

Diffuse Large B-Cell Lymphoma (DLBCL)

Lymphoma Australia
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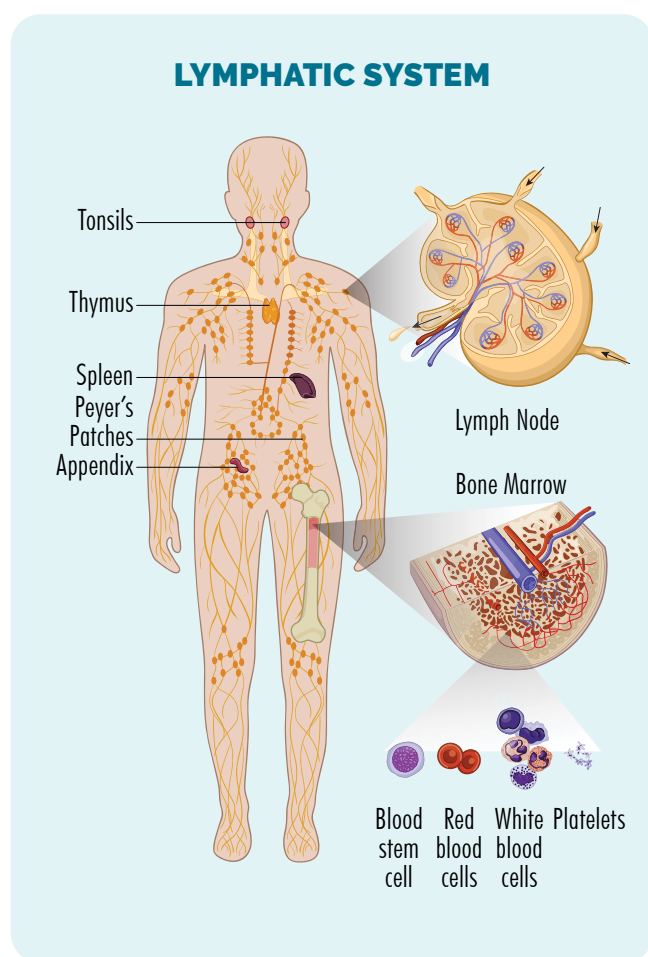
Learning about your lymphoma can be like learning a new language. It takes time and practice. Please keep this document handy so you can refer back to it as often as you need to. **It will become easier to understand the more you read it.**

Introduction

Diffuse Large B-Cell Lymphoma (DLBCL) is a subtype of non-Hodgkin Lymphoma (NHL). If you've been diagnosed with DLBCL, you have a type of fast-growing blood cancer. Fast growing cancers are sometimes called "aggressive". But, even though this is an aggressive blood cancer, it usually responds well to treatment, and many people may even be cured with the right treatment.

DLBCL affects a type of white blood cells called B-cell lymphocytes (B-cells). These cells are made in your bone marrow (the spongy middle part of your bones), before moving into your lymphatic system. They usually live in your lymph nodes or your spleen, and can also be found in your blood.

B-cells fight infection and diseases to keep you healthy. They remember infections you had in the past, so if you get the same infection again, your immune system can fight it more effectively. If you have an infection, some of your B-cells move out of your spleen and lymph nodes,



through the lymphatic system and to the area where your infection is. This means B-cells can be found in any part of your body. When these cells don't grow or

work properly, you can be diagnosed with lymphoma. You will have cancerous B-cells called lymphoma cells.

There are more than 80 different subtypes of lymphoma, and DLBCL is the most common. About three out of every ten people (30%) diagnosed with lymphoma will have DLBCL. It can affect people of all ages including children, but is most common in people over the age 60 years.

Signs & Symptoms

Because this is a fast-growing blood cancer, you may notice a lump that comes up quickly - usually in your neck, armpit or groin. You may even get a lump in your chest or abdomen, but these may be harder to feel. It may or may not be painful, depending on where it is, and if it is putting pressure on any other parts of your body, like nerves or organs. Other symptoms you may have are:

- feeling unusually tired (fatigued)
- feeling out of breath
- bruising or bleeding more easily than usual
- infections that don't go away, or keep coming back (recurrent)
- sweating at night more than usual
- losing weight without trying
- B-symptoms

B-SYMPTOMS

B-symptoms are a group of three distinct symptoms that some people with lymphoma can get. They often occur together and may indicate that your lymphoma is more advanced.

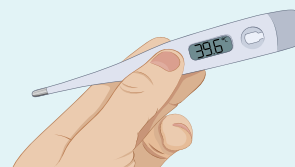
Contact your doctor as soon as possible if you get B-symptoms.



Drenching night sweats
– where your clothes and bedding become saturated.

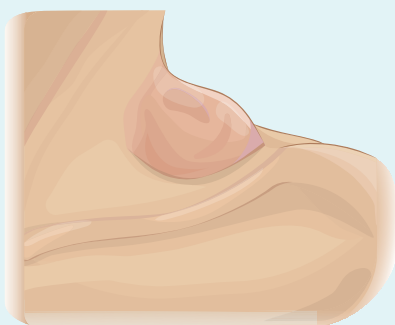


Losing weight without trying,
and without other reason.



A high fever of 37.5° or more that keeps coming back or does not go away even when you don't have an infection. You may even get chills.

LUMP IN NECK



Diagnosis and Staging

If your doctor suspects you may have lymphoma you will need a biopsy. A biopsy is a procedure to remove part, or all of an affected lymph node or a sample of your bone marrow. The biopsy is then checked by scientists in a laboratory to see if there are changes that help the doctor diagnose DLBCL. When you have a biopsy, you may have a local or general anaesthetic. This will depend on what part of your body the biopsy is taken from.

From the biopsy, your doctor will be able to tell you if you have a type of DLBCL called "germinal centre B-cell" (GCB) or "activated B-cell" (ABC). However, whichever one you have, your treatment will likely be the same. Other subtypes of DLBCL include:

- T-cell/Histiocyte Rich B-cell Lymphoma (T/HRBCL)
- EBV-Positive DLBCL not otherwise

specified (NOS)

- ALK-Positive Large B-Cell Lymphoma
- Intravascular Large B-cell Lymphoma
- Primary Central Nervous System Lymphoma (PCNSL)
- Cutaneous (skin) B-cell Lymphoma (CBCL)

These subtypes are grouped depending on where they start, how they look and what viral or protein markers they have. However for each of these, the treatment is usually the same. The exception is PCNSL which requires a different type of treatment. This different treatment is needed so the medication can cross the "blood brain barrier" (BBB) and reach the lymphoma in your brain and spinal cord. For more information on PCNSL please click [here](#).

Your doctor will organise more tests to check if the DLBCL has spread to other parts of your body. These tests are called "staging". Your DLBCL stage will depend on where your lymphoma cells are, and how many there are. You might have Stage 1, 2, 3 or 4.

Staging tests

Staging tests may include:

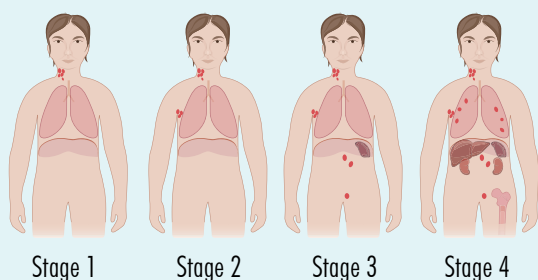
- [Positron Emission Tomography \(PET\) scan](#)
- [Computed Tomography \(CT\) scan](#)
- [Bone Marrow Biopsy](#)
- [Lumbar Puncture](#)

You can find more information on staging tests at our [website](#). Just look down the left-hand side to find the test you want.

Stage I (1) and II (2) lymphoma are considered early-stage lymphomas, meaning that only one or two areas either above OR below your diaphragm have lymphoma. Stage III (3) lymphoma is considered an advanced stage and means that you have lymphoma on both sides of your diaphragm.

Stage IV (4) lymphoma is the most advanced stage, and means you have lymphoma on both sides of your diaphragm, and in one of your organs such as your liver, lungs, brain, bones or bone marrow.

STAGING OF LYMPHOMA



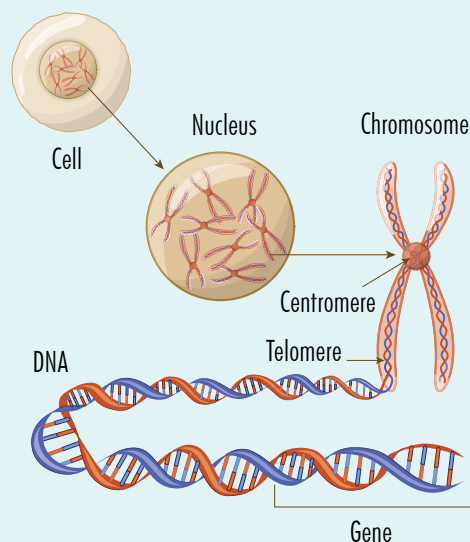
Cytogenetic tests

Cytogenetics are tests on your blood and biopsies that look for changes in your chromosomes or genes. We usually have 23 pairs of chromosomes, and they are numbered according to their size. If you

have DLBCL, your chromosomes may look a little different.

On your chromosomes are many genes that tell the proteins and cells in your body how to look or act. If there is a change (variation) in these chromosomes or genes, your proteins and cells will not work properly.

CYTOGENETICS



The changes to your cytogenetics will not usually impact your treatment. However, if your cytogenetics show you have a mutation in two or three genes (including genes called MYC, BCL2 and/or BCL6), you will be diagnosed with either double or triple hit B-cell lymphoma. Double and triple hit mutations are seen in several aggressive lymphoma subtypes and need to be treated differently than other DLBCL subtypes. If you have been diagnosed with

double or triple hit lymphoma, you can find more information [here](#) or scan the QR code at the end of the document.

As well as the above tests, you may have some extra tests to check how well your body's organs are working, including your lungs, liver and heart. This is done to make sure it is safe for you to have treatment, and as a "baseline" so your doctor can make sure that your treatment does not cause too much damage to them.

Before you start treatment

Before you start treatment you will also need to have some baseline tests done. These can include blood tests to check how well your liver and kidneys are working, scans on your heart, or lung function tests. These are to make sure that you are well enough to have treatment without it causing you to become too unwell. Throughout your treatment you will have regular blood tests which will be compared to these baseline tests. You may also have further lung tests and heart scans to make sure that the treatment has not caused any damage to your organs.

Fertility – some cancer treatments can make it harder to fall pregnant, or to get somebody pregnant. If you (or your child) are planning to have children later in life, talk to your doctor about how to preserve your fertility."

Questions to ask your doctor – Starting treatment can feel overwhelming, and

even knowing what questions to ask can be difficult. To help get you started, we have put together some questions you may like to consider asking. Click [here](#) to download our "Questions to ask your Doctor" or scan the QR code at the end of this document.

Treatment

You will start treatment soon after you are diagnosed. This treatment may have a combination of different medicines, including chemotherapies, and a monoclonal antibody. You may also have radiotherapy.

Radiation/Radiotherapy – Radiation therapy is a cancer treatment that uses high doses of radiation, to kill cancer cells and shrink tumours. Before having radiation, you will have a planning session. This session is important for the radiation therapists to plan how to target the radiation to the lymphoma, and avoid nearby healthy tissue. Radiation therapy is usually given over 3-5 weeks. During this time, you will need to go to the radiation centre everyday (Monday-Friday) for treatment.

If your doctor recommends having radiation treatment you will have radiation every day. If you need help with a place to stay during treatment, please talk to your doctor or nurse about what help is available to you. You can also contact the Cancer Council or Leukemia Foundation in your state to see if they can help with somewhere to stay.

Chemotherapy (chemo) – Chemotherapy are types of medications that kill fast-growing cells. Because they kill fast-growing cells, they can be very effective at treating DLBCL. Unfortunately, chemotherapy cannot tell the difference between healthy cells and lymphoma cells, so you can get unwanted side-effects from chemo. These can include hair loss, a sore mouth, nausea and vomiting, diarrhea or constipation.

Monoclonal Antibody (MAB) – MABs attach to lymphoma cells and attract disease fighting white blood cells and proteins to the cancer. This helps your own immune system to fight the DLBCL.

Targeted therapy – taken as a tablet either at home or in hospital. Targeted therapies attach to the lymphoma cell and block signals it needs to grow and produce more cells. This stops the cancer from growing and causes the lymphoma cells to die off.

Starting treatment

The first time you start treatment it's called first-line treatment. First-line treatment lasts for several months and you will have the medicines at regular times. Each time you have the treatment it is called a "cycle". Once you finish your first-line treatment, you **may be cured and not need treatment again**. For some people though, the DLBCL may come back in the future. If this happens it is called a "relapse".

In other people, DLBCL may not go away with your first-line treatment. If this happens it is called "refractory". This may happen in about 5-7 people out of every 20 (25-35%) receiving treatment for DLBCL. If you have relapsed or refractory DLBCL, you may need a different type of treatment. This new treatment will be called "second line treatment".

First-line treatment

Some of the treatments you may be offered for your first-line treatment include:

- **R-CHOP** – This includes a monoclonal antibody called rituximab (or a medication similar to rituximab called a biosimilar) and 3 different types of chemotherapy called doxorubicin, vincristine and cyclophosphamide. You will also get a steroid called prednisolone and anti-sickness medicines.
- **R-EPOCH** – This includes the same medications as R-CHOP but has an extra chemotherapy called etoposide (This may also include DA-EPOCH-R. The DA in this means dose adjusted so your doctor may adjust the dose to manage your side effects and symptoms better).
- **Methotrexate** – This is chemotherapy, and may be given to you if you have, or are at risk of getting DLBCL in your brain or spinal cord. The doctor will give you a needle in your back (under sterile conditions), and inject the methotrexate

into the fluid surrounding your spinal cord. You may have this with either R-CHOP or R-EPOCH.

- **Radiotherapy**
- **Clinical trial** – These may include targeted therapies and other treatments. Ask your doctor if you are eligible for any clinical trials.

Second-line and subsequent treatment

If you have relapsed or refractory DLBCL, your doctor will want to give you a different type of treatment, which may work better than the first-line treatment you had. These may include:

- A combination of different chemotherapies and/or monoclonal antibodies.
- Chemotherapy followed by a stem-cell transplant.
- Chimeric antigen receptor therapy (CAR T-cell therapy) – Available as third line treatment if relapsed or refractory after second line treatment.
- Clinical trial – These may include targeted therapies and other treatments. Ask your doctor if you are eligible for any clinical trials.

Clinical Trials

Clinical trials are important to find new medicines, or combinations of medicines to improve treatment for people with DLBCL in the future. They may also offer you a chance to try a new medicine, before

it would otherwise be available. If you are interested in participating in a clinical trial, ask your doctor what clinical trials you are eligible for. You can also read our '[Understanding Clinical Trials](#)' to find a clinical trial.

Follow Up

Finishing treatment can be a time of mixed emotions. You may feel relieved and excited, or you may feel worried and scared. You may even alternate between all of these emotions. This is very normal. However, you will not be alone. You will continue to see your specialist team on a regular basis, and be checked for any signs and symptoms of your lymphoma relapsing, and your doctor will also want to make sure you're not having any side effects from your treatment. Your doctor will let you know how often they want to see you, however the longer time you are in remission the less often they will need to see you.

If you have any concerns or worries please contact your healthcare team or contact our lymphoma care nurses on 1800 953 081. You can also email us on nurse@lymphoma.org.au.

Summary

- DLBCL is a type of aggressive blood cancer affecting your B-cell lymphocytes, which fight infection and disease.
- DLBCL is the most common subtype of

lymphoma, however there are different types of DLBCL.

- Many people can be cured, or go into remission from DLBCL, even when diagnosed at stage 4.
- You need to report symptoms, such as B-symptoms, shortness of breath, unusual bleeding or bruising or frequent, infections to your doctor.
- Talk to your doctor about preserving your fertility before you start treatment.
- There are different treatment types, but DLBCL is initially treated with chemotherapy and a monoclonal antibody.
- CAR T-cell therapy is approved for people with DLBCL, but only as a third-line treatment.
- Relapse can happen, but the longer you are in remission, the greater the chance it will not come back.

Resources and support

Lymphoma Australia offers a wide range of resources and support for people living with lymphoma or CLL, and their carers.

How to access our resources:

- **Visit** our website www.lymphoma.org.au for more information.
- **Phone** our Lymphoma Care Nurse Hotline on 1800 953 081.
- **Email** our Lymphoma Care Nurses nurse@lymphoma.org.au
- **Booklet:** Understanding Non-Hodgkin Lymphoma (NHL)

- **Downloadable information:** Visit our [website](#), or give us a call if you would like some more information on a variety of topics related to lymphoma
- **Join** our Facebook page [Lymphoma Down Under](#) (make sure you complete all the membership questions when you join).

Cancer Council offers a range of services, including free counselling, to support people affected by cancer, including patients, families and friends. Services may be different depending on where you live. You can contact them at www.cancer.org.au or by phone on 13 11 20.

Medicare Australia: Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan is funded by Medicare and can provide you with up to 10 sessions with a registered psychologist. More information can be found [here](#).

WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

Canteen provides support for young people aged 12-25 years who have cancer, or, who have a parent with cancer. Find out more at their website here www.canteen.org.au.

Health Translations: A collection of health related information collected by the Victorian Government with resources in different languages. You can visit their website at www.healthtranslations.vic.gov.au.

Useful links

Stem cell transplants



CAR T cell therapy in Australia - an update



Treatments



Questions to ask your doctor



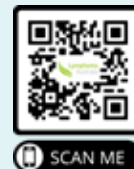
Understanding clinical trials



Double_Triple hit lymphomas



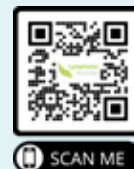
Definitions



eviQ_Lymphoma treatments



Tests, Diagnosis and Staging



Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this document is accurate and up-to-date. However, this information is intended for educational purposes only and does not substitute for medical advice. If you have any concerns about your health or wellbeing, please contact your treating team.

Notes
