

Not an actual patient.



Diffuse Large B-cell Lymphoma (DLBCL)

Your guide to this condition and helping determine your next steps forward

Remember that your healthcare team is the single best source of medical advice regarding your health. Please consult your healthcare team if you have any questions about your condition.

See [page 9](#) for a list of questions you may want to ask your healthcare team.

Your Journey Starts Here

Whether it is a first diagnosis, the disease has returned, or it has not responded to treatment, learning that you or a loved one has DLBCL can be overwhelming.

This guide provides some basic information about the disease, potential management approaches, and questions you may want to ask your or your loved one's healthcare team to help you understand the next steps in your journey.

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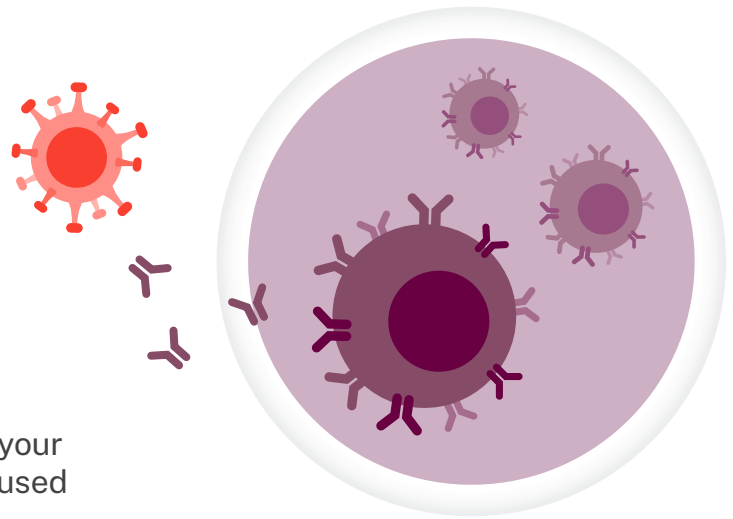
Understanding DLBCL

What is DLBCL?

Diffuse large B-cell lymphoma (DLBCL) is a fast-growing cancer that affects white blood cells known as B cells. Normally, B cells help your immune system defend against infections caused by bacteria or viruses.

However, in DLBCL, abnormal B cells become cancerous. This means that they multiply uncontrollably and live longer than normal cells.

DLBCL is the most common type of *non-Hodgkin lymphoma*, making up about 30% of all lymphomas.



~30%

of all lymphomas
are DLBCL

Who is affected by DLBCL?

Having certain characteristics may put you at higher risk for DLBCL:



Age

DLBCL is most frequently diagnosed between 65–74 years of age.

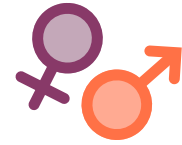


Medical History

Conditions that weaken your immune system may increase your risk for DLBCL.

Examples include:

- HIV/AIDS
- Autoimmune diseases like rheumatoid arthritis or psoriasis
- Human T-lymphotropic virus type I or Epstein-Barr virus infection
- Bacterial infections like *Helicobacter pylori*
- Inherited immune disorders



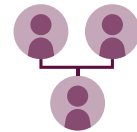
Gender

Men are ~1.5 times more likely than women to develop DLBCL.



Medications

Medications that suppress the immune system, such as those given after an organ transplant, may also increase your risk for DLBCL.



Family History

In a large population-based database study that evaluated 8974 relatives of 2517 people with DLBCL, children and siblings of people with DLBCL were at increased likelihood to develop DLBCL themselves.

What are the symptoms of DLBCL?

The first sign of lymphoma like DLBCL is often an enlarged **lymph node** in the neck, underarm, or groin. Other common symptoms may include:



Fever for no known reason



Pain in the chest, abdomen, or bones for no known reason



Feeling very tired



Weight loss for no known reason



Skin rash or itchy skin



Drenching night sweats

Relapsed/Refractory DLBCL

What do “relapsed” and “refractory” mean?



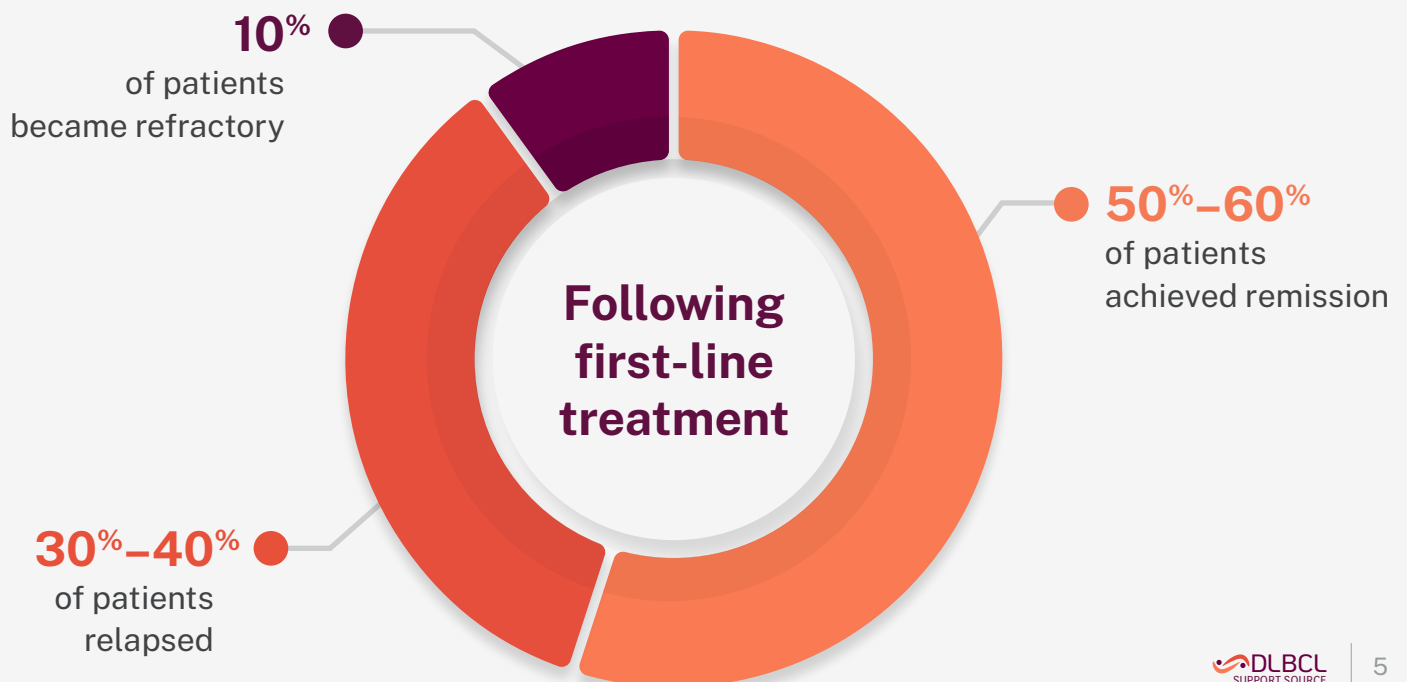
Relapsed DLBCL means that the disease, or the signs and symptoms of the disease, has returned following at least one previous treatment. This means that after a period of showing fewer symptoms, your DLBCL has returned.



Refractory DLBCL means that the disease did not respond to previous treatment.

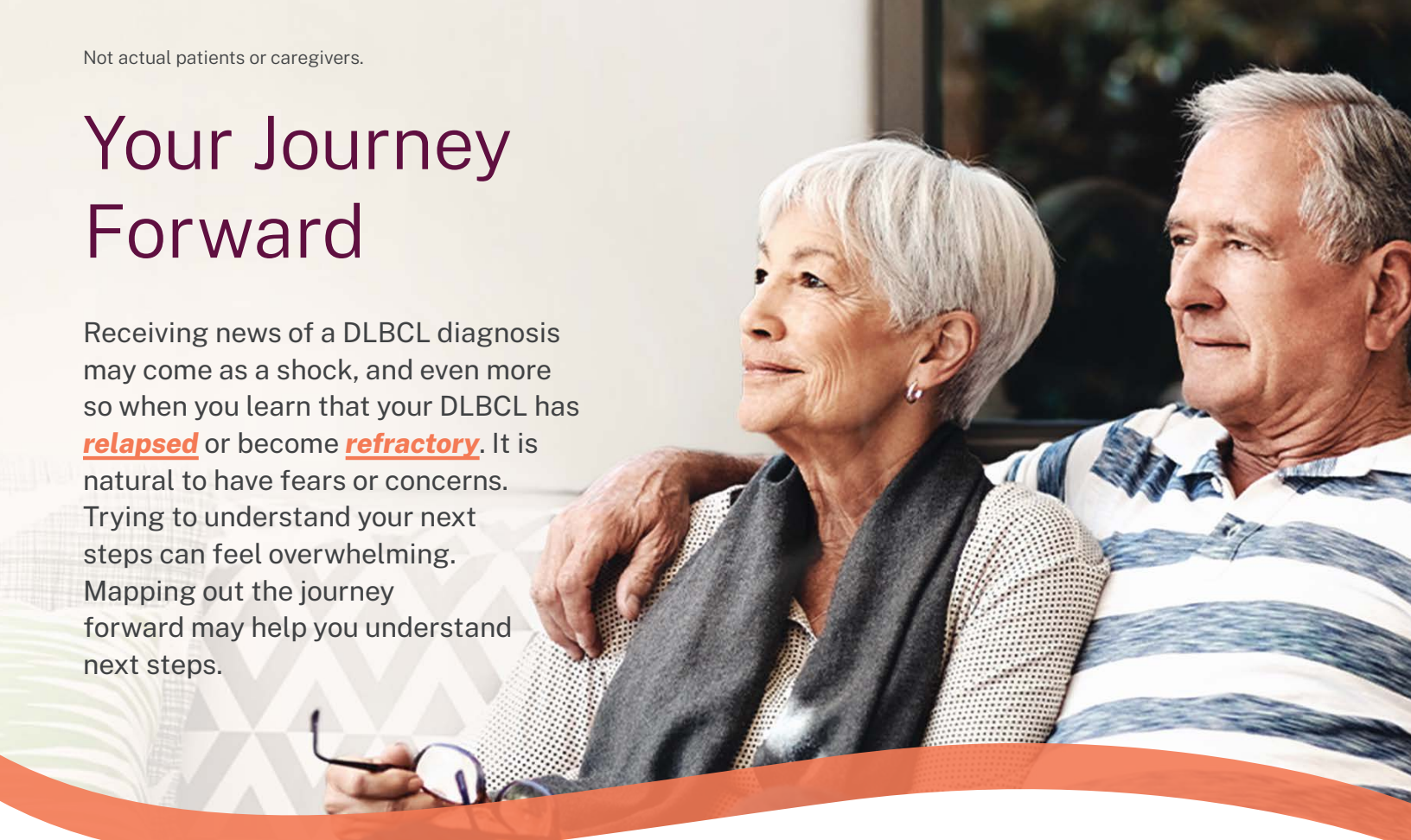
How common is relapsed or refractory DLBCL?

If you have experienced relapsed or refractory DLBCL, you are not alone. Overall, approximately 30% to 40% of people diagnosed with DLBCL experience a relapse, while about 10% of patients experience refractory DLBCL.



Your Journey Forward

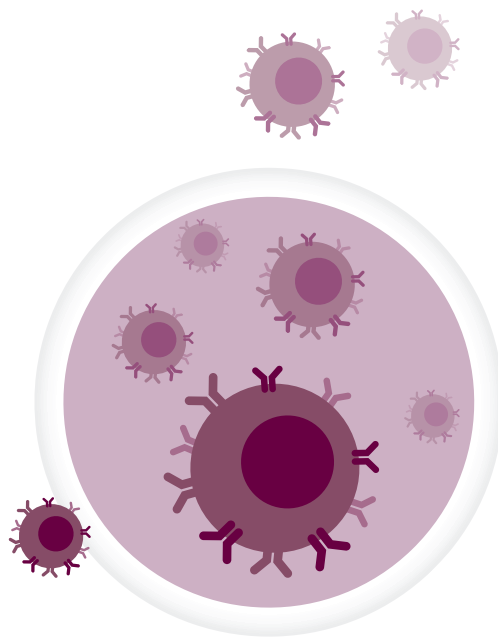
Receiving news of a DLBCL diagnosis may come as a shock, and even more so when you learn that your DLBCL has **relapsed** or become **refractory**. It is natural to have fears or concerns. Trying to understand your next steps can feel overwhelming. Mapping out the journey forward may help you understand next steps.



Learning about your diagnosis

You've received the news that your DLBCL has returned or has not responded to treatment. Now is the time to discuss next steps with your healthcare team, including potential treatment options.

You can learn more about relapsed and refractory DLBCL on [page 5](#).



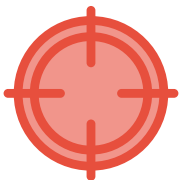
Understanding your treatment options

There are different treatment approaches available to people who have relapsed or refractory DLBCL. These may include:



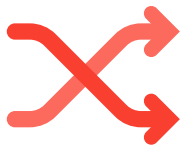
Chemotherapy

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.



Targeted therapy

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



Stem-cell transplant

All blood cells are formed from special cells called blood stem cells, which can be damaged or destroyed by radiation or high-dose chemotherapy. A stem-cell transplant replaces damaged or destroyed cells with healthy 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.

Some treatments may be given alone, while others may be given in combination with other types of treatments. You and your healthcare team will decide which treatment approach best suits your individual needs moving forward.

Receiving treatment

Once you and your healthcare team have decided on a treatment approach, it's time to prepare for treatment. You will learn how your treatment is given, and how often you will need to receive it.

Some treatments may require you to visit an infusion center or healthcare professional's office, while others may be taken at home. In addition, you may also receive regular blood tests to monitor how well treatment is working.



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Moving forward

As you adjust to your new routine, living with DLBCL and receiving treatment, you will likely have questions or concerns. Don't hesitate to contact your healthcare team; they are the best source of information about your DLBCL.

You can find a list of questions on [page 9](#) that you may want to ask your healthcare team.

Asking the Right Questions

Finding out that you have DLBCL or that your DLBCL has relapsed or has not responded to treatment can easily catch you off guard. You may feel overwhelmed, confused, or uncertain about what your next steps should be.

Remember, your healthcare team is the best source of information about your disease and how to move forward. Here you will find a list of questions you may want to ask your healthcare team at different stages to help you make informed decisions.

At first diagnosis

| How advanced is my DLBCL?

| What is my prognosis (probable course and outcome of my disease, chances of recovery)?

| What are my treatment options? Which option would you recommend?

| Will I need to travel to a treatment center for my treatment? If so, how often?

| How likely is it that my DLBCL will respond to treatment?

| What possible side effects should I expect?

| What do we do if my DLBCL returns after treatment or does not respond to treatment?

When DLBCL first relapses or becomes refractory

| Why did my DLBCL return?

| How advanced is my DLBCL?

| Has it spread to other parts of my body?

| What is my prognosis (probable course and outcome of my disease, chances of recovery)?

| What are my treatment options? Which option would you recommend?

| How is this treatment different from my previous treatment?

| Is this treatment chemotherapy? If so, are there any different treatment approaches available?

When beginning treatment

| What is the name of my treatment?

What type of treatment is it? (Read more about treatment approaches for DLBCL on [page 7.](#))

How does this treatment work?

How is this treatment given and how often will I receive it?

If my treatment is given intravenously, how long will each infusion session take?

If my treatment is given intravenously, what will I need to do to prepare for my infusion?

What possible side effects should I be aware of while on treatment?

How will this treatment affect me physically?

How much will this treatment cost? Does my insurance cover it?

Personal considerations

If I need to travel, how will I get to my treatment?

Which family members and friends should I notify?

Who can I ask for assistance with daily activities if needed?

Are there any local or online support groups available to me?

Preparing for the future

How likely is it that my DLBCL will return again or that treatment won't work this time?

What options are available to me if my DLBCL returns again or treatment doesn't work?

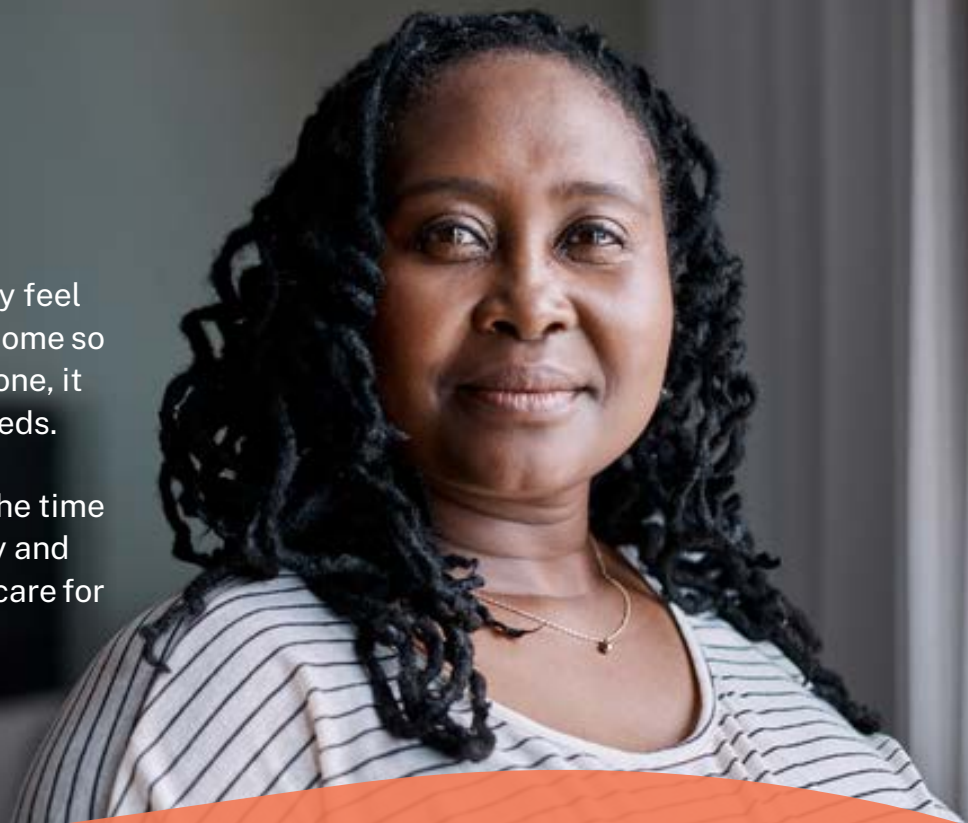
What signs or symptoms should I look for that might mean that my DLBCL has returned?

Notes

Support for Caregivers

Caring for someone with DLBCL may feel overwhelming at times. You may become so focused on the needs of your loved one, it may be easy to neglect your own needs.

It's important to remember to take the time to care for yourself—both physically and emotionally—so that you can better care for your loved one.



Communicating with your loved one

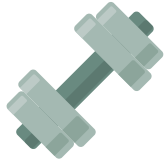
If you have trouble talking to your loved one about their cancer, you are not alone. It can be hard knowing what to say to someone with cancer. The most important thing is to listen. It's important to try to hear and understand how your loved one feels without judging. Let them know that you are open to talking whenever they are ready, even if they don't feel like it at the moment.

Create a support system

Remember, you are not alone. It's OK to ask for help. Family and friends may be willing to take on certain tasks to help ease your burden, so don't be afraid to ask. Local or online caregiver support groups may also be a source of support. Talking with other caregivers who can relate to your situation can help ease loneliness, and may even be a source of additional helpful ideas. To help you cope as a caregiver, be sure to discuss any medical or disease-related information with your loved one's healthcare team. Remember that each patient's journey may be different.

Your physical health is important

Here are a few tips to help you better care for yourself physically:



Be sure to get enough exercise. In addition to helping you improve your health, exercise may also help reduce stress and anxiety.



Eat well-balanced meals to get the nutrition your body needs.



Try to get enough sleep at night, and take time to rest during the day.



Seek proper medical care for yourself by seeing your own primary care provider.

Remember to always ask your physician or healthcare provider before starting any new exercise or diet program.

Remember to take a break

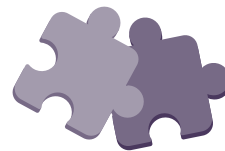
It's important to remember to take time for yourself. However, depending on your loved one's situation, it may not always be possible to take a full day off. But even taking 30 minutes a day for yourself can be a big help.



Take a few minutes here and there to try deep breathing techniques or listen to relaxing music.



Take a short walk around the block.



Participate in a favorite hobby or activity.



Don't be afraid to ask for help. Take family and friends upon offers to help.

Remember to always ask your physician or healthcare provider before starting any new exercise program.

Help your loved one maintain a feeling of independence

You may not need to take care of everything for your loved one. Encourage them to perform normal daily activities such as cooking meals or paying bills if they are able to do so. This may help your loved one maintain their sense of independence and feel better about receiving care from others.



Not actual patients or caregivers.



Are you looking for additional caregiver support?

The American Cancer Society and Leukemia & Lymphoma Society offer online resources to help support caregivers.

Additional Support Resources

The patient organizations and websites listed here provide helpful information about DLBCL and may help you locate national support groups.

Remember to discuss any information you find here with your healthcare team. Your healthcare team is the best source of information about your DLBCL.

American Cancer Society

[cancer.org](https://www.cancer.org)

1-800-227-2345

Cancer Care

[cancercaresupport.org](https://www.cancercaresupport.org)

1-800-813-HOPE (1-800-813-4673)

Cancer Support Community

[cancersupportcommunity.org](https://www.cancersupportcommunity.org)

1-888-793-WELL (1-888-793-9355)

COA Patient Advocacy Network

[coaadvocacy.org](https://www.coaadvocacy.org)

1-202-729-8147

Leukemia & Lymphoma Society

[lls.org](https://www.lls.org)

1-800-955-4572

Lymphoma Research Foundation

[lymphoma.org/DLBCL](https://www.lymphoma.org/DLBCL)

1-800-500-9976

Medline Plus

[medlineplus.gov](https://www.nlm.nih.gov/medlineplus)

National Coalition for Cancer Survivorship

[canceradvocacy.org](https://www.canceradvocacy.org)

1-877-NCCS-YES (1-877-622-7937)

National Comprehensive Cancer Network Foundation

[nccn.org/patients](https://www.nccn.org/patients)

215-690-0300

NIH/National Cancer Institute

[cancer.gov](https://www.cancer.gov)

1-800-4-CANCER (1-800-422-6237)

Patient Empowerment Network

[powerfulpatients.org](https://www.powerfulpatients.org)

MorphoSys and Incyte are not affiliated with these organizations but may have provided funding for some of their educational programs. This is not a complete list of organizations within the DLBCL community. The organizations listed are independent groups whose names are provided as a service and should not be considered an endorsement.

Commonly Used Terms

During your journey, you will likely come across various abbreviations or scientific terms that may be confusing. Here you will find an explanation of some of these terms. Please ask your healthcare team if you have any questions regarding these terms and definitions.

Advanced:

Describes cancer that has spread from where it started to other nearby tissues or distant parts of the body.

Biomarker:

A molecule found in blood, other body fluids, or tissues that may be used as a sign of a normal or abnormal bodily process, or of a disease. Biomarkers may be used to see how well a person is responding to treatment. This may also be called a “molecular marker” or “signature molecule.”

Biopsy:

The removal of cells or tissues from the body to be examined by healthcare professionals. There are different types of biopsy procedures and they can involve the removal of solid tissues or fluids using surgery or needles.

B lymphocyte:

Also called B cell. This is 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 center 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 blood count (CBC):

A blood test that measures the number of red blood cells, white blood cells, and platelets in the blood. The amount of hemoglobin (a protein in red blood cells that carries oxygen) and hematocrit (the amount of whole blood made up by red blood cells) is also measured.

Complete response:

The disappearance of all detectable signs of cancer in response to treatment. This does not always mean the cancer has been cured.

Core needle biopsy:

A type of biopsy in which a sample of tissue is removed from the body with a wide needle for examination under a microscope.

Disease-free survival:

A measurement of the length of time after cancer treatment ends that a person lives without any signs or symptoms of that cancer. In clinical trials, disease-free survival may be used to measure how well a treatment is working.

DLBCL:

An abbreviation for “diffuse large B-cell lymphoma.”

Fine needle aspiration:

A type of biopsy in which a thin needle is used to remove fluid and cells from the body for examination under a microscope.

Hematocrit:

A measurement of the amount of whole blood that is made up of red blood cells. The measurement depends on the amount and size of the red blood cells in the blood.

Hemoglobin:

A protein inside red blood cells that carries oxygen from the lungs to tissues throughout the body and carries carbon dioxide from those tissues back to the lungs.

Infusion

A method of administering fluids, including medications, directly into the bloodstream. This may also be called “intravenous infusion.”

Lymph node:

A small structure that is part of the immune system. Lymph nodes contain white blood cells, also called lymphocytes, that help the body fight infections. There are hundreds of lymphocytes located throughout the body connected to each other by lymph vessels.

Lymphoma:

A type of cancer that begins in the cells of the immune system. There are many types of lymphomas that are classified into two groups: Hodgkin lymphoma and non-Hodgkin lymphomas. DLBCL is a type of non-Hodgkin lymphoma.

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.

Overall response rate (ORR):

A measure used in clinical studies to see how well a treatment may be working. Overall response rate includes the percentage of people in the study who have a complete response or partial response to treatment.

Overall survival (OS):

A measurement of the length of time beginning at diagnosis or start of treatment that people diagnosed with cancer are still alive. In clinical trials, overall survival may be used as a measurement to see how well a treatment works.

Partial response (PR):

A decrease in the size of a tumor or the extent of cancer in the body in response to treatment.

Platelet:

A tiny piece of a cell found in the blood and spleen that helps to form clots to help wounds heal by slowing or stopping bleeding. Platelets are produced by very large cells called megakaryocytes which are found in the bone marrow.

Progression-free survival (PFS):

A measurement of the length of time during and after treatment that a person with cancer lives with the disease without it getting worse. In clinical trials, progression-free survival may be used as a measurement to see how well a treatment is working.

R-CHOP:

An abbreviation for a combination of chemotherapy drugs used to treat DLBCL and other types of non-Hodgkin lymphomas. R-CHOP includes the drugs rituximab, cyclophosphamide, doxorubicin hydrochloride (hydroxydaunorubicin), vincristine sulfate (**Oncovin**), and prednisone.

Red blood cell:

A type of blood cell that contains a protein called hemoglobin. Red blood cells carry oxygen from the lungs to tissues throughout the body.

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.”

Stable disease (SD):

Refers to cancer that is neither decreasing nor increasing in extent or severity.

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 such as radiation or chemotherapy. 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.



Looking for a word or abbreviation that's not on this list?

The National Cancer Institute's online Dictionary of Cancer Terms may help provide the answer you're looking for. You can access it at:

www.cancer.gov/publications/dictionaries/cancer-terms



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