

# Follicular Lymphoma (FL)

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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

Follicular Lymphoma (FL) is a subtype of non-Hodgkin Lymphoma (NHL). If you've been diagnosed with FL, you have a type of slow growing blood cancer. This blood cancer affects a type of white blood cells called B-cell lymphocytes (B-cells).

## What do B-cells do

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. When these cells don't grow or work properly, you can be diagnosed with lymphoma. This means you will have cancerous B-cells called lymphoma cells. Lymphoma cells can travel to any part of your body.

## How common is Follicular Lymphoma

There are more than 80 different types of lymphoma, and FL is a fairly common subtype. About one out of every five

people (20%) diagnosed with lymphoma will have FL. It is most common in people over 50 years old. However children, teenagers and young adults can also get FL.

## Symptoms of Follicular Lymphoma

If you have FL, you may not have any symptoms at first. Many people are diagnosed when they have a blood test, scans, or a physical exam for something else. If you do have symptoms, they might include:

- 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
- a new lump in your neck, under your arms, your groin, or other areas of your body (this is caused by lymphoma cells)

gathering in the follicles of your lymph nodes and making it grow larger). These lumps may or may not hurt, depending on where they are located.

- B-symptoms.

### Diagnosis and staging

Your doctor may suspect you have lymphoma when they get your blood test results, X-ray or other scan results, or do a physical exam. But to diagnose FL, you will need a biopsy. A biopsy is a procedure to remove part, or all of an affected lymph node or bone marrow. Your bone marrow is the spongy part inside your bones where your blood cells are made. The biopsy is then checked by scientists in a laboratory to see if there are changes that help the doctor diagnose FL.

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.

If you have FL, your doctor will organise more tests to check if the lymphoma has spread to other parts of your body.

### Staging tests

Staging tests may include:

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

### 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.

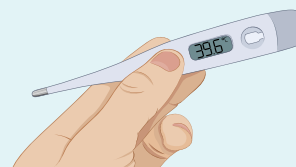
**Contact your doctor as soon as possible if you get B-symptoms.**



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



Losing weight without trying,  
and without other reason.



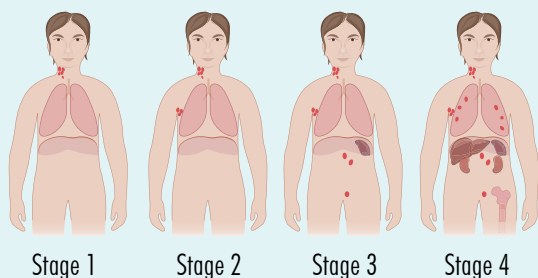
A high fever of 37.5° or more that keeps coming back or does not go away even when you don't have an infection. You may even get chills.

You can find more information on staging tests at our website. Just look down the left-hand side to find the test you want more information on: <https://www.lymphoma.org.au/lymphoma/tests-diagnosis-and-staging/>.

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.

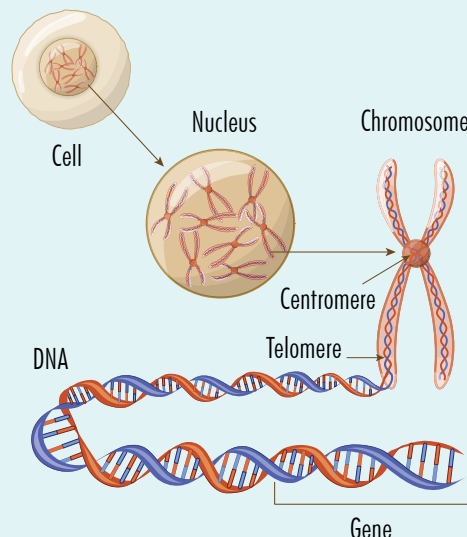
### STAGING OF LYMPHOMA



### Cytogenetic tests

Cytogenetics are tests on your blood and biopsies that look for changes in your

### CYTOGENETICS



The three main changes that can happen with FL are called a deletion, a translocation and a mutation.

### Deletion

A deletion is when part of your chromosome is missing. If you have a deletion of part of the 6<sup>th</sup> chromosome it is called "del(6q)". The "q" tells the doctor it is the lower part of the chromosome that is missing. A "p" means the top part is missing. It is the same for other deletions.

### Translocation

If you have a variation in one of your genes called *BCL2* or *BCL6* it can result in changes to your chromosomes. Sometimes in FL, these genes can be rearranged by the cancer, that causes

a change called a **"translocation"**. A translocation occurs when two different chromosomes swap a part of their chromosome. The two most common chromosomes involved in FL are the 14<sup>th</sup> and 18<sup>th</sup> chromosome. A translocation of these chromosomes is often written as t(14:18).

### Other mutations

If you have a mutation in a gene called EZH2 or a del(6q), it may mean one of your proteins called sestrin cannot work properly. Sestrin gives instruction to mTOR. mTOR is like a switch that tells your cells when to grow and when to stop growing. If you have a mutation affecting sestrin, then it cannot tell mTOR to switch off. This means mTOR is permanently on, so the cancerous cells keep growing. Some clinical trials are looking at medications that target EZH2 and mTOR to help turn off the mTOR switch.

Your doctor will look at your cytogenetics and be able to work out the best treatment for you, based on the changes in your chromosomes and genes. There are other possible variations than the ones explained above. **Please make sure you ask your doctor to explain your individual changes.**

### 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.

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" factsheet or scan the QR code at the end of this document.

### Paediatric (Childhood) type Follicular Lymphoma

Paediatric FL is rare, and mostly affects children. However, adults less than 40 years old can also have paediatric type FL. The difference between paediatric and standard FL is the cytogenetics. Paediatric FL will have a normal BCL2 and BCL6 gene, whereas standard FL will have a

variation in these genes. Depending on which type you have, your doctor will recommend and talk with you about the best treatment option for you.

### Treatment options

Because FL is generally a slow growing cancer, you may have it for years without any signs or symptoms. When you are diagnosed, you still may not need any treatment at all. Some people will only need to see their doctor and have a check-up (including some blood tests or scans) to watch if the lymphoma starts growing more quickly. This is called **'watch and wait'**.

Some patients call this "watch and worry", because it can be uncomfortable not doing anything to fight the cancer. But, watch and wait is a great way to start. It means your own immune system is fighting the cancer and doing a good job keeping it under control. If your immune system is keeping it under control, you will not need extra help to fight the cancer. Extra medicine that can make you feel quite sick or cause long term side effects, are unlikely to help at this point. Research shows there is no benefit starting treatment early, when your type of cancer will not respond. Your health will not be improved, and you will not live longer by starting treatment earlier. If your FL starts to grow more, or you start to get symptoms from your disease, you might start treatment.

If you need treatment, talk to your doctor about having **genetic testing done before you start**. These tests can tell your doctor what treatment might work best for you. There are many choices available to treat FL, and more medicines are being developed and tested in clinical trials. Your doctor will consider several things when making choices about your treatment.

These include:

- your genetic changes
- how fast your lymphoma is growing
- how bad your symptoms are
- your age
- your overall health

Treatments can include:

**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 usually lasts between 2-4 weeks. During this time, you will need to go to the radiation centre everyday (Monday-Friday) for treatment.

**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 actively growing lymphoma. 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)** – Given as an infusion in a cancer clinic or hospital. MABs attach to the lymphoma cell and attract other disease fighting white blood cells and proteins to the cancer so your own immune system can fight the FL.

**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. Once you finish your first-line treatment, you may not need treatment again for weeks, months or even years. Some people will not need treatment again at all.

If your FL gets to a point where you do need treatment again, it is called a "relapse". Treatment after a relapse is called second-line treatment (or third-line etc). But some people may not respond to their first line treatment. If your FL does not respond to the treatment, it is called "refractory" disease. In these cases, you may need to start a different type of treatment. If you have refractory disease,

and start a new treatment, this is also called second-line treatment.

### First-line treatment

If you have stage one or two lymphoma, and need treatment, you may be offered radiation treatment. Some people will only ever need to have one course of radiotherapy, and will not need any other treatment. Some people may have radiation treatment and chemotherapy. This is called chemo-radiation.

If you have stage 3 or 4 FL you may need more treatment. This can be a combination of treatments such as chemotherapy and a monoclonal antibody. You may or may not have this with radiation treatment.

Some of the combination treatments you may be offered are:

- Bendamustine (chemotherapy) and rituximab (or a medication similar to rituximab called a biosimilar) OR obinutuzumab (monoclonal antibody)
- CHOP (chemotherapy – including the chemo medications cyclophosphamide, doxorubicin and vincristine, with a steroid called prednisolone), with a monoclonal antibody - either rituximab (R-CHOP) or obinutuzumab (O-CHOP)
- CVP (chemotherapy – including chemo medications cyclophosphamide, vincristine with a steroid called prednisolone) with a monoclonal antibody either rituximab (R-CVP) or

obinutuzumab (O-CVP)

- Chlorambucil (chemotherapy tablet) and rituximab (monoclonal antibody)
- Once chemotherapy ends, you may be offered "Maintenance treatment". This means you will continue to have treatment with the monoclonal antibody (either rituximab or obinutuzumab) for a further two years.
- You may also be eligible to participate in a clinical trial – Ask your doctor about this.

### Second line treatment

You may not need treatment again, but if you do, your doctor may offer you one of the above treatments or offer you:

- idelalisib (tablet) – idelalisib is a targeted therapy called a P13K kinase inhibitor. It targets proteins that give the lymphoma signals to grow and blocks these signals, preventing further growth and causing lymphoma cells to die off.
- Radiotherapy with or without chemo or monoclonal antibody
- Stem-cell transplant – to learn more about stem cell transplants please see out factsheets
- Transplants in Lymphoma
- Allogeneic stem cell transplants
- Autologous stem cell transplants
- Chimeric antigen receptor therapy (CAR T-cell therapy) – Please see our factsheet for more information on

CAR T-cell therapy. [All factsheets are available on our website](#). If you do not have access to a computer and would like a paper copy, please call us on 1800 359 081 or email us at [enquiries@lymphoma.org.au](mailto:enquiries@lymphoma.org.au)

- You may also be eligible to participate in a clinical trial –ask your doctor about this

Further information on different treatment protocols can be viewed [here](#).

### Clinical trials

Clinical trials are important to find new medicines, or combinations of medicines to improve treatment of FL in the future. They can 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](#)' fact sheet for websites to find a clinical trial. Some treatments being tested for FL in clinical trials include:

- Monoclonal antibodies not previously used in FL
- Immune checkpoint inhibitors (these medications block checkpoints that prevent your immune system from fighting the lymphoma)
- Targeted therapy (these medications target different parts of the lymphoma cell to stop it from growing - including EZH2 and mTOR discussed above)

- New medication that has not been put in a group yet and has not been used in people, or has only been given to very few people
- New techniques for radiation treatment
- Combination treatments including different types of medication

### Transformed Lymphoma

Slow growing lymphomas like FL can sometimes transform into a faster growing lymphoma. If this happens to you, your treatment options will change. To learn more about transformed lymphoma please see our Transformed Lymphoma factsheet.

### Summary

- Follicular Lymphoma is the most common indolent subtype of lymphoma.
- FL is a type of blood cancer affecting B-cell lymphocytes, that fight infection and disease.
- Many people with FL will start on watch and wait, and only have treatment if the FL is actively growing.
- You will be actively monitored by your specialist doctor while you are on watch and wait.
- Talk to your doctor about preserving your fertility before you start any treatment if you plan to have children.
- If you experience B-symptoms or other symptoms you are concerned

about, notify your doctor as soon as possible.

### 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](mailto:nurse@lymphoma.org.au).

### 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](http://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](mailto: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 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](http://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](#).

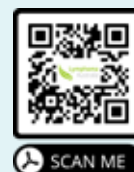
**WeCan** is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at [www.wecan.org.au](http://www.wecan.org.au).

**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](http://www.canteen.org.au).

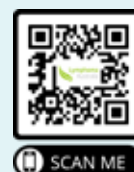
**Health Translations:** A collection of health related information collected by the Victorian Government with resources in different languages. You can visit their website at [www.healthtranslations.vic.gov.au](http://www.healthtranslations.vic.gov.au).

### Useful links

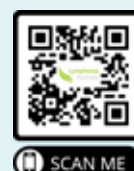
Questions to ask your doctor



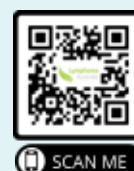
Car T-cell webpage



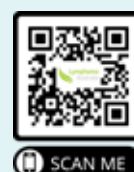
Definitions



Facebook Lymphoma Down under



FL website



### Health Translations



**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.



