

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 move to 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 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. However, there are some terms that you should become familiar with as you discuss treatment options with your health care team. Some key ones to know are:

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.

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 a certain treatment include:

- Your age
- Your 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

SOME OF THE TREATMENTS AVAILABLE INCLUDE:

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 in combination with immunotherapy. This is called chemoimmunotherapy.

Immunotherapy: Immunotherapy is a type of cancer treatment that uses the body's natural defenses (immune system) to identify, attack, and kill cancer cells.

Targeted therapy: Targeted therapies are drugs that “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: CAR T cell therapy uses a patient's own immune cells and “re-engineers” them to better fight cancer.

Clinical trials: These studies are done to test new drugs, combinations of drugs, or different ways of doing stem cell/bone marrow transplant.

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 or tiredness			
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, or depressed			
Fever or chills or getting sick often			
Problems eating, weight gain, weight loss			
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 to be sure the goals of your care team’s treatment 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 each treatment might affect the goals that you have for your life. Possible goals may be to live as long as possible, to live as normally and as well as

possible, to make it to a special event/milestone, or to contribute to progress by taking part in research. Let your health care team know about 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:

Physical Health and Well-Being	<i>What is most important for you to be able to do?</i>
Family and Social Relationships	<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>
Work/School	<i>Do you want to continue working? Can you adjust your schedule or responsibilities? Do you want to explore retirement or disability?</i>
Community/Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Other	<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 for a mentor or to be matched with another person with DLBCL.
- Lymphoma survivors recommend having a caregiver take notes when you meet with your doctor.
- 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 to a nonprofit organization for help managing the financial issues and costs.
- Reach out to your health insurance company to find out what resources they have that could help you. Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment is far away, ask if there are assistance programs that can help cover your travel costs. There are also housing/lodging programs that can provide temporary lodging throughout your 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

Things might move quickly after your diagnosis and you may start treatment right after your diagnosis. You can always ask questions even if you are currently receiving treatment. Below are some questions that you might ask:

AT DIAGNOSIS/WHEN GETTING A SECOND OPINION

1. What type & subtype of DLBCL do I have? What does that mean for my treatment & prognosis?
Did I test positive for 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)?
2. What is your goal for my treatment? What would a cure look like for me?
3. If a cure is not the goal, what is the goal for my treatment?
4. My top personal goals are *[Fill in your answers from the goals section, on page 4]*:
_____. Is the treatment I am currently on the best treatment for me to meet my personal goals?
5. What other treatments are available to me based on my health profile?
6. Would I qualify for an “auto” stem cell/bone marrow transplant? If so, how would that fit into my treatment?
7. Would CAR T Cell Therapy be right for me? If so, should I get a consult now? When would that fit into my treatment?
8. What are the pros and cons of each treatment option that is available for me? What are the chances that this treatment may harm me? What are the chances that this treatment may cure me?
9. Are there any new treatments or clinical trials that may be right for me?
10. What are my treatment options if I relapse?
11. What is my prognosis?
12. What treatment will I need next? Will that be given in the hospital? How much time will the therapy take?
13. How can I manage treatment costs? Will it be covered by my insurance? Is there a financial navigator or social worker that I can talk with? How do I apply for disability?
14. What side effects might I expect, and how can I prepare for them? What side effects should I be concerned with and monitoring? What side effects should I let you know about right away?
15. Will I need a full-time caregiver during treatment? Can I drive after treatment?

DURING TREATMENT

16. How many cycles of this treatment will I have?
17. What are some side effects that I may experience? How will I feel after each cycle of treatment?

QUESTIONS FOR MY HEALTH CARE TEAM (CONTINUED)

18. Is there anything I can do to lessen the side effects?
19. How do we know if I am in remission? When does this happen?
20. How long will I receive this treatment? How much time will each treatment session take?
21. How long will I be hospitalized or need to stay close to my treatment center?

GENERAL QUESTIONS TO ASK ANY TIME:

22. 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.] _____ .
What can we do to manage these symptoms?
23. Could palliative (supportive) care help manage my symptoms and side effects? Can you refer me to a palliative care specialist?
24. Do I need to avoid any activities? Should I exercise or not? Can I drive?
25. What do I need to do to avoid infection? Avoid crowds? People with illnesses?
26. 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?
27. How do I find a caregiver or support at home? Are there support services for caregivers?
28. How do I find a therapist or other help for coping with Lymphoma?
29. How do I find support groups or supportive online communities?
30. How can I manage pain or neuropathy? Do you recommend physical therapy?

MORE RESOURCES

For more information and key questions to ask about your treatment visit 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

American Cancer Society • 800-227-2345 • www.cancer.org/cancer/non-hodgkin-lymphoma.html

BMT Infonet • 888-597-7674 • www.bmtinfonet.org

Leukemia & Lymphoma Society • 800-955-4572 • www.lls.org/lymphoma/non-hodgkin-lymphoma/

Leukemia & Lymphoma Society First Connection Program • 800-955-4572 • www.lls.org/firstconnection

Lymphoma Research Foundation • 800-500-9976 • 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 for more info.

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.

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

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.

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.

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.

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. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org or call 888-793-9355.

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