



You and Your Doctor:

Actively Participating in Your Care

A Toolkit For Those Living With Or Caring For Someone
With Diffuse Large B-Cell Lymphoma (DLBCL)

Developed in Partnership with:



Actively Participating in your Care

Welcome!

The purpose of this Toolkit is to help support your experience as someone living with Diffuse Large B-Cell Lymphoma (DLBCL) or as a care partner by providing information to help you build a deeper understanding of DLBCL. This Toolkit was created by a group of patients, care partners, advocates and healthcare professionals brought together by Incyte and MorphoSys, pharmaceutical companies working on behalf of the DLBCL community.

This Toolkit includes information and resources that have been created by the following patient advocacy groups: CancerCare, Cancer Support Community, The Leukemia & Lymphoma Society, Lymphoma Coalition, Lymphoma Research Foundation, National Comprehensive Cancer Network and Patient Empowerment Network.

We encourage you to add to what you learn from this Toolkit with the full resources these groups have created, which can be found in the Appendix. Some terms used throughout the Toolkit may vary (for example, the use of “caregiver”

and “care partner” to describe individuals who care for someone with a DLBCL diagnosis). Some resources reference a cure or curative therapy. You may want to spend time thinking about what a cure would look like for you. The resources listed in the Appendix can help provide context to the terms used in the Toolkit.

Take your time going through this information as you are ready to learn more about each topic. The Toolkit is meant to be a guide to help you have conversations with your doctor about your DLBCL treatment and care.

Introduction to the Toolkit

Executive summary

This Toolkit Includes:

Information about understanding your/your loved one’s diagnosis, care and coverage, getting started with treatment, monitoring Diffuse Large B-Cell Lymphoma (DLBCL) and determining treatment success, and treating relapsed/refractory DLBCL

Worksheets that you can go over with your doctor, including questions to ask at each stage of your process

An appendix with direct web links to all resources referenced throughout the toolkit, as well as a few others you may find helpful

Journaling pages to support you in preparing for and taking notes during doctor’s appointments, or to reflect on your experiences

Tips for Accessing Additional Resources:

To view the original resources that are referenced in this toolkit, use the QR codes or web link:

- To scan a QR code, open the camera app on any smart phone or device. Select the rear-facing camera. Center the QR code you want to scan on the screen and hold your phone steady for a couple of seconds. Tap the notification that pops up to open the link.
- To use a web link, click directly on the URL if you are using a digital version of the Toolkit. You can also copy the text of the URL into a web browser.

QR codes and URLs for each resource can also be found in the appendix at the end of the Toolkit



What is a QR Code?

Anytime you see one of these images in the Toolkit, follow the instructions above for scanning the code to view the resource being shared

Acronym overview

The acronyms listed below may be used in the Toolkit. Use this page as a reference if you are ever unsure of what an acronym stands for.

BMT	Bone Marrow Transplant
CAR T-Cell Therapy (also referred to as CAR-T)	Chimeric Antigen Receptor T-Cell Therapy
CBC	Complete Blood Count
CD20	Protein expressed on the surface of B-cells
CMP	Comprehensive Metabolic Panel
CR	Complete Response
CT Scan	Computed Tomography Scan
DLBCL	Diffuse Large B-Cell Lymphoma
HCT	Hematopoietic Cell Transplant
LDH	Lactate Dehydrogenase
IHC	Immunohistochemistry
IPI	International Prognostic Index
ISRT	Involved-site radiation therapy
MRI	Magnetic Resonance Imaging
MUGA	Echocardiogram or Multigated Acquisition
NHL	Non-Hodgkin Lymphoma
PET scan	Positron Emission Tomography scan
PS	Performance Status
R-CHOP	Antibody Rituximab/Chemotherapy Combination
R/R	Relapsed/Refractory
RT	Radiation Therapy
SCT	Stem Cell Transplant

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Understanding Your Diagnosis

Understanding Your Diagnosis

What is DLBCL?

Information about Diffuse Large B-cell Lymphoma

Diffuse Large B-Cell Lymphoma (DLBCL) is a cancer of B lymphocytes (B-cells). In DLBCL, B-cells stop responding to signals that usually limit the growth and reproduction of cells. This causes the B-cells to undergo a malignant transformation where they become much bigger than normal lymphocytes. This subtype of lymphoma is called diffuse large B-cell because of the way the cancerous large B-cells are scattered throughout (diffuse) the lymph nodes when examined with a microscope. This growth pattern contributes to the aggressive behavior of DLBCL.¹

Non-Hodgkin Lymphoma (NHL) can be formed from either B-cell, T-cell, or NK-cell lymphocytes. DLBCL starts in mature B-cells. B-cells produce antibodies that are used to attack invading bacteria, viruses, and toxins. The antibody molecules latch onto and destroy invading viruses or bacteria.

DLBCL accounts for about 3 out of every 10 NHLs. Large-celled, fast-growing tumors are commonly found in lymph nodes, spleen, liver, bone marrow, or other tissues and organs. Symptoms can include fever, night sweats, fatigue, and weight loss. These symptoms are referred to as B symptoms. Not everyone has the same symptoms and tumors can be found anywhere in the body.²

Key Takeaways²



DLBCL is the most common type of non-Hodgkin lymphoma (NHL)



There are many subtypes of DLBCL. If you have DLBCL along with another lymphoma, it will likely be treated as DLBCL



3 main types of lymphocytes:

- B lymphocytes or B-cells
- T lymphocytes or T-cells
- Natural killer (NK)-cells



Cancer Support Community¹


Resource provided by Cancer Support Community that details types of DLBCL, risk factors, signs & symptoms, diagnosis, staging, treatment and side effects. <https://tinyurl.com/3499uuuk>



¹ Courtesy of Lymphoma Coalition
² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](https://www.nccn.org).

Testing and scans

General Tests Used For DLBCL²


1	Biopsy, histology grading, and pathology review	7	Positron Emission Tomography (PET) / Computed Tomography (CT) scan
2	Immunophenotyping with immunohistochemistry (IHC) and flow cytometry	8	Calculation of International Prognostic Index (IPI), which predicts overall and progression-free survival in DLBCL based on risk factors
3	Physical exam with attention to node-bearing areas, including Waldeyer’s ring, and to size of liver and spleen	9	Hepatitis B testing
4	Performance status (PS)	10	Echocardiogram or multigated acquisition (MUGA) scan if certain treatments will be used
5	B symptoms (fever, drenching night sweats, and loss of more than 10 percent of body weight over 6 months)	11	Pregnancy test if chemotherapy or radiation therapy will be used
6	Complete blood count (CBC) with differential, lactate dehydrogenase (LDH), comprehensive metabolic panel (CMP), and uric acid	<div></div> <div>More detail on page 15 on each test https://tinyurl.com/ynru93m9</div>	

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

Organizing Test Results and Records²


- Make copies of blood tests, imaging results, and reports about your specific type of cancer. It will be helpful when getting a second opinion.
 - Choose a binder/folder that meets your needs! Consider a zipper pocket to include a pen, small calendar, and insurance cards.
 - Create folders for insurance forms, medical records, and test results. You can do the same on your computer.
- Use online patient portals to view your test results and other records. Download or print the records to add to your binder.
 - Organize your binder/folder in a way that works for you! Add a section for questions and to take notes.
 - Bring your medical binder to appointments. You never know when you might need it!
- ² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).


Additional Resources



The Leukemia & Lymphoma Society


Scan for lab terms on page 18 that will help you understand the information on a lab report. <https://tinyurl.com/jt8esmhh>

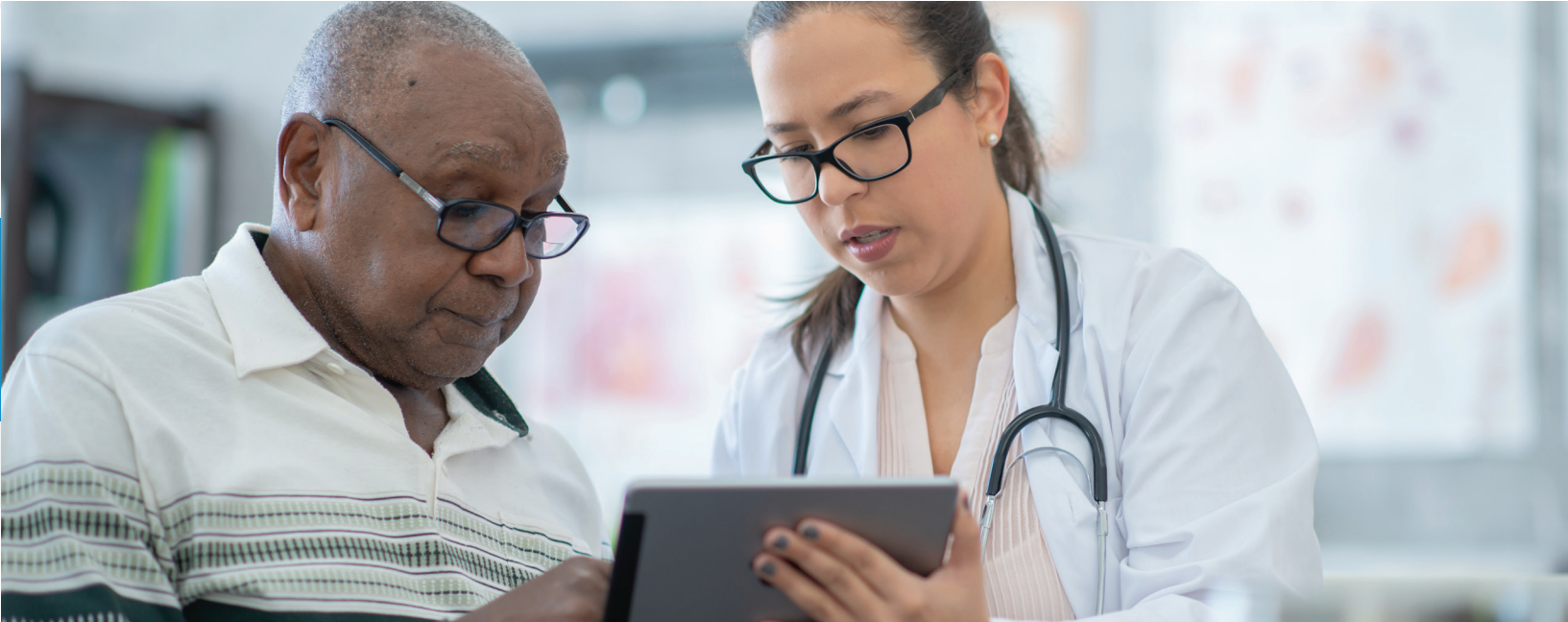




Lymphoma Research Foundation

Scan to download their mobile app, Focus on Lymphoma, for content and tools. <https://tinyurl.com/48ymtn9b>





Hear the doctors’ and patients’ perspectives

Video And Audio Resources To Hear Direct Perspectives From Patients And Providers

Scan the QR codes or use links to hear doctors and patients sharing more about the diagnosis journey. Open the camera app on any smart phone or device. Select the rear-facing camera. Center the QR code you want to scan on the screen and hold your phone steady for a couple of seconds. Tap the notification that pops up to open the link.



Cancer Support Community

Watch a video of Lisa, a DLBCL survivor, as she shares her cancer journey. <https://tinyurl.com/yc6hjd2p>



CancerCare

Listen to this webcast with a panel of experts addressing a variety of topics related to DLBCL, including staging and grading, standard of care and emerging treatment approaches, research and clinical trials, telemedicine, and Q&A with panel.⁵ <https://tinyurl.com/38ts373f>



The Leukemia & Lymphoma Society

Listen to The Bloodline with LLS, a podcast series that offers opportunities to listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients.⁴ <https://tinyurl.com/y9z92ex6>



⁴ Courtesy of The Leukemia & Lymphoma Society
⁵ Courtesy of CancerCare

Questions to ask your doctor: Understanding your diagnosis²


The questions below will help you and your care team share information, discuss options, and agree on a treatment plan. Treatment decisions are very personal and should start with an honest conversation between you and your care team.

Doctor’s Name	Date of appointment or call
<hr/>	<hr/>
What subtype of DLBCL do I have? What does this mean in terms of my prognosis and treatment options?	Is there a cancer center or hospital nearby that specializes in my subtype of DLBCL?
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
What tests do I need? What other tests do you recommend?	Will I have a biopsy? What type? What will be done to make me comfortable?
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
How do I prepare for testing? Would you give me a copy of the pathology report and other test results?	Who will talk with me about the next steps? When? Will I start treatment before the test results are in?
<hr/>	<hr/>
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Note: Please feel free to ask your care team about anything you don’t understand. Ask them to draw it or use an interpreter so that you can understand it fully.
² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).


Questions for your doctor: Communicating your preferences and values³

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.




Physical Health & Well-Being

What is most important for you to be able to do?




Family & Social Relationships

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?



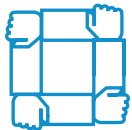
Work/School

Do you want to continue working? Can you adjust your schedule or responsibilities? Do you want to explore retirement or disability?




Personal & Spiritual Growth

How is your confidence and self-esteem? Are you able to do things you enjoy?



Community/ Involvement

Are you getting the support you need from your community? Are you able to stay active/ involved in your community?



Other

What else is important to you?

³ Courtesy of Cancer Support Community

Questions your doctor may ask: Communicating about pain

To help you talk to your doctor about any pain you feel, it may be helpful to keep a pain diary. A pain diary is a written record that helps you keep track of when you have pain, how bad it is, what causes it, and what makes it better or worse. Use a pain diary to discuss your pain with your care team. You may be referred to a specialist for pain management.²

Options to include in a pain diary:²

- Time and dose of all medicines
- When pain starts and ends/lessens
- Where you feel pain
- Describe your pain. Is it throbbing, sharp, tingling, shooting, or burning? Is it constant, or come and go?
- Does the pain change at different times of day? When?
- Does the pain get worse before or after meals? Does certain food or drink make it better?
- Does the pain get better or worse with activity? What kind of activity?
- Does the pain keep you from falling asleep at night? Does pain wake you up in the night?
- Rate your pain from 0 (no pain) to 10 (worst pain you have ever felt)
- Does pain get in the way of you doing the things you enjoy?

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).



Your loved one’s diagnosis: Support for care partners³

Overview

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.

Take Care of Yourself:

Just as the person with DLBCL needs to pay attention to their diet, exercise, and sleep, so do you.

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.

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.

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 care for the person with DLBCL. Or have them help with chores, childcare, or errands.

 ³ Courtesy of Cancer Support Community. Scan for more from Cancer Support Community’s Frankly Speaking About Cancer. <https://tinyurl.com/ycx9a2tc>

Caregiver Resources



CancerCare
Information on CancerCare’s caregiver support group.
<https://tinyurl.com/5xw3t38a>



The Leukemia & Lymphoma Society
Workbook offering steps for creating a self-care plan, a worksheet for delegating tasks, and more.
<https://tinyurl.com/yvs74k4h>



Lymphoma Research Foundation
Understanding Caregiving and Lymphoma Fact Sheet.
<https://tinyurl.com/2mbdpj8p>



Getting connected with support resources for patients and care partners



The Pro-Active DLBCL Patient Toolkit

The DLBCL Patient Toolkit provides actionable advice and downloadable resources to help you communicate clearly and effectively with your healthcare team. The Toolkit includes videos providing the DLBCL basics, treatment approaches, and tips for self-advocacy and printer-friendly patient & care partner planners and resource guides. <https://tinyurl.com/3ye2u7fb>



Patient and Caregiver Support Resources

CancerCare® is the leading national organization dedicated to providing free professional support services including resource navigation, counseling, support groups, educational workshops, publications, and financial assistance to anyone affected by cancer. All CancerCare® services are provided by master’s-prepared oncology social workers. This page also references our Hopeline (800-813-4673). <https://tinyurl.com/2kee59n8>



Mental Health Support

The Leukemia & Lymphoma Society provides education, support, and resources for blood cancer patients and caregivers experiencing relationship stress, anxiety, depression, survivor guilt and more. Services include one-on-one support, webcasts, podcasts, blogs, and social network connections. <https://tinyurl.com/mrxmnh5>





Lymphoma Research Foundation

The Lymphoma Support Network (LSN) is a one-to-one peer support program for people with lymphoma and their caregivers. The LSN connects patients and caregivers with volunteers who have had similar experiences. Volunteers are there to offer words of encouragement and understanding.

<https://tinyurl.com/y53dz9d>



Cancer Support Helpline

The Cancer Support Helpline is staffed by community navigators, resource specialists and a Helpline navigator who have over 170 years of combined experience helping people affected by cancer. The Helpline provides guidance, resources, and support to cancer patients and their loved ones. <https://tinyurl.com/3dnxk5te>



Care & Coverage

Care & Coverage

Learning about your care team

Care Team Structure and Involved Specialists

Oncologists and hematologists are specialists who treat persons with leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative diseases. The oncologist or hematologist-oncologist coordinates a treatment and follow-up plan that involves other doctors as well as nurses, social workers, case managers and nutritionists.

Depending on your diagnosis, your team might include the following:

Radiologists — doctors trained to read imaging studies such as a computed tomography (CT) scan or magnetic resonance imaging (MRI)

Radiology or lab technicians — healthcare professionals who withdraw blood or take images of your body

Pathologists — doctors who identify diseases by studying cells and tissues using microscopes

Hematopathologists — doctor-pathologists who are board-certified in both anatomical and clinical pathology and who examine your blood, bone marrow and tissue samples

Hematologist-oncologists — doctors specially trained to diagnose and treat patients with blood cancers

Nurse practitioners — nurses who have advanced training in diagnosing and treating illness

Oncologists — doctors who treat patients with cancer

Oncology nurses — nurses who specialize in treating people who have cancer

General surgeons — doctors who perform surgical procedures such as splenectomies, lymph node biopsies and other tissue biopsies

Gastroenterologists — doctors who specialize in digestive tract diseases

Nephrologists — doctors who specialize in treating patients with kidney diseases

Choosing Your Providers⁴



Specialists

One of your first choices as an active participant in your care is to either select a specialist to manage your treatment or to choose a treatment center



Referrals

There are a number of ways to find a specialist, including: asking your primary care doctor for a recommendation, contacting your community cancer center, or reaching out to a doctor and/or insurance referral service. Some insurance plans require a referral from your primary care doctor for a consultation with any type of specialist.



Treatment Centers

Selecting a cancer treatment center may depend on several factors including your specific diagnosis, location and insurance coverage. You will want to choose an accredited treatment center with the medical expertise to provide the type(s) of treatment you will need. Most U.S. healthcare organizations and programs are evaluated for accreditation by The Joint Commission on Accreditation of Healthcare Organizations.

Additional Resources



The Leukemia & Lymphoma Society⁴

Scan for a worksheet with questions you should ask to help choose a specialist. <https://tinyurl.com/2p8v5a66>



National Comprehensive Cancer Network²

Scan for additional specialist types on page 31. <https://tinyurl.com/ynru93m9>



² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

⁴ Courtesy of The Leukemia & Lymphoma Society

Insurance coverage and support⁵

Introduction

Understanding Insurance and Coverage Basics

Managing and navigating a cancer diagnosis can be very stressful. Knowing what questions to ask to better understand your insurance coverage is important.

Important Questions to Consider and Ask

Your insurance coverage...

- How much is your deductible?
- What medical procedures and expenses does your insurance plan cover?

- Can you appeal decisions your insurance provider makes about which medical procedures and expenses they cover?
- Does your insurance plan cover a second opinion?
- Do you need a referral to see a specialist or another doctor besides your primary care doctor?
- How can you find a specialist in network?

Your medication copayments...

- Will your medication require a co-payment?
- Is there a less expensive option for your medication?
- Will your prescription cost be an ongoing or a one-time expense?

Resources and Support



Lymphoma Research Foundation

Offers financial support for people currently undergoing treatment for lymphoma. Through this program, Lymphoma Research Foundation may be able to assist lymphoma patients with expenses related to their treatment. <https://tinyurl.com/3v356h2c>



CancerCare

Offers limited financial assistance for cancer-related costs and co-pays, and its professional oncology social workers can help you find additional resources. <https://tinyurl.com/2mf8efhx>



The Leukemia & Lymphoma Society

Offers a variety of financial support programs, including a co-pay assistance program, financial relief, patient aid program and others. <https://tinyurl.com/4jdz9t9ck>



⁵ Courtesy of CancerCare



Getting Started
with Treatment

Getting Started with Treatment

Education and overview

Understanding first-line therapy²

DLBCL is treatable and curable. You may hear your care team use the term first-line therapy, which refers to the first phase of treatment. The goal of first-line therapy is complete response (CR) or remission. During and at the end of the first-line therapy, you will have tests to look for a response (remission).

Supportive care is health care given during all cancer stages. It aims to prevent, reduce, and relieve suffering, and to improve quality of life. Supportive care might include pain relief (palliative care), emotional or spiritual support, financial aid, or family counseling. It is very important to take care of yourself by eating well, drinking plenty of fluids, exercising, and doing things that make you feel energized. Strength is needed to sustain you during treatment.

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).
⁴ Courtesy of The Leukemia & Lymphoma Society

Overview of common treatment plans⁴

Typically, patients are treated initially with a standard therapy known as R-CHOP, which stands for the antibody rituximab, (which binds to the protein called CD20) plus cytotoxic chemotherapy. Therapy with R-CHOP was developed more than two decades ago and remains the mainstay for most DLBCL patients.

This regimen is highly effective in about 60 percent of patients and can eradicate the disease. Such patients may be considered cured, although they still require vigilant follow up to monitor if the disease returns many years later or if they experience secondary effects of the therapy.

The remaining 40 percent of patients treated with R-CHOP or similar therapy will either fail to respond or transiently respond followed by a relapse. Relapsed/refractory DLBCL (R/R DLBCL) is more difficult to treat, but therapeutic alternatives have been approved by the FDA or are in late-stage clinical trials.



Key Takeaways



DLBCL is Treatable and Curable

The goal of treatment is to achieve a complete response (CR) or remission.^{2*}

** Patient's disease will require lifelong monitoring.*



Supportive Care

Supportive care is health care that relieves symptoms caused by cancer or its treatment and improves quality of life.²



Common Treatment

Typically, patients are treated initially with a standard therapy known as R-CHOP.⁴

Additional Resources



Lymphoma Research Foundation⁶

Watch Dr. Ann LaCasce of Dana-Farber Cancer Institute discuss treatment options for DLBCL. <https://tinyurl.com/444wmpay>



Patient Empowerment Network⁷

Go here to access Patient Empowerment Network's DLBCL Toolkit. <https://tinyurl.com/4du4z5cf>



² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).
⁴ Courtesy of The Leukemia & Lymphoma Society
⁶ Courtesy of Lymphoma Research Foundation
⁷ Courtesy of Patient Empowerment Network

Treatment regimen outline

There is more than one treatment for DLBCL. Not everyone will receive the same treatment. Treatment options are based on many factors. It is important to have regular talks with your care team about your goals for treatment and your treatment plan.

Treatment Terms²

Systemic Therapy is drug therapy that works throughout the body. Types include chemotherapy, targeted therapy, and immunotherapy. Systemic therapy might be used alone or with other therapies.

Chemotherapy kills fast-growing cells throughout the body, including cancer cells and some normal cells. More than one chemotherapy may be used to treat DLBCL. In most cases, chemotherapy is given in cycles of treatment days followed by days of rest.

Chemoimmunotherapy also called immunochemo-therapy, includes chemotherapy and immunotherapy drugs to treat cancer

Immunotherapy is drug therapy that increases the activity of your immune system. By doing so, it improves your body’s ability to find and destroy cancer cells. Immunotherapy can be given alone or with other types of treatment. The two major types of immunotherapy are monoclonal antibody therapy and CD19–targeting chimeric antigen receptor T cell (CAR T)–cell therapy.

Targeted therapy is drug therapy that focuses on specific or unique features of cancer cells. Targeted therapies seek out how cancer cells grow, divide, and move in the body. These drugs stop the action of molecules that help cancer cells grow and/or survive

Radiation therapy (RT) uses high-energy radiation from photons, electrons, or protons, and other sources to kill cancer cells and shrink tumors. It is given over a certain period of time. Radiation therapy can be given alone or with certain systemic therapies.

Hematopoietic cell transplant (HCT) replaces damaged hematopoietic stem cells. You might hear it called a stem cell transplant (SCT) or a bone marrow transplant (BMT). There are 2 types of HCTs: Autologous (stem cells come from you) and allogeneic (stem cells come from a donor).

¹ Courtesy of Lymphoma Coalition
² NCCN Guidelines for Patients® for Diffuse Large B–Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

Additional Resource



Lymphoma Coalition¹
Overview of therapies and Lymphoma Coalition database of clinical trials and treatments by country, region or subtype.
<https://tinyurl.com/yc48d8ha>



Questions for your doctor: Making informed treatment decisions^{3,4}

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. Here are a few examples of questions you can ask your doctor.

Doctor’s Name	Date of appointment or call
<hr/> <hr/>	<hr/> <hr/>
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?	Would I qualify for an “auto” stem cell/bone marrow transplant? If so, when would that fit into my treatment?
<hr/> <hr/>	<hr/> <hr/>
What treatment would be best to meet my goals?	Would CAR T Cell Therapy be right for me? If so, should I get a consult now? When would that fit into my treatment?
<hr/> <hr/>	<hr/> <hr/>
What treatments or clinical trials are available to me? Explain the pros and cons of each treatment option.	How much will treatment cost? Is it covered by my insurance? Is there a financial navigator or social worker that can help talk about costs?
<hr/> <hr/>	<hr/> <hr/>
Are there any foods, vitamins, medications, or supplements that I need to avoid because they can interact with the drug after infusions?	Are there any precautions my caregiver or myself need to take once coming home after an infusion?
<hr/> <hr/>	<hr/> <hr/>

³ Courtesy of Cancer Support Community | ⁴ Courtesy of The Leukemia & Lymphoma Society

Questions for your doctor: Making informed treatment decisions²

Doctor's Name	Date of appointment or call
What will happen if I do nothing?	What are the possible complications and side effects?
How do my age, overall health, and other factors affect my options?	Does any option offer long-term cancer control? Are the chances any better for one option than another? Less time-consuming? Less expensive?
What if I'm pregnant? What if I'm planning to get pregnant in the near future?	
	What decisions must be made today? How long do I have to decide about treatment?
Am I a candidate for a hematopoietic cell transplant (HCT)?	
	Is there a social worker or someone who can help me decide?
Am I a candidate for a clinical trial? Can I join a clinical trial at any time?	Is there a hospital or treatment center you can recommend for treatment? Can I go to one hospital for radiation therapy and a different center for systemic therapy?
Which option is proven to work best for my cancer, age, and other risk factors?	

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

Questions for your doctor: Treatment side effects²

Doctor's Name	Date of appointment or call
What are the side effects of treatment?	What emergency department or ER should I go to? Will my treatment team be able to communicate with the ER team?
What are the side effects of DLBCL?	
	What medicines can I take to prevent or relieve side effects? What medicines may worsen side effects of treatment?
How long will these side effects last? Do any side effects lessen or worsen in severity over time?	
	Will you stop treatment or change treatment if there are side effects? What do you look for?
What side effects should I watch for? What side effects are expected, and which are life threatening?	
	What can I do to lessen or prevent side effects? What will you do?
When should I call the doctor? Can I text? What should I do on weekends and during non-office hours?	
	What are some of the likely permanent side effects that I might have from the treatment?

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

Questions for your doctor: For caregivers supporting decision-making⁴

Doctor's Name	Date of appointment or call
<hr/>	<hr/>
What does the treatment plan include?	What signs and/or symptoms indicate I should call the healthcare team? Whom can I contact after working hours?
<hr/>	<hr/>
How will the treatment be administered? Will the patient be treated in the hospital or at an outpatient treatment center?	What signs and/or symptoms indicate that a trip to the emergency room is necessary?
<hr/>	<hr/>
How long will the treatment last?	Will the patient need to follow a special diet or avoid specific foods, medications or supplements while receiving this treatment?
<hr/>	<hr/>
Does a caregiver need to be with the patient while the treatment is administered?	Are there any other precautions that need to be taken, by either the patient or myself, while the patient is receiving this treatment?
<hr/>	<hr/>
What are the side effects and long-term effects of this treatment?	What kind of testing will be done to monitor the disease and treatment? How often will the testing be needed?
<hr/>	<hr/>
Can the patient be referred to a palliative care specialist to get help with managing side effects?	How will we know if the treatment is effective? What options are available if the treatment is not effective?
<hr/>	<hr/>

⁴ Courtesy of The Leukemia & Lymphoma Society



Monitoring DLBCL
& Determining
Treatment Success

Monitoring DLBCL & Determining Treatment Success

Overview

Following Up With Your Doctor⁶

At the first visit following completion of treatment, patients should discuss their follow-up schedule with the doctor. This schedule will be different for each patient depending on his or her lymphoma type and stage, age, and overall health. It is critical that patients adhere to their schedule of follow-up visits — these are very important for monitoring disease recurrence, as well as detecting and treating any new health problems that may arise because of the treatment.

During these follow-up visits, the doctor asks about any medical changes since the last appointment and conducts a physical examination. The doctor may also prescribe blood, imaging, or other laboratory tests.

Signs and Symptoms to Look Out For⁶

What is the Difference Between Long-term Effects and Late Effects?

Long-term effects are toxicities that occur during cancer treatment and continue for months or years. Fatigue, menopausal symptoms, and neuropathy are examples of long-term effects. In contrast, late effects of treatment appear only after treatment has

ended — sometimes months, years, or even decades after treatment is completed. Infertility, osteoporosis, heart problems, and secondary cancers are examples of late effects.

Testing and Scans²

After completing all 6 cycles of R-CHOP, a PET scan will be done. Involved-site radiation therapy (ISRT) might be done to treat any bulky or bone disease sites. Surveillance is a period of testing that begins after remission to monitor for relapse or the return of cancer.

- **Surveillance** includes physical exam, health history, and blood tests every 3 to 6 months for 5 years. After 5 years, testing will be done once a year or as needed.
- **Surveillance imaging** is used for monitoring those without symptoms (asymptomatic). It includes a chest/abdominal/pelvic CT no more than every 6 months for 2 years. After 2 years, imaging testing will be done as needed.

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

⁶ Courtesy of Lymphoma Research Foundation

For More Information:



Lymphoma Research Foundation⁶

Scan or click for information on common side effects of various treatments, found on page 99 of the linked resource.
<https://tinyurl.com/3un9j235>



Resources

Below are a few resources for monitoring DLBCL and understanding treatment success and options. To access the resource, open the camera app. Select the rear-facing camera. Center the QR code you want to scan on the screen and hold your phone steady for a couple of seconds. Tap the notification that pops up to open the link.



Is My DLBCL Treatment Working? What Happens if it Doesn't Work

Go here to access Patient Empowerment Network's resources on DLBCL and a video of DLBCL expert Dr. Kami Maddocks describing how a treatment's effectiveness is evaluated and reviewing the options available for refractory patients.
<https://tinyurl.com/2297tnux>



Connect Education Workshops

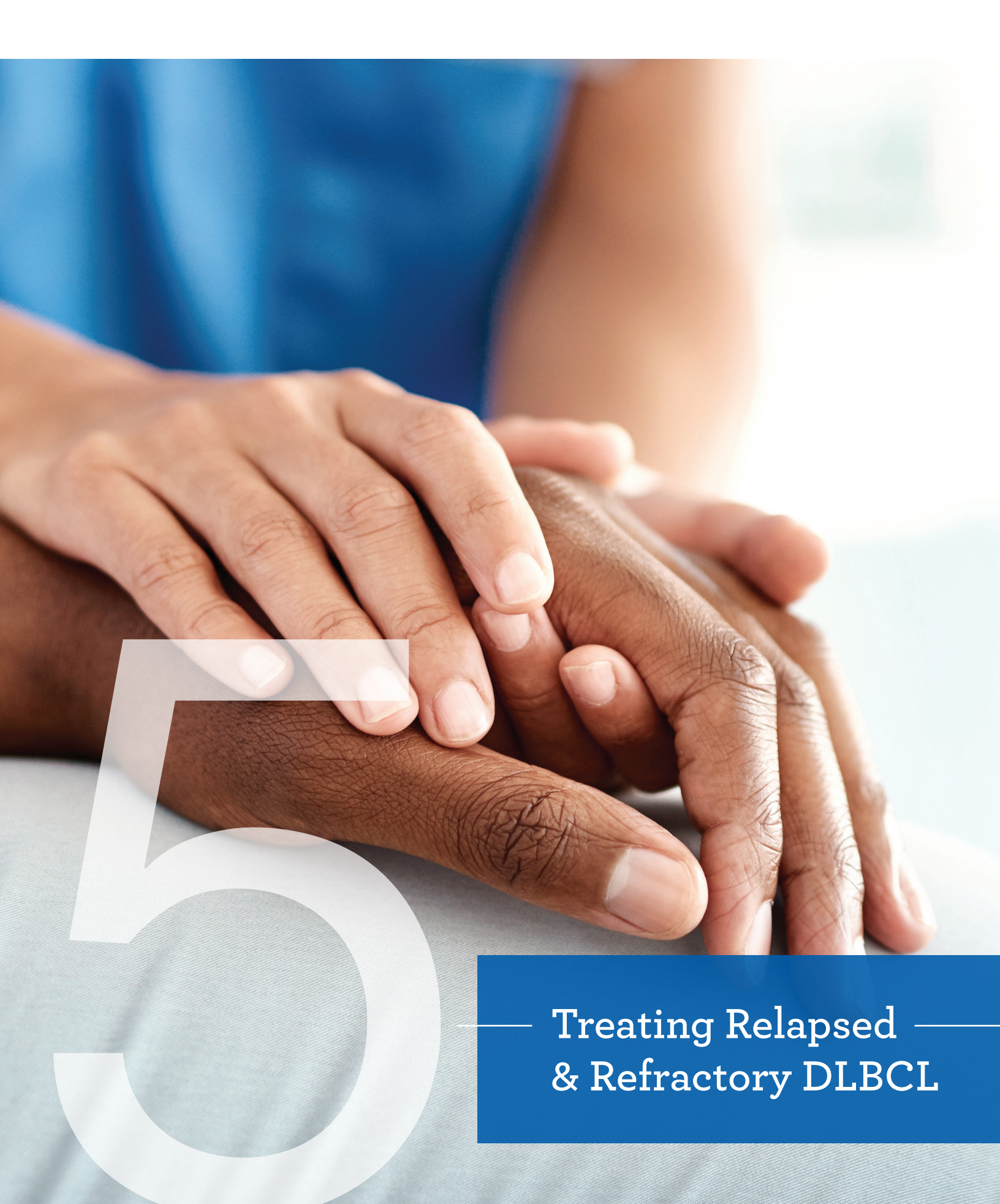
Part of CancerCare's Connect Education Workshop Series, listen here for an update on Diffuse Large B-Cell Lymphoma (DLBCL). Five experts explain the use of CT and PET scans, outline the differences, and offer other treatment explanations.
<https://tinyurl.com/38ts373f>



Understanding Blood Cancers and Treatment Options

Caregiver workbook that shares information on different types of treatment options, side effects, questions to ask a healthcare provider, caregiver responsibilities, and more. <https://tinyurl.com/jt8esmhh>





Treating Relapsed & Refractory DLBCL

Treating Relapsed & Refractory DLBCL

Introduction

Relapsed or Refractory Disease⁶

Although DLBCL is often cured, up to 40% of patients can relapse (disease returns after treatment) or become refractory (disease does not respond to treatment). These patients are eligible for second-line treatment, which can reduce symptoms, control cancer growth, provide a second chance at a cure, and extend life.

The Lymphoma Research Foundation outlines treatment options for patients who are:

- Refractory to first-line chemoimmunotherapy or relapsed within 1 year of first-line chemoimmunotherapy
- Candidates for stem cell transplant
- Patients who are not candidates for stem cell transplant

Treatment options may change as new treatments are discovered and current treatments are improved, so it is important that patients check with their physician for any treatment updates that may have recently emerged.

⁶ Courtesy of Lymphoma Research Foundation https://lymphoma.org/wpcontent/uploads/2023/06/LRF_DLBCLLRR_Fact_sheet.pdf

Treatment Considerations²

- Treatment options for relapsed disease are based on the time since your last treatment was completed. The goal of treatment is to achieve remission again.
- If cancer returned and it has been less than 12 months since treatment ended, then treatment will be based on if CAR T-cell therapy is planned.
- If cancer returned after more than 12 months since treatment ended, then treatment will be based on if a stem cell transplant is planned.
- After completing treatment, you will be monitored for the return of cancer. Keep all follow-up doctor visits and imaging test appointments.
- Treatment options for relapsed or refractory DLBCL may include:
 - + CAR T-Cell Therapy
 - + Chemotherapy
 - + Clinical Trial
 - + Immunotherapy
 - + Palliative Involved Site-Radiation Therapy (ISRT)
 - + Stem Cell Transplant

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](https://www.nccn.org/patients/guidelines/).

Additional Resources



Lymphoma Research Foundation⁶
Scan or click for information. <https://tinyurl.com/mrswfhby>



National Comprehensive Cancer Network²
Scan or click for information. <https://tinyurl.com/ynru93m9>



Clinical trials

Clinical Trial Basics⁶

Clinical trials are carefully designed research studies that involve patients who volunteer to participate. The purpose of cancer clinical trials is to answer specific questions about new ways to prevent, diagnose, treat, or manage a disease or the side effects caused by a new or existing treatment.

The Benefits of Joining a Clinical Trial⁷

- Helping current and future patients
- Learning more about a therapy and good practices for the future
- Gaining access to a new therapy that might not be available otherwise
- Personalized care and closer monitoring

Questions to Ask about Participation⁷

- What is the therapy being studied?
- What is the alternative?
- What are the eligibility criteria? Do I qualify?
- What are the logistics? Location, treatment schedule, etc.?
- What is the cost of joining a trial?

Resources to Help You Consider Clinical Trials



Lymphoma Research Foundation⁶

Clinical Trials & Advances in Treatment, found on page 140 of the linked resource.
<https://tinyurl.com/3un9j235>



Patient Empowerment Network⁷

Go here to access Patient Empowerment Network's resources on DLBCL and video: What Are the Risks & Benefits of Joining a Clinical Trial.
<https://tinyurl.com/23zx7pm8>



Lymphoma Coalition¹

The Lymphoma Coalition believes that clinical trials are a necessity and, in many cases, an important treatment option for lymphoma patients.
<https://tinyurl.com/yc48d8ha>



¹ Courtesy of the Lymphoma Coalition
⁴ Courtesy of The Leukemia & Lymphoma Society

⁶ Courtesy of The Lymphoma Research Foundation
⁷ Courtesy of the Patient Empowerment Network

Assistance for Clinical Trial Participation



The Leukemia & Lymphoma Society⁴

Offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process.
<https://tinyurl.com/42n7acaj>



Patient Empowerment Network⁷

Scan to access Patient Empowerment Network's DLBCL Toolkit and video: How Can Clinical Trials Be Accessed?
<https://tinyurl.com/4ss9kswa>



Treatment regimen outline

Making Decisions For Your Next Treatment²

- There is more than one treatment for DLBCL
- Not everyone will receive the same treatment
- Treatment options are based on many factors
- Together, you and your care team will choose a treatment plan that is right for you

A Comprehensive Guide²

In 2022, The National Comprehensive Cancer Network (NCCN) has compiled guidelines for patients with Diffuse Large B-Cell Lymphomas. This guide is:

- Step-by-step guides to the cancer care options likely to have the best results
- Based on treatment guidelines used by health care providers worldwide
- Designed to help you discuss cancer treatment with your doctors

Additional Resources

NCCN® | NCCN FOUNDATION®
PATIENT RESOURCES

National Comprehensive Cancer Network

NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).



Helping Your Loved One Choose A Treatment Plan⁴

Your loved one may ask you to participate in the process for choosing a treatment plan. You can help in some of the following ways:

- Research and collect information on the patient's diagnosis and suggested treatment options.
- Be the patient's second set of ears or offer to take notes at appointments.
- Help the patient find a blood cancer specialist for a second opinion to confirm the treatment plan.
- Help the patient keep a running list of questions to ask members of the healthcare team.
- Be a sounding board for the patient to discuss each treatment option.

Remember, ultimately, treatment decisions are up to the patient. In an open discussion, you can share your perspective with the patient. Be respectful and supportive of the patient's decisions, even if you disagree with the choices he or she is making.

Caregivers often become the primary "researchers" for disease information and support in an effort to assist the person with cancer and to help him or her better understand the disease, treatment options and side effects. Be wary of information found online. Always check to make sure the information is provided by a reliable source.

² NCCN Guidelines for Patients® for Diffuse Large B-Cell Lymphomas, 2022©. 2023 National Comprehensive Cancer Network, All Rights Reserved. Accessed June 15, 2023. To view the most recent and complete version of the NCCN Guidelines for Patients, visit [here](#).

⁶ Courtesy of Lymphoma Research Foundation

⁴ Courtesy of The Leukemia & Lymphoma Society



Appendix & Journaling Pages

Appendix

Overview

The next pages include QR codes and web links to resources you may find helpful, including all resources used in this Toolkit. Resources come from:



This Toolkit also references the National Comprehensive Cancer Network DLBCL Guidelines:

NCCN® | NCCN FOUNDATION®
PATIENT RESOURCES

National Comprehensive Cancer Network

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NCCN=National Comprehensive Cancer Network® (NCCN®)



CancerCare

Website: www.cancercares.org | Contact: 1-800-813-HOPE (4673)



Cancer Counseling: By Oncology Social Workers
<https://tinyurl.com/2urpuexj>



Caring For a Loved One with Cancer Support Group
<https://tinyurl.com/aj742wzj>



Coping with Cancer Uninsured
<https://tinyurl.com/2zkfjujn>



Counseling for Caregiving: Cancer: Resources for Caregivers
<https://tinyurl.com/ya7bpzyy>



DLBCL Connect Education Workshops Tagged 'Diffuse Large B-cell Lymphoma'
<https://tinyurl.com/2nszkjfn>



Research on Cancer Caregivers and Decision-Making
<https://tinyurl.com/3njw4bay>



Understanding Your Insurance Coverage
<https://tinyurl.com/29d9826j>



Understanding the Costs of Care and Your Health Care Coverage
<https://tinyurl.com/yrzb7xvr>

Cancer Support Community

Website: www.cancersupportcommunity.org | Contact: 1-888-793-9355



Cancer Support Helpline
<https://tinyurl.com/3dnxk5te>



Explore Cancer Types: Diffuse Large B-Cell Lymphoma
<https://tinyurl.com/523zf6e8>



Frankly Speaking About Cancer: Diffuse Large B-Cell Lymphoma
<https://tinyurl.com/2s38b3mk>



Frankly Speaking About Cancer: Lymphoma
<https://tinyurl.com/ycx9a2tc>



Helping Your Loved One Making Treatment Decisions (for caregivers)
<https://tinyurl.com/2ya3vjbz>



Lisa's DLBCL Story (2021)
<https://tinyurl.com/yc6hjd2p>



Making Treatment Decisions that are Right for You
<https://tinyurl.com/548u3tuv>



Navigating Cancer — Caregivers
<https://tinyurl.com/3rzs9p9x>



When Diffuse Large B-Cell Lymphoma (DLBCL) Doesn't Respond to Treatment
<https://tinyurl.com/ypbnhtvt>

The Leukemia & Lymphoma Society

Website: www.lls.org | Contact: 1-800-955-4572



Caregiver Support
<https://tinyurl.com/mrxm2xsk>



Caregiver Workbook: Caring for Yourself
<https://tinyurl.com/yvs74k4h>



Caregiver Workbook: Understanding Blood Cancers and Treatment Options
<https://tinyurl.com/jt8esmhh>



Diffuse Large B-Cell Lymphoma (DLBCL)
<https://tinyurl.com/99xhj3bh>



Financial Support
<https://tinyurl.com/4jdz9ck>



Non-Hodgkin Lymphoma Booklet
<https://tinyurl.com/ycycewb2>



Podcast: The Bloodline with LLS
<https://tinyurl.com/y9z92ex6>



Printable Question Guides
<https://tinyurl.com/49mhreez>



Mental Health Awareness Month
<https://tinyurl.com/mrxmnh5>

Lymphoma Coalition

Website: <https://lymphomacoalition.org>



Clinical Trials
<https://tinyurl.com/yc48d8ha>



Effects of Lymphoma
<https://tinyurl.com/mt9fbpzz>



Global Patient Survey
<https://tinyurl.com/yve8f56s>



Lymphoma Subtypes
<https://tinyurl.com/bdhyw3k8>



Therapies
<https://tinyurl.com/ye5hmhw8>



What is Lymphoma?
<https://tinyurl.com/yvj8bfcj>

Lymphoma Research Foundation

Website: <https://lymphoma.org> | Contact: 1-800-500-9976



Diffuse Large B-Cell Lymphoma with Dr. Ann Lacasce Everything You Need to Know (video)
<https://tinyurl.com/897tx4ba>



Diffuse Large B-Cell Lymphoma Treatment Options (video)
<https://tinyurl.com/444wmpay>



Financial Support
<https://tinyurl.com/3v356h2c>



Focus on Lymphoma Mobile App
<https://tinyurl.com/48ymtn9b>



Support Services
<https://tinyurl.com/y53dz9d>



Understanding Caregiving and Lymphoma
<https://tinyurl.com/2mbdpj8p>



Understanding Diffuse Large B-Cell Lymphoma with Jennifer Amengual, MD (video)
<https://tinyurl.com/34cp7uhb>



Understanding Non-Hodgkin Lymphoma: A Guide for Patients, Survivors, and Loved Ones (2018)
<https://tinyurl.com/3un9j235>

Patient Empowerment Network

Website: <https://powerfulpatients.org>

Contact: You can now receive personalized support from our Empowerment Leads by texting 'EMPOWER' to +1-833-213-6657



Help By Cancer Diagnosis: Diffuse Large B-Cell Lymphoma (DLBCL)

<https://tinyurl.com/9c2b5zha>



PEN-Powered Activity Guides

<https://tinyurl.com/28y3xy8e>



Is my DLBCL Treatment Working? What Happens If It Doesn't Work? (video, 2022)

<https://tinyurl.com/2297tnux>



The Pro-Active DLBCL Patient Toolkit

<https://tinyurl.com/3ye2u7fb>



Understanding DLBCL Treatment Classes (video, 2022)

<https://tinyurl.com/4du4z5cf>



What Are the Risks and Benefits of Joining a Clinical Trial? (video, 2022)

<https://tinyurl.com/23zx7pm8>

Journaling

A place to record how you're feeling or questions you might have

[illegible]

A place to record how you're feeling or questions you might have

[illegible]

A place to record how you're feeling or questions you might have

[illegible]

Thank You!

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