask questions, even after treatment starts. Before each doctor's visit, write down the top 3 questions you want to ask.

### AT DIAGNOSIS OR WHEN GETTING A SECOND OPINION

- Tell me more about the specific type and subtype of DLBCL that I have. \_\_\_\_\_  
\_\_\_\_\_
- Did I test positive to any biomarkers like MYC, BCL2, BCL6, or p53? \_\_\_\_\_  
\_\_\_\_\_
- Is my DLBCL ABC (started in activated B-cells) or GCB (started in germinal center B-cells)?  
\_\_\_\_\_  
\_\_\_\_\_
- What does this mean for my treatment and prognosis? \_\_\_\_\_  
\_\_\_\_\_

### WHEN PLANNING FOR TREATMENT OR MAKING TREATMENT DECISIONS

- What is your goal for my treatment? What would a cure look like for me? If a cure is not the goal, what is the goal for my treatment? \_\_\_\_\_  
\_\_\_\_\_
- My top personal goals are *[Fill in your answers from the goals section, on page 3]*: \_\_\_\_\_  
\_\_\_\_\_
- What treatment would be best to meet my goals? \_\_\_\_\_  
\_\_\_\_\_
- What treatments or clinical trials are available to me? Explain the pros and cons of each treatment option. \_\_\_\_\_  
\_\_\_\_\_
- Would I qualify for an "auto" stem cell/bone marrow transplant? If so, when would that fit into my treatment? \_\_\_\_\_  
\_\_\_\_\_
- Would CAR T Cell Therapy be right for me? If so, should I get a consult now? When would that fit into my treatment? \_\_\_\_\_  
\_\_\_\_\_
- How much will treatment cost? Will it be covered by my insurance? Is there a financial navigator or social worker that can help talk about costs? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## QUESTIONS FOR MY HEALTH CARE TEAM (CONTINUED)

### PRIOR TO STARTING TREATMENT

- Where will treatment be given? How many cycles of this treatment will I have? How much time will each cycle take? \_\_\_\_\_  
\_\_\_\_\_
- If all goes well, what is my prognosis? What if all doesn't go well? \_\_\_\_\_  
\_\_\_\_\_
- What are some side effects that I may experience? How will I feel after each cycle of treatment? \_\_\_\_\_  
\_\_\_\_\_
- How can I prepare for or manage side effects? Which side effects should I let you know about right away? \_\_\_\_\_  
\_\_\_\_\_
- Can I drive to my treatments? Can someone stay with me? Does someone have to stay with me? \_\_\_\_\_  
\_\_\_\_\_
- How do I find a caregiver or support at home? Are there support services for loved ones who are helping with my care? \_\_\_\_\_  
\_\_\_\_\_

### TOWARD THE END OF TREATMENT

- What are my next steps? \_\_\_\_\_  
\_\_\_\_\_
- How will you know if I am in remission? \_\_\_\_\_  
\_\_\_\_\_
- What are next steps if I don't stay in remission? \_\_\_\_\_  
\_\_\_\_\_

### ABOUT SIDE EFFECTS

- The symptoms and side effects that are bothering me the most are *[Fill in your answers from page 3]*:  
\_\_\_\_\_  
\_\_\_\_\_
- They are affecting my daily life in these ways *[Fill in your answers from page 3]*: \_\_\_\_\_  
\_\_\_\_\_

## QUESTIONS FOR MY HEALTH CARE TEAM (CONTINUED)

- What can we do to manage these symptoms? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- How can I manage pain or neuropathy? Do you recommend physical therapy? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- Could palliative (supportive) care help manage my symptoms and side effects? Can you refer me to a palliative care specialist? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### ASK AT ANY TIME

- Do I need to avoid any activities? Should I exercise or not? \_\_\_\_\_  
\_\_\_\_\_
- What do I need to do to avoid infection? Avoid crowds? People with illnesses? \_\_\_\_\_  
\_\_\_\_\_
- When can I go back to work/school? Can I play with my pets and/or kids? Can I work in my garden? Can I have dental work done? \_\_\_\_\_  
\_\_\_\_\_
- How do I find a therapist or other help for coping with Lymphoma? \_\_\_\_\_  
\_\_\_\_\_
- How do I find support groups or supportive online communities? \_\_\_\_\_  
\_\_\_\_\_

### MORE RESOURCES

For more information and key questions to ask about your treatment visit [www.CancerSupportCommunity.org/DLBCL](http://www.CancerSupportCommunity.org/DLBCL).

The Cancer Support Community's **Open to Options**® program can help you think through treatment options by preparing 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.



# Lymphoma Information, Survivorship & Support

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

**American Cancer Society** • 800-227-2345 • [www.cancer.org/cancer/non-hodgkin-lymphoma.html](http://www.cancer.org/cancer/non-hodgkin-lymphoma.html)

**BMT Infonet** • 888-597-7674 • [www.bmtinfonet.org](http://www.bmtinfonet.org)

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

**Leukemia & Lymphoma Society First Connection Program** • 800-955-4572 • [www.lls.org/firstconnection](http://www.lls.org/firstconnection)

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

## Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org) for more info.

**Cancer Support Helpline**<sup>®</sup> — 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.

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

**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).

**Open to Options**<sup>®</sup> — 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.

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

**THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:**



The Cancer Support Community provides 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.

For more information and resources, or to download and print this worksheet yourself, please visit [www.CancerSupportCommunity.org/DLBCL](http://www.CancerSupportCommunity.org/DLBCL). For print copies of this booklet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org) or call 888-793-9355.

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