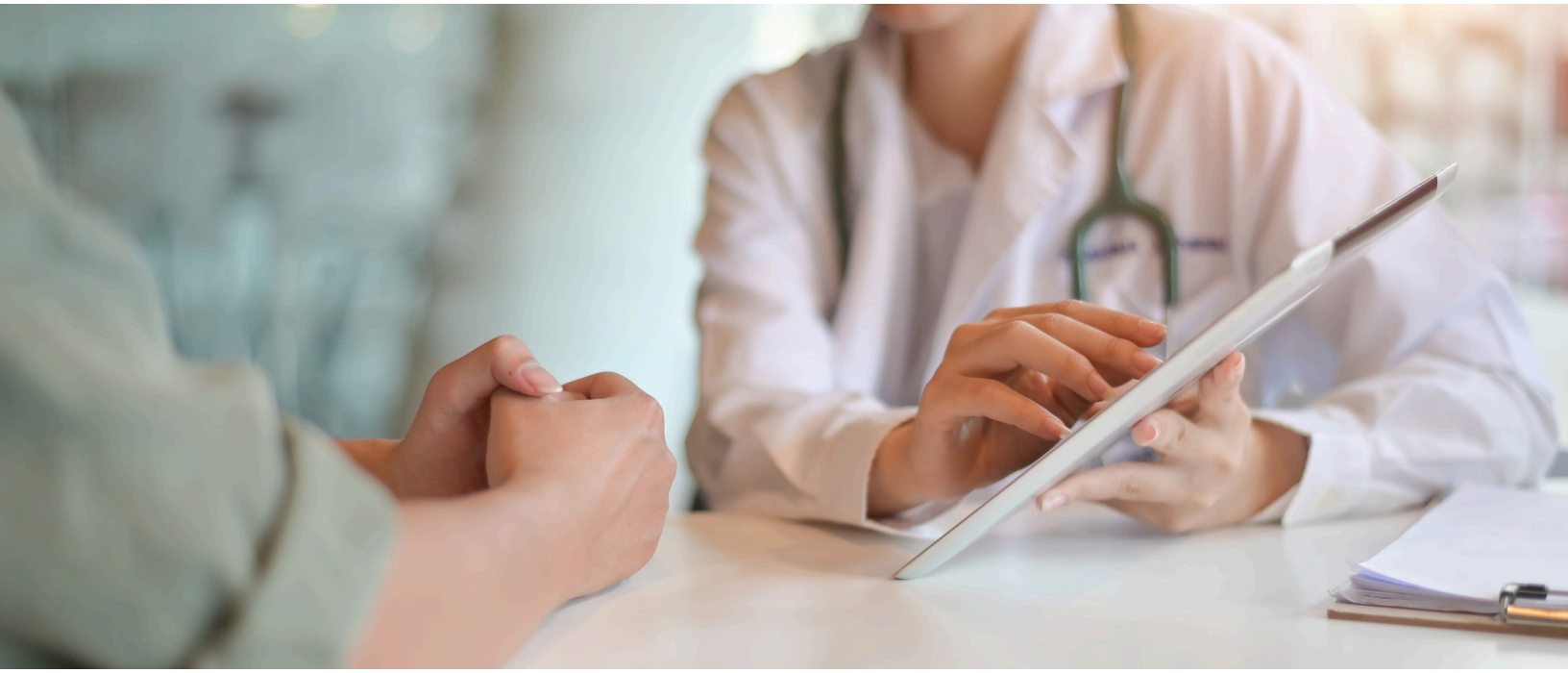
Talking About Diffuse Large B-Cell Lymphoma (DLBCL)

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A PROGRAM OF THE CANCER SUPPORT COMMUNITY

A Guide for Talking With Your Healthcare Team



Being diagnosed with Diffuse Large B-Cell Lymphoma (DLBCL) can be overwhelming. This guide can help you feel more prepared, confident, and informed when talking with your healthcare team.

This guide includes:

- An overview of DLBCL and treatment options
- Tips for you to take an active role in your care
- Key questions to ask your care team
- Reliable resources for information and support

Use this guide to get the answers you need and make decisions that feel right for you.

To learn more about DLBCL, visit:
www.CancerSupportCommunity.org/Diffuse-Large-B-Cell-Lymphoma-DLBCL

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GILDA'S CLUB

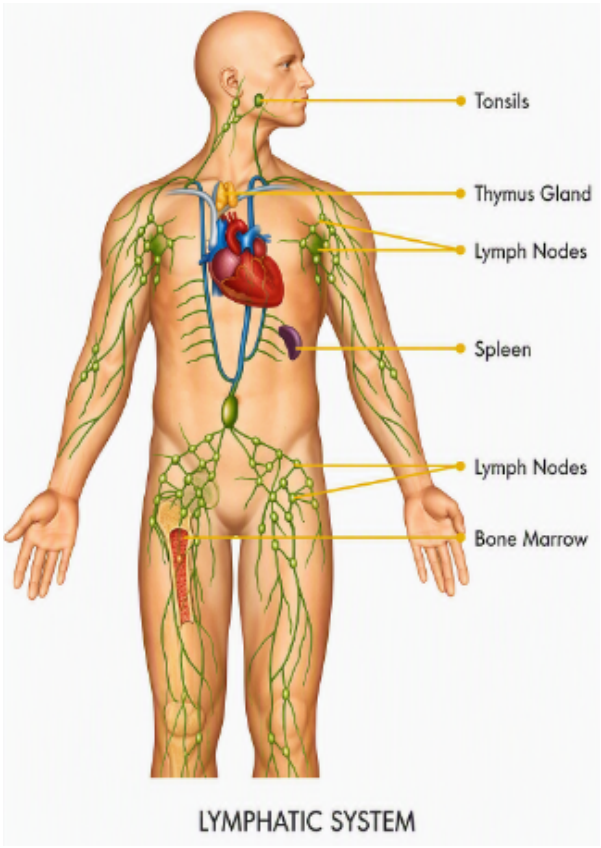
WHAT IS DIFFUSE LARGE B-CELL LYMPHOMA (DLBCL)?

Diffuse large B-cell lymphoma (DLBCL) is a type of lymphoma. Lymphoma is a cancer of white blood cells. It often starts in the lymphatic system. This system is part of your body's natural defenses, called the immune system. It helps you fight germs and stay healthy.

There are two main kinds of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma. DLBCL is the most common type of non-Hodgkin lymphoma.

DLBCL gets its name from the type of cell it starts in — B cells. B cells are a type of white blood cell that helps fight infections. Under a microscope, the cancer cells look larger than normal B cells and are more spread out in the tissue — which is why it's called diffuse large B-cell lymphoma.

DLBCL can appear in lymph nodes, the spleen, liver, or bone marrow. It can also appear in other organs in your body.



Adapted from: **Lymphoma Canada**

There are several subtypes and stages of DLBCL. Doctors determine this depending on:

- Where the cancer is in your body and how advanced it is
- Your signs and symptoms
- The characteristics of your DLBCL based on your biopsy

Doctors use different tests to diagnose DLBCL. These tests will confirm the exact subtype and stage of your disease. These may include:

- **A physical exam:** Your doctor feels your lymph nodes in your neck, underarms, and groin to see if they are swollen.
- **A lymph node biopsy:** Your doctor removes all or part of a lymph node and looks at it under a microscope.
- **Bone marrow biopsy or aspiration:** Your doctor inserts a needle into your hip bone to see if DLBCL cells are present in your bone marrow.
- **Lumbar puncture:** Your doctor inserts a needle into your lower back to collect fluid that surrounds the brain and spinal cord.
- **Imaging tests:** X-rays, CT scans, MRI scans, and PET scans
- **Blood tests**

TREATMENT FOR DLBCL

Treatment will depend on the stage of your DLBCL, how far it has progressed, and your overall health. Treatments might include:

Chemoimmunotherapy: This is the most common treatment for DLBCL. It combines chemotherapy with immunotherapy. Chemotherapy uses drugs to kill cancer cells. Immunotherapy uses drugs that use the body's natural defenses (the immune system) to fight cancer. This is a systemic (whole body) treatment. It may be given by IV (through a vein or port), in pill form (by mouth), or as an injection (a shot).

Immunotherapy: Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells. There are different types of immunotherapy treatments for DLBCL. These include:

- Monoclonal antibody therapy (mAbs)
- Antibody-drug conjugates (ADCs)
- T-cell engagers (TCEs)
- CAR T-cell therapy

Stem cell transplant (SCT): In a SCT, patients get an infusion of healthy blood-forming cells (stem cells). The most common type used in DLBCL is an autologous stem cell transplant, which uses the patient's own stem cells. SCT is not a standard treatment for DLBCL at the time of initial diagnosis/first treatment. It is only used when other treatments do not work or when the cancer comes back. This is an intensive treatment. Doctors will not recommend it if you are older or have other health problems.

Clinical trials: Clinical trials provide patients access to new therapies. They are research studies to test new treatments or learn how to use current treatments better. There are several therapies and drugs being tested for DLBCL at all stages of the disease and treatment (newly diagnosed, refractory, or relapsed).

Radiation therapy: Radiation therapy uses high-energy rays to kill or damage cancer cells. It is often done together with chemotherapy. This is usually for patients with early stage DLBCL (stage 1 or 2) or bulky disease (represented by an X added to your stage).

Surgery: Surgery is not a typical treatment for DLBCL. In some cases, it can be done to remove a lymph node for biopsy. Surgery is also used to remove a large tumor to help with pain and symptoms.

MANAGING SIDE EFFECTS

Everyone's experience with treatment is different. Side effects depend on the type of therapy you receive. It helps to learn about possible side effects before treatment starts. This way, you know what to expect and can work with your care team to manage them.

Below are some of the treatment side effects patients with DLBCL may experience. Think about how often you experience each one. Share this with your care team during your next visit. They can talk with you about how to best manage them.

PHYSICAL SIDE EFFECTS	Rarely	Sometimes	Often
Feeling very tired or weak			
Pain (general or in specific area)			
Shortness of breath or trouble breathing			
Frequent infections or getting sick often			
Bruising or bleeding easily			
Nausea, vomiting, or loss of appetite			
Changes in taste, mouth sores			
Diarrhea or constipation			
Weight loss or gain			
Swelling (lymphedema)			
Tingling or numbness			
Darkening of the skin and nails			
Hair loss			
Skin problems			
Other:			










For more information about how to manage treatment side effects, visit:
www.CancerSupportCommunity.org/Managing-Side-Effects

EMOTIONAL AND MENTAL HEALTH SIDE EFFECTS	Rarely	Sometimes	Often
Fear of disease progression, treatments, or upcoming appointments			
Feeling sad or depressed			
Feeling nervous, anxious, overwhelmed, or afraid			
Difficulty thinking clearly or remembering (brain fog or "chemo brain")			
Experiencing stigma			
Infertility-related concerns			
Intimacy concerns			
Financial concerns			
Other:			

For more information and ways to support for your mental health, visit
www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

PALLIATIVE CARE

Palliative care is support that helps you feel better during and after treatment for DLBCL. A palliative care specialist can help you manage side effects from treatments, such as pain, tiredness, nausea, loss of appetite, trouble sleeping, neuropathy (tingling or numbness in your hands or feet), mouth sores, constipation, diarrhea, or emotional strain.

Palliative care is not the same as hospice. It can start at any time — even right after diagnosis — and it is available for people with any stage of DLBCL, whether your cancer is early stage, advanced, or in remission.

To learn more about palliative care and other treatment options, visit
www.CancerSupportCommunity.org/Treatment-Options-Cancer

WORKING WITH YOUR CARE TEAM

Cancer care can be complex and is always changing. You deserve a care team you trust. This team may include doctors, nurses, social workers, and other experts who work together. This is called multidisciplinary care. The members of your care team may vary at different points throughout your care. **These members may include:**

Hematologist-oncologist	This is the main doctor leading your care. They specialize in blood cancers like DLBCL and create your treatment plan.
Pathologist	This doctor looks at biopsy and other tissue samples to confirm that you have DLBCL and helps your healthcare team choose the best treatment.
Nurse practitioner (NP) or physician assistant (PA)	These healthcare providers work closely with your doctor. They help manage your care, check on your symptoms, answer questions, and provide treatments.
Oncology nurse	A nurse who specializes in cancer care. They give treatments, help manage side effects, and provide support throughout your care.
Infusion center nurse	A nurse who gives the treatment for DLBCL, usually in a separate area of the hospital called the infusion center.
Radiation oncologist	This doctor specializes in radiation treatment. If radiation is part of your care, they will plan and oversee your treatment.
Oncology pharmacist	A pharmacist who specializes in cancer medicines. They help make sure your treatments are safe and work well together.
Oncology social worker and therapist/ counselor	Helps you and your caregiver find resources to cope with cancer and its treatment side effects. This includes emotional and mental support, financial resources, transportation, and other services you may need.
Patient navigator	Helps you navigate your care experience from the time you are diagnosed through treatment. They can help you talk with your healthcare team, set up appointments, and help with home care needs.
Financial navigator	Helps you and your loved ones understand the cost of different treatments and how your insurance plan may help cover costs. They may also help find financial assistance programs or payment plans to help ease the burden of receiving treatment.



To learn about care team members, visit
www.CancerSupportCommunity.org/Article/Your-Cancer-Care-Team

QUESTIONS TO ASK YOUR CARE TEAM:

What is the stage of my DLBCL? In what area(s) of the body is it located?
What is the subtype of my DLBCL? And what does that mean?
What are my treatment options? What are the pros and cons of each treatment?
How often will I need treatment and for how long? How long will each session take?
Where will I receive treatments?
What side effects should I look out for once I start treatment? What can we do to manage them?
How will treatment affect my daily life? What type of help will I need from a caregiver during my treatment?
Is there a palliative care specialist to help me manage my quality of life?
Do I need to avoid certain things (e.g. activities, driving, crowds, pets, dental treatments)?
What can I do to keep myself as healthy as possible before, during, and after treatments?
What long-term side effects are possible from my treatment? What kind of follow-up care will I need?
Are there any new treatments or clinical trials that might be appropriate for me?
Who can I reach out to for support? Are there support groups or counseling options that are available to me and my partner/caregiver?
What is the contact information for when I have questions? Is there a patient portal that would make communication easier?
How can I manage the costs of treatment? Is there a financial navigator or social worker I can talk with about expenses or insurance questions?



BE YOUR OWN ADVOCATE

You are an important part of your care team. It is important to ask questions, share concerns, and speak up before, during, and after treatment. Your needs and preferences help guide your care and help you feel more in control.

If your concerns are not being heard, advocate for yourself. Even when you feel tired or unwell, it is important to get the support you need. You know your body best, so reach out for care when you notice new symptoms or side effects.

TIPS FOR APPOINTMENTS



Write down your questions before each doctor's visit. Bring a notebook to take notes or use this resource guide to track your progress over time.



Ask your doctor to explain anything you don't understand when they are talking about your DLBCL. Ask if they can provide any printed material to help you and your caregiver(s) understand. You can contact your care team at any time if you want more information.



Bring someone with you to appointments, for support and an extra set of eyes and ears. If you attend alone, take notes or ask if you can record the conversation — always check with your doctor first to make sure recording is allowed.



Consider getting a second opinion. A second opinion can confirm the diagnosis and treatment plan, offer other options, and provide different perspectives. Do not worry about hurting anyone's feelings. It is important to feel comfortable with your treatment plan, diagnosis, and care team. But remember, cancer treatment should not be delayed when deciding whether to seek more than one opinion.

Read more about seeking a second opinion at
www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion

MANAGING COSTS

Before you start treatment, talk with your care team or a financial navigator about any financial concerns. They can help you understand what costs to expect, explore ways to manage expenses, and find resources that may reduce your financial stress. This support lets you focus on your care and recovery.

For more information, visit **www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment**



TAKING CARE OF YOURSELF AND FOCUSING ON WHAT MATTERS MOST



Take care of your physical health by staying active (as approved by your care team), eating a healthy diet, getting enough sleep, staying hydrated, and avoiding tobacco, alcohol, and highly processed foods.



Support your emotional well-being by asking for help when you feel anxious or stressed. Your care team can connect you with counseling, support groups, patient organizations, or peer support. Try stress relief activities, such as deep breathing or meditation. Ask your care team about other resources available through your cancer center.

Think about your treatment and personal goals. Ask your care team about your treatment options and how each one may affect your life. Consider what matters most to you, including your relationships, work or daily responsibilities, spiritual or cultural beliefs, and the activities that bring you meaning, peace, or joy. Share your priorities and goals with your care team.

Here are some questions to consider and discuss with your doctor, family, or loved ones.

Physical, Emotional, and Sexual Health and Well-Being

- What is most important for you to be able to do, during or after treatment?
- What symptoms or side effects do you want to avoid or manage?
- How important is it to maintain your fertility and sexual health?
- What does feeling "emotionally well" look like for you?

Family and Social Relationships

- Are there people in your life that you want to spend more time with or support?
- Are there upcoming family milestones or events you want to be present for?
- How can you maintain meaningful relationships during treatment?
- Who do you want to be involved in your treatment decisions?
- Who do you want to make medical decisions for you if you are unable?

Work/School/Home

- What financial or insurance concerns do you need to consider?
- Do you want or need to continue working or attending school? What kind of support or changes could help you balance treatment with your responsibilities?
- What kind of help do you need at home or with daily tasks?

Social Support and Community Involvement

- Are you getting the support you need from friends, family, or community?
- What would good support look like for you right now?
- Is getting or staying involved in your community, advocacy, or support groups important?

Personal and Spiritual Growth

- How are you taking care of yourself spiritually and emotionally?
- What spiritual and wellness practices are important to you? Are there spiritual practices or beliefs that bring you comfort?
- What personal or emotional goals do you want to focus on?

GETTING SUPPORT

It helps to have emotional support, both during and after cancer treatment. Talking with people who understand your experience can help you cope and feel in control. A good support system can also help you with practical things. Talk with your care team about resources for social, emotional, and practical support. Ask if they can connect you to a support group for patients with DLBCL. A social worker can be a great resource for mental health, financial, and transportation support. They may also connect you with other healthcare providers about managing side effects of treatment.

Below is a list of trusted organizations. Cancer Support Community and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others impacted by DLBCL.

RESOURCES

DLBCL RESOURCES

Cancer Support Community
CSC-867-5309 (or outside of the U.S., toll-free 888-793-9355)
www.CancerSupportCommunity.org/Diffuse-Large-B-Cell-Lymphoma-DLBCL

American Cancer Society
800-227-2345
www.Cancer.org/Cancer/Types/Non-Hodgkin-Lymphoma/About.html

Blood Cancer United
BloodCancerUnited.org/Blood-Cancer/Lymphoma/Non-Hodgkin-Lymphoma-NHL

Lymphoma Research Foundation
800-500-9976
https://Lymphoma.org/Publication/Diffuse-Large-B-Cell-Lymphoma-Guide/

Lymphoma Coalition
LymphomaCoalition.org/Diffuse-Large-B-Cell-Lymphoma-DLBCL/

My Lymphoma Team
www.MyLymphomaTeam.com/Resources/Diffuse-Large-B-Cell-Lymphoma-Your-Guide-To-DLBCL/List

National Cancer Institute
www.Cancer.Gov/Types/Lymphoma/Patient/Adult-NHL-Treatment-pdq

National Comprehensive Cancer Network (NCCN)
www.NCCN.org/PatientResources/Patient-Resources/Guidelines-For-Patients/Guidelines-For-Patients-Details?PatientGuidelineId=9

NCI Clinical Trials
www.Cancer.gov/ClinicalTrials

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline at CSC-867-5309 (or outside of the U.S., toll-free 888-793-9355), available in 200 languages.

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 over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more **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 secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Diffuse-Large-B-Cell-Lymphoma-DLBCL**.

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

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Medically reviewed by: Carla Casulo, MD

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 healthcare professionals to answer questions and learn more.

Photos are stock images posed by models.

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