

# My Diffuse Large B-Cell Lymphoma (DLBCL) Discussion Guide

This guide is designed to help you have more focused discussions with your care team about your treatment as a person with DLBCL or for you as a caregiver supporting someone with relapsed/refractory (r/r) DLBCL.



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Co-created with  
Lymphoma Patient  
Organizations



## ● Understanding DLBCL

*Learning that your or a loved one's DLBCL has come back, or previous treatment did not work, can be overwhelming.*

This discussion guide can help you to discuss your thoughts and feelings about your DLBCL treatment with your health care team.

You may wish to use the guide:

- Before an appointment, to make a note of questions and to navigate discussions at your clinic visit
- During appointments, to make notes about your treatment and help track the topics discussed
- After appointments, to record your thoughts and feelings during your treatment plan and daily life

### FINDING THE RIGHT WORDS

As you will know, your clinical visits are really important. Not only will you receive information about your treatment, but this is also a good time to tell your care team how you are feeling. They will want to know your thoughts about your treatment and how this is affecting your daily life.

*Use this guide to help navigate those discussions.*



## ● Finding the right words and asking the right questions

As with treatments you have received in the past, you may have questions you want to ask your health care team. They are the best people to ask about your treatment at different stages. **Use the examples below to understand more about your treatment.** You can also use the notes section on page 6 of this booklet to write down any of your thoughts, feelings and questions.

### Understanding this stage of my DLBCL

- 1 Why did my DLBCL return – and is this common?
- 2 How advanced is my DLBCL?
- 3 What is my prognosis and chances of recovery? Can I be cured?

### Day-to-day living with my DLBCL

- 1 Can I still go on holiday and pursue my usual hobbies?
- 2 What kind of testing will be done to monitor my cancer and the results of my treatment?
- 3 How long do I have to make a decision on my treatment?
- 4 Where can I get psychosocial support?
- 5 Is there a patient organisation/forum that I can refer to?

### Understanding your treatment options for my DLBCL

- 1 What are my treatment options now?
- 2 What are the differences between available therapies that I should understand?
- 3 My previous treatment didn't work, how is this one different?
- 4 What happens if my new treatment doesn't work?

- 5 How is this treatment given and how often will I receive it? How long will each session take?
- 6 Will I need to stay in hospital overnight?
- 7 What do I need to do to prepare for my treatment?
- 8 Is there a risk of side effects and, if so, how do I manage these?
- 9 If I experience any side effects, when should I contact the hospital?
- 10 How long can side effects last?
- 11 What is known about late side effects?
- 12 Will the treatment affect my physical abilities?
- 13 What can I eat and drink – am I able to drink alcohol?
- 14 How likely is it that this treatment will work for me?
- 15 When will I know if my treatment is/isn't working?
- 16 What signs or symptoms should I look for that might mean that my DLBCL has returned?
- 17 Will I need a caregiver to help me during the treatment?



## ● My DLBCL treatment

You will have already received treatment for DLBCL, so you will be aware of some of the therapies available to you, such as chemotherapy, targeted therapy, stem-cell transplants or CAR-T therapy.

If you require further treatment for your DLBCL, it is best to talk to your health care team about this and the options available to you.

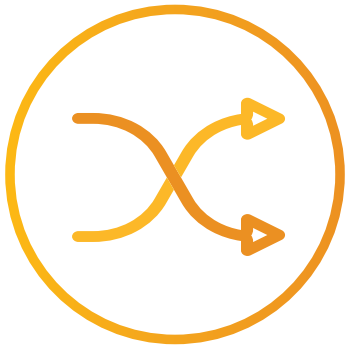
These may include:\*



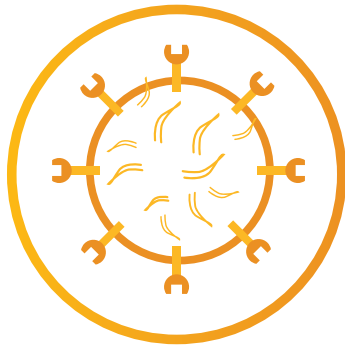
Chemotherapy



Targeted therapy



Stem-cell transplant



CAR-T



\* There are several treatments that may be available to you. This is not an exhaustive list of treatments and not all these treatments may be available to you. Your healthcare team will discuss the best options in your circumstances.

## ● My DLBCL discussion guide

Once you have started your new treatment, you might want to reflect on how you are coping and how it's making you feel.

### 1 Living with DLBCL

Living with DLBCL might affect your wellbeing and how you cope with everyday activities.

Use the scales below to rate how DLBCL affects your day-to-day life.

#### Coping with DLBCL symptoms

- How do your continued DLBCL symptoms impact your daily life (including pain, tiredness, weight loss, etc.)?



#### Feeling on top of things

- Do you feel able to carry out everyday tasks like washing yourself, getting dressed, cooking, doing household chores and shopping?



#### Emotional wellbeing

- Do you feel positive (in control of your thoughts and feelings) or negative (anxious, upset or worried)?



#### Pursuing hobbies

- Do you feel you are able to pursue the activities you enjoy doing?



#### Spending time with friends and family

- Do you feel you can spend time with or care for friends and family in the way you want to?



#### Taking part in exercise

- Do you feel you are able to take part in physical exercise and if so, do you enjoy this?



### 2 My DLBCL treatment

To help you to live your life the way you want to, it is important to speak to your care team about how your treatment makes you feel. Use the scales below to rate how you feel about your DLBCL treatment.

How well do you feel your treatment helps you to manage your DLBCL symptoms (including fatigue, weight loss, pain etc.)?



How do you feel during and after your treatment? Have you experienced any side effects?



How do you feel about how frequently you have to receive treatment?



How do you feel about the number of check-ups needed to monitor your treatment?



How do you find the treatment administration?



How easy is it for you to fit your treatment schedule into your lifestyle?



Do you feel your treatment regimen is convenient for you to access?



Are you satisfied with how long it takes you to travel to the treatment centre?



Overall, how satisfied do you feel with your treatment and/or care?



Discuss your answers to these questions with your health care team at your clinic visits.



You might still have lots of questions about adjusting to your new routine and continuing to live with DLBCL.

Use the space provided on these pages to make a note of some of your questions to ask your health care team. Also, try to capture and express some of your own thoughts and feelings:



## ● Commonly used terms

**Advanced:** Describes cancer that has spread from where it started to other tissues of the body.

**Biomarker:** A molecule found in blood, body fluids, or tissues that may be used as a sign of a normal bodily process, or of a disease. Biomarkers may be used to see how well a person is responding to treatment.

**Biopsy:** The removal of cells or tissues from the body to be examined by healthcare professionals.

**B-cell:** A type of white blood cell in your immune system that produces antibodies to help fight infections.

**Bone marrow:** Soft, spongy tissue found in the centre of most bones that contains stem cells.

**CAR-T:** An abbreviation for "chimeric antigen receptor T-cell" therapy. A type of cancer treatment in which a type of immune cells called T cells are taken from a patient's blood and modified in the laboratory so they will attack cancer cells.

**Chemotherapy:** These drugs treat cancer by killing rapidly dividing cells throughout the body or by stopping them from dividing. Chemotherapy can be given alone or in combination with other treatment options. It may be given orally, by injection under the skin, or intravenously and can affect both normal and cancer cells.

**Complete response (CR):** The disappearance of all detectable signs of cancer in response to treatment. This does not always mean the cancer has been cured.

**Computed tomography (CT) scan:** A CT scan is a medical imaging technique used to obtain detailed internal images of the body.

**DLBCL:** An abbreviation for "diffuse large B-cell lymphoma." You may also hear DLBCL called: Non-Hodgkin Lymphoma, B-cell lymphoma or just lymphoma.

**Infusion:** A method of administering fluids, including medications, directly into the bloodstream. This may also be called "intravenous infusion."

**Non-Hodgkin lymphoma (NHL):** A large group of different types of cancers that affect white blood cells. There are many different types of NHL; some are fast growing, while others are slow growing. DLBCL is one type of NHL.

**Partial response (PR):** A decrease in the size of a tumour or the extent of cancer in response to treatment.

**Positron emission tomography (PET) scan:** PET is an imaging technique used to evaluate organs and/or tissues for the presence of disease or other conditions.

**Refractory:** Describes cancer that does not respond to treatment. The cancer may not respond to treatment from the start, or may stop responding during treatment.

**Relapse:** This occurs when cancer returns after a period of improvement following treatment.

**R/R:** An abbreviation that stands for "relapsed or refractory." For example, "R/R DLBCL" means "relapsed or refractory diffuse large B-cell lymphoma."

**Stem cell:** A type of cell from which other cells grow. For example, various types of blood cells grow from blood stem cells.

**Stem-cell transplant:** A procedure in which a person receives healthy blood stem cells to replace their own stem cells that have been destroyed by cancer treatments. The healthy stem cells may be taken from the person before treatment, or taken from another person altogether.

**Targeted therapy:** A type of cancer treatment that helps blocks the growth and spread of cancer by interfering with specific molecular targets on cancer cells. These treatments can affect both normal and cancer cells.

**White blood cell:** A type of blood cell made in the bone marrow and found in the blood and lymph tissue. White blood cells are part of the body's immune system and help fight infections and other disease.



## ● Additional support resources

Listed here are some patient organisations and websites that may provide helpful information about DLBCL and could help you locate national support groups.

Remember to discuss any information you find here with your healthcare team. They are the best source of information about your DLBCL treatment plan.

- **Lymphoma Coalition**  
<https://lymphomacoalition.org/>
- **Lymphoma Coalition Europe**  
<https://lymphomacoalition.org/europe/>
- **Lymphoma action – close Facebook support groups**  
<https://lymphoma-action.org.uk/index.php/facebook-support-group>
- **Cancer Research UK – Cancer Chat**  
<https://cancerchat.cancerresearchuk.org/search?q=later%20line%20dlbcl>
- **Blood Cancer UK – UK online community forum**  
<https://forum.bloodcancer.org.uk/>
- **Macmillan Cancer Support – Online Community**  
<https://community.macmillan.org.uk/>
- **DLBCL Support Source (US residents only) – Facebook group and support resources**  
<https://www.dlbclsupportsource.com/understanding-dlbcl-cancer>
- **Cancer Hope Network – Peer and caregiver support groups**  
<https://cancerhopenetwork.org/patient-and-caregiver-support/>
- **Cancer Support Community – US online community forum**  
<https://www.cancersupportcommunity.org/mylifeline>
- **The Patient Story – Read about other patient stories and share your own experiences**  
<https://thepatientstory.com/share-your-story/>
- **HealthTree Foundation Connect for diffuse large B-cell lymphoma – Online patient and caregiver community**  
<https://healthtree.org/dlbcl/connect/my-feed>
- **HealthTree Foundation MOVES – online goal and challenge community for those with DLBCL**  
<https://healthtree.org/moves>

