

# Care Plan for Your Aggressive Lymphoma



Patients with lymphoma should have regular visits with a physician who is familiar with their medical history and the treatments they have received.

Medical tests such as computerized tomography (CT) and positron emission tomography (PET) scans may be required at various times during remission to evaluate the need for additional treatment.

Some treatments can cause long-term side effects or late side effects, which can vary based on duration and frequency of treatments, age, gender, and the overall health of each patient at the time of treatment.

A physician will check for these effects during follow-up care. Visits may become less frequent the longer the disease remains in remission. Patients and their care partners are encouraged to keep copies of all medical records and test results as well as information on the types, amounts, and duration of all treatments received. This documentation will be important for keeping track of any side effects resulting from treatment or potential disease recurrences.

## Section 1: General Patient Information

Name: \_\_\_\_\_ Date of Birth (MM/DD/YYYY): \_\_\_\_\_ Gender:  Male  Female  Prefer not to identify

Patient ID: \_\_\_\_\_ Patient's Email: \_\_\_\_\_

Patient Phone (Cell/Home/Other) Primary: \_\_\_\_\_ Secondary: \_\_\_\_\_ ( Cell  Home  Other: \_\_\_\_\_)  
( Cell  Home  Other: \_\_\_\_\_)

Support Person Name: \_\_\_\_\_ Relationship to Patient: \_\_\_\_\_

Support Contact Info:  Cell Phone:  
 Home Phone:  
 Email:

Diffuse large B-cell lymphoma (DLBCL) is the most common form of non-Hodgkin lymphoma (NHL), accounting for about one out of every three lymphomas in the United States. DLBCL occurs in both men and women, although it is slightly more common in men. DLBCL can occur in childhood, however its incidence generally increases with age, and roughly half of patients are over the age of 60 years. DLBCL is an aggressive (fast-growing) lymphoma that can arise in lymph nodes, and often the spleen, liver, bone marrow, or other organs are also affected.

Often, the first sign of DLBCL is a painless, rapid swelling in the neck, underarms, or groin that is caused by enlarged lymph nodes.

For some patients, the swelling may be painful. Other symptoms may include night sweats, fever, and unexplained weight loss. Patients may notice fatigue, loss of appetite, shortness of breath, or pain.

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 for curing, and extend life.

Early evaluation at a specialized lymphoma management center is recommended for patients with relapsed/refractory DLBCL.

## Section 2: The Care Team

	Name	Affiliation/ Institution	Contact Information (Phone/Email)
Primary Care Provider			
Hematologist/Oncologist			
Radiation Oncologist			
Surgeon			
Transplant Coordinator			
Other Providers:			
Dermatologist			
Endocrinologist			
Fertility Specialist			
OB-GYN			
Physical Therapist			
Psychologist/ Mental Health Provider			
Social Worker			

## Section 3: Treatment Summary

### 3A. Diagnosis

Diagnosis Date (MM/DD/YYYY):	<p>Cancer Type: <input type="checkbox"/> CLL/SLL (Chronic Lymphocytic Leukemia/Small Lymphocytic Lymphoma)  <input type="checkbox"/> HL (Hodgkin's Lymphoma) <input type="checkbox"/> NHL (Non Hodgkin's Lymphoma)</p> <p>Cancer Subtype (List):</p>
Stage/Staging Classification	<p>Ann Arbor: _____ Lugano: _____ Other: _____</p> <p><input type="checkbox"/> New <input type="checkbox"/> Recurrent      <input type="checkbox"/> New <input type="checkbox"/> Recurrent      <input type="checkbox"/> New <input type="checkbox"/> Recurrent</p>

Diagnosis Confirmed By:	Study	Date (MM/DD/YYYY)	Study Type	Findings
Biopsy				
Blood Test				
Genetic Test				
Scan				

### Patient Pretreatment

Weight: \_\_\_\_\_

Height: \_\_\_\_\_

Blood Type: \_\_\_\_\_

### 3B. Treatments

Diffuse Large B-cell Lymphoma (DLBCL) treatment typically begins shortly after diagnosis, with the intent of obtaining a durable remission or cure. A combination of chemotherapy and a monoclonal antibody targeting CD20 remains the backbone of most treatments. CD20 is a molecule expressed on the cell surface of lymphoma cells, and antibodies such as rituximab (Rituxan® [for intravenous infusion]) target this molecule. Rituxan Hyclea®, a form of rituximab that is injected subcutaneously (under the skin), may be an option for some patients.

The most widely used combination chemotherapy regimen for DLBCL is R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone) that is usually given in 21-day cycles. Sometimes etoposide (VePesid®, Toposar™, Etopophos®) is added to the R-CHOP regimen, resulting in a drug combination called R-EPOCH. Sometimes treatment may involve radiation therapy. For many patients with DLBCL, the initial treatment can lead to disease remission (disappearance of signs and symptoms).

First-Line Chemotherapy/Other Systemic Therapies:  Yes  No

Regimen/Agents	Agents Initiation	End Date Dose	Route of Administration Schedule	Cycles Dose Reduction	Comments
1.					
2.					
3.					
4.					

Radiation:  Yes  No

Type	Initiation/End Dates	Body Area	Treated Dose	Comments
1.				
2.				

#### Relapsed or Refractory Disease

For patients who do not respond to first-line chemoimmunotherapy (e.g., R-CHOP) or who progress within 12 months of first-line chemoimmunotherapy, chimeric antigen receptor T cell therapy (CAR T cell therapy) may be an option. For patients who experience a recurrence of lymphoma beyond 12 months, second-line chemoimmunotherapy is typically used. In patients who are able to achieve a good response to chemoimmunotherapy, high-dose chemotherapy with autologous stem cell transplantation may be recommended to consolidate their successful second-line treatment.

Patients in complete remission undergoing a stem cell transplant commonly receive their own stem cells (autologous stem cell transplant). Occasionally, a patient will receive stem cells from a donor (allogeneic stem cell transplant). After a stem cell transplant, patients may also receive involved-site radiation therapy (ISRT) to treat a specific area.

Relapsed/refractory patients who are not candidates for or who choose not to have a stem cell transplant have other treatment alternatives. Chemotherapies such as bendamustine hydrochloride (Treanda®) or (gemcitabine

HCl (Gemzar®), or targeted drugs like lenalidomide (REVLIMID®) may be used in these patients in combination with rituximab (Rituxan®) or other monoclonal antibodies. Patients with relapsed or refractory DLBCL after two prior therapies may also be eligible for treatment with polatuzumab vedotin-piiq (Polivy®) or selinexor (Xpovio®). Relapsed/refractory disease in adult patients can also be treated with tafasitamab-cxix (Monjuvi), a monoclonal anti-CD19 antibody; or loncastuximab tesirine-lpyl (Zynlonta®), a CD19-directed antibody-drug conjugate. Patients may also be candidates for second-line CAR T cell therapy with axicabtagene ciloleucel (Yescarta®), tisagenlecleucel (Kymriah®), or lisocabtagene maraleucel (Breyanzi®). For more information, view the CAR T cell Therapy in Lymphoma fact sheet on Lymphoma Research Foundation's website ([lymphoma.org/publications](http://lymphoma.org/publications)).

Stem Cell Transplant:  Yes  No

Inpatient  Outpatient

Admission Date: \_\_\_\_\_

Discharge Date: \_\_\_\_\_

Type:  Allogeneic  Autologous

Donor Relationship and Information:

Conditioning Treatment	Conditioning Treatment Date	Transplant Date	Engraftment/Reactions/Comments

Surgery:  Yes  No

Procedure	Surgery Date	Location	Treated Dose	Findings/Comments
1.				
2.				

Other Treatments:  Yes  No

Procedure	Surgery Date	Location	Treated Dose	Findings/Comments
1.				
2.				

**3C. Treatment Outcomes**

Treatment Part of a Clinical Treatment:  Yes  No      Study Number (NCT):

Treatment Goal:

Response to Treatment:

Serious Toxicities/Side Effects *During* Treatment:

Ongoing Toxicities/Side Effects *After* Treatment:

Patient Pretreatment      Weight: \_\_\_\_\_      Height: \_\_\_\_\_      Blood Type: \_\_\_\_\_

## Section 4: Follow-Up Care

Some patients may relapse (disease returns after treatment) or become refractory (disease does not respond to treatment) to their previous treatment. These patients are eligible for additional lines treatment, which can reduce symptoms, control cancer growth, provide a second chance for curing, and extend life.

### 4A. Maintenance/Adjuvant Treatment

Treatment Name:

Route of Administration:

Dose:

Planned Schedule and Duration:

Possible Side Effects:

Results:

### 4B. Possible Late Effects and Long-Term Side Effects

#### Living With Treatment Side Effects

After your treatments have ended, you may still experience side effects. Some side effects develop during treatment and last for months or longer (called “long-term side effects”), and others appear long after the treatment has ended (called “late side effects”). These effects may vary for each survivor and depend on the type of lymphoma you had, the treatment you received, and your age and overall health. While blood cancer survivors don’t always have serious long-term or late effects of treatment, it is important to know that some side effects may take time to go away and may even be permanent. Talk to your healthcare team about what these possible effects might be and ask for ways to prevent and/or relieve them.

Long-term and late treatment effects may include “chemo brain” or “brain fog” (decreased memory, concentration and inability to multitask); psychological effects (anxiety, depression, and post-traumatic stress disorder); or a variety of physical effects, which are highly dependent on the treatment:

- Decreased bone density and osteoporosis (a condition that weakens bones, making them fragile and more likely to break)
- Dental and mouth problems
- Eye and vision problems
- Fertility issues
- Heart disease
- Infections
- Lung damage
- Nerve damage
- Other cancer
- Thyroid problems

List Late Effects/Long-Term Side Effects Here:

#### 4C. Follow-Up Visits

	Type of Visit	When/How Often	Person to Contact
Hematologist/Oncologist			
Blood Work/Lab Tests			
Imaging (CT, PET, ETC.)			
Primary Care Physician			
Other			

#### 4D. Revaccination Schedule

Patients should follow the recommended revaccination schedule as directed by their physician

Vaccination	Date to Receive	Vaccination	Date to Receive
<input type="checkbox"/> Hepatitis B (HBV)		<input type="checkbox"/> Measles, mumps, and rubella (MMR)	
<input type="checkbox"/> Haemophilus influenzae type B (Hib) series		<input type="checkbox"/> Tetanus, diphtheria, and acellular pertussis (Tdap)	
<input type="checkbox"/> Influenza		<input type="checkbox"/> Varicella	
<input type="checkbox"/> Meningococcal conjugate		<input type="checkbox"/> Other:	
<input type="checkbox"/> Pneumococcal conjugate series		<input type="checkbox"/> Other:	
<input type="checkbox"/> Polio		<input type="checkbox"/> Other:	

#### COVID-19 Vaccination and Boosters

Most lymphoma patients should receive the COVID-19 vaccine as soon as it is available to them because studies have shown that blood cancer patients may be at higher risk for negative outcomes from COVID-19 infection than the general population. However, given that some lymphoma treatments might affect the efficacy of a vaccine (by impacting the immune system), lymphoma patients and survivors should consult their oncologist or healthcare

team prior to receiving the COVID-19 vaccine, any booster, or pre-expose prophylaxis – particularly if they are in the midst of lymphoma treatment or have had treatment recently (e.g., within the last 6-12 months). Some healthcare providers may suggest that some patients wait a period of time after their last treatment before receiving the vaccine. Studies at this point suggest that the COVID-19 vaccines are safe for even those who have underlying health conditions (with the rare exception of some of those with a history of severe allergic reactions).

### Section 5. Wellness Concerns and Cancer Screening and Prevention

<input type="checkbox"/> Alcohol Use	<input type="checkbox"/> High Blood Pressure Control
<input type="checkbox"/> Bone Health/DEXA Scan	<input type="checkbox"/> Mammography and Pap Tests (Women only)
<input type="checkbox"/> Cholesterol Management	<input type="checkbox"/> Mental Health
<input type="checkbox"/> Colonoscopy	<input type="checkbox"/> Prostate-Specific Antigen (PSA) and Rectal Exam (Men Only)
<input type="checkbox"/> Diabetic Screening/Management	<input type="checkbox"/> Sexual Health and Fertility
<input type="checkbox"/> Diet and Nutrition/Weight management	<input type="checkbox"/> Tobacco Use/Stopping
<input type="checkbox"/> Exercise/physical activity	<input type="checkbox"/> Other:

## Health Screening to Consider

As a survivor, there are specific health screenings and exams that you may do at an earlier age than the general population. These will be adapted to the type of lymphoma you had and the treatment you received. For instance, due to the increased risk of secondary breast cancer from radiation therapy, women who received radiation therapy to the chest area during childhood, adolescence, or young adulthood should have clinical breast examinations yearly until age 25, then every six months thereafter. In addition, these women should receive yearly mammograms and breast magnetic resonance imaging (MRI) beginning at age 25 or eight years after completion of the radiation therapy, whichever comes last.

Other health screenings the physician may suggest include:

- Bone density scans
- Chest or whole-body imaging
- Cardiovascular monitoring
- Dental screenings
- Eye exams
- Lipid blood tests
- Screening for other cancers (e.g., colorectal or skin)
- Thyroid function tests

Because everyone is different, survivors should talk with their physicians about which screenings are most appropriate and when they should be started.

## Section 6. Self-Assessment of Symptoms

Check any symptoms you experience to discuss symptom management and treatment options with a health care provider.

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> Abdominal pain             | <input type="checkbox"/> General weakness                                    | <input type="checkbox"/> Pain with urination                  |
| <input type="checkbox"/> Changes in appetite        | <input type="checkbox"/> Hair loss   | <input type="checkbox"/> Relationship problems                |
| <input type="checkbox"/> Chest pain                 | <input type="checkbox"/> Hearing loss  | <input type="checkbox"/> Sexual dysfunction/lack of desire    |
| <input type="checkbox"/> Chronic diarrhea           | <input type="checkbox"/> Heartburn/indigestion                               | <input type="checkbox"/> Shortness of breath                  |
| <input type="checkbox"/> Constipation               | <input type="checkbox"/> Hot flashes/night sweats                            | <input type="checkbox"/> Skin changes, rashes, lumps or bumps |
| <input type="checkbox"/> Cough or wheezing          | <input type="checkbox"/> Irregular heartbeat/ palpitations                   | <input type="checkbox"/> Sleep disturbances                   |
| <input type="checkbox"/> Decreased exercise ability | <input type="checkbox"/> Jaundice (yellowing of skin or eyes)                | <input type="checkbox"/> Slurred speech                       |
| <input type="checkbox"/> Dental problems            | <input type="checkbox"/> Joint pain or muscle aches                          | <input type="checkbox"/> Swelling of arm or leg               |
| <input type="checkbox"/> Difficulty breathing       | <input type="checkbox"/> Leg pain with exertion                              | <input type="checkbox"/> Swollen lymph nodes                  |
| <input type="checkbox"/> Dizziness                  | <input type="checkbox"/> Memory/concentration issues                         | <input type="checkbox"/> Urinary incontinence (leaking urine) |
| <input type="checkbox"/> Dry Mouth                  | <input type="checkbox"/> Negative body image                                 | <input type="checkbox"/> Vision problems                      |
| <input type="checkbox"/> Easy bruising or bleeding  | <input type="checkbox"/> Neuropathy (pins and needles sensation or numbness) | <input type="checkbox"/> Weight gain or overweight            |
| <input type="checkbox"/> Fatigue                    | <input type="checkbox"/> New/changed moles or freckles                       | <input type="checkbox"/> Weight loss or loss of appetite      |
| <input type="checkbox"/> Fertility concerns         | <input type="checkbox"/> Numbness/weakness on one side                       |   |
| <input type="checkbox"/> Fever and sweats           | <input type="checkbox"/> Pain or problems with eating                        |   |

### Women Only

- |  |  |  |  |  |
|--|--|--|--|--|
| <input type="checkbox"/> Abnormal vaginal bleeding | <input type="checkbox"/> Irregular periods | <input type="checkbox"/> Vaginal discharge | <input type="checkbox"/> Painful intercourse | <input type="checkbox"/> Premature menopause |
|--|--|--|--|--|

### Men Only

- |   |
|---|
| <input type="checkbox"/> Erectile dysfunction |
|---|

## Clinical Trials

Clinical trials are crucial in identifying effective drugs and determining optimal doses for patients with lymphoma. Patients interested in participating in a clinical trial should view the *Understanding Clinical Trials* fact sheet on the Foundation's website ([lymphoma.org/publications](https://lymphoma.org/publications)), talk to their physician, or contact the Helpline for an individualized clinical trial search by calling (800) 500-9976 or emailing [helpline@lymphoma.org](mailto:helpline@lymphoma.org).

## Lymphoma Care Plan

Keeping your information in one location can help you feel more organized and in control. This also makes it easier to find information pertaining to your care and saves valuable time. The Foundation's Lymphoma Care Plan document organizes information on your health care team, treatment regimen, and follow-up care. You can also keep track of health screenings and any symptoms you experience to discuss with your health care provider during future appointments. The Lymphoma Care Plan document can be accessed by visiting [lymphoma.org/publications](https://lymphoma.org/publications).

## Patient Education Programs

The Foundation also offers a variety of educational activities, including live meetings and webinars for individuals looking to learn directly from lymphoma experts. These programs provide the lymphoma community with important information about the diagnosis and treatment of lymphoma, as well as information about clinical trials, research advances and how to manage/cope with the disease. These programs are designed to meet the needs of a lymphoma patient from the point of diagnosis through long-term survivorship. To view our schedule of upcoming programs, please visit [lymphoma.org/programs](https://lymphoma.org/programs).

## Helpline

The Foundation's Helpline staff are available to answer your general questions about lymphoma and treatment information, as well as provide individual support and referrals to you and your loved ones. Callers may request the services of a language interpreter. The Foundation also offers a one-to-one peer support program called the Lymphoma Support Network and clinical trials information through our Clinical Trials Information Service. For more information about any of these resources, visit our website at [lymphoma.org](https://lymphoma.org), or contact the Helpline at (800) 500-9976 or [helpline@lymphoma.org](mailto:helpline@lymphoma.org).

Para información en Español, por favor visite [lymphoma.org/es](https://lymphoma.org/es). (For Information in Spanish please visit [lymphoma.org/es](https://lymphoma.org/es)).

## Focus on Lymphoma Mobile App

Focus on Lymphoma is the first app to provide patients and their care partners with tailored content based on lymphoma subtype, and actionable tools to better manage diagnosis and treatment. Comprehensive lymphoma management, conveniently in one secure and easy-to-navigate app, no matter where you are on the care continuum. Get the right information, first, with resources from the entire Lymphoma Research Foundation content library, use unique tracking and reminder tools, and connect with a community of specialists and patients. To learn more about this resource, visit our website at [lymphoma.org/mobileapp](https://lymphoma.org/mobileapp), or contact the Foundation's Helpline at (800) 500-9976 or [helpline@lymphoma.org](mailto:helpline@lymphoma.org).

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Helpline: 800 500 9976 [lymphoma.org](https://lymphoma.org)