

# Understanding Watch and Wait (W&W)

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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.**



## AT A GLANCE: WATCH AND WAIT

- Safe, evidence-based option for slow-growing lymphomas when you have no symptoms or only mild symptoms.
- You are closely monitored with regular check-ups, blood tests, and scans.
- Overall survival is similar whether you start treatment straight away or wait until it is needed.
- About 3 out of 10 people on watch and wait may never need treatment.
- A large Australian study showed no deaths were related to watch and wait.
- Early rituximab may delay the time to next treatment for **some people**, but long-term survival remains similar to those who were on watch and wait.

## What does watch and wait mean?

If you have a slow-growing (also called indolent) lymphoma, watch and wait (W&W) might be the safest and most effective option for you. This means you will not start treatment now, but your medical team will watch your health closely.

You will have regular check-ups with your specialist haematologist or oncologist, and you will have blood tests and may have scans before your appointments. This helps your team check that your lymphoma is stable and that you are staying well and living your best possible quality of life.

“Watch and wait” can sound like nothing is happening, but that is not true. Many doctors prefer to call it active monitoring or active surveillance because they are actively watching for any signs that may show you need to start treatment.

### What subtypes of lymphoma can be managed with W&W?

W&W is usually recommended for people with **indolent lymphomas who have no or very mild symptoms**. These include:

- Follicular Lymphoma (FL)
- Chronic Lymphocytic Leukemia (CLL) or Small Lymphocytic Lymphoma (SLL)
- Marginal Zone Lymphoma (MZL)
- Lymphoplasmacytic Lymphoma (Waldenström's Macroglobulinemia)
- Mantle Cell Lymphoma (MCL) – in rare cases where the disease is behaving in an indolent (slow growing) way.
- Nodular Lymphocyte-Predominant B-cell Lymphoma (Previously called Nodular Lymphocyte-Predominant Hodgkin Lymphoma (NLPHL) – if slow growing and without symptoms.

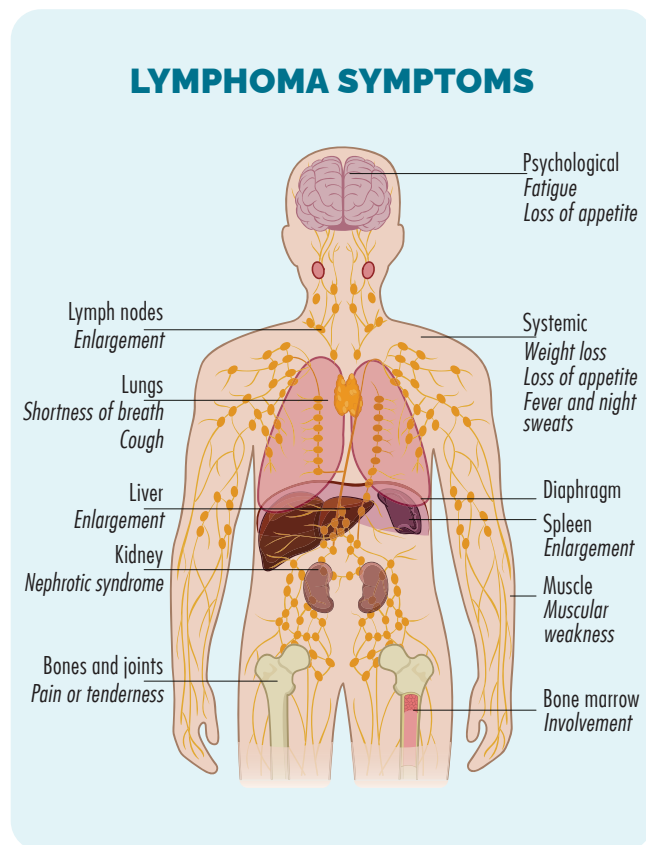
### Monitoring while on W&W

Being on W&W means you are still receiving care. You will have regular appointments with your specialist, blood tests to check your overall health, and may have scans (such as CT or PET scans) to look for changes.

### Symptoms to tell your doctor about

Tell your doctor if you notice any new or worsening symptoms. Symptoms may include:

- fevers
- night sweats,



- weight loss,
- new lumps,
- bruising or bleeding,
- shortness of breath or dizziness,
- repeated infections.

These symptoms **may** mean your lymphoma is becoming more active and you may need treatment.

### Is it better to start treatment straight away?

Not always. If your lymphoma is slow growing and you have no symptoms, research shows it is safe to wait. For many people, this is the best choice.

Long-term studies show that starting treatment early does **not improve** how long people live (overall survival). About 3 out of 10 people with slow-growing lymphoma may never need treatment, even after ten or more years. Starting treatment too early could mean taking on side effects and risks with no real benefit.

### What are the benefits of W&W?

W&W gives you time, freedom, and quality of life. Benefits include:

- No side effects from chemotherapy or other medicine until treatment is truly needed.
- Keeping treatment options available for later – when they are likely to be of more benefit.
- Living months or years free of treatment side-effects - if your lymphoma remains stable.
- Fewer hospital visits and more time for everyday life.
- Not having to remember to take tablets every day.

### Recent studies comparing early treatment to W&W

In the past, lymphoma was treated with chemotherapy, radiotherapy and/or surgery. However, these treatments showed no benefit for people with indolent lymphomas with small tumours and no symptoms.

However, clinical trials have led to the development of newer treatments that work differently. These include:

- Rituximab – a medicine that helps your immune system find and attack lymphoma cells.
- BTK inhibitors (e.g. ibrutinib, acalabrutinib, zanubrutinib) – tablets that block a protein signal inside lymphoma cells.
- Obinutuzumab and Venetoclax – Obinutuzumab works like rituximab, and Venetoclax turns off a “life switch” for lymphoma cells.

These medicines may delay the need for chemo, improve quality of life, and reduce anxiety. They are not yet standard for everyone with indolent lymphoma, and research continues to identify who benefits most.

### Common side effects of newer treatments

If your doctor offers you a choice of starting one of these newer medicines, or being on watch and wait, it can help to know about possible side effects. Not everyone has side effects, and your team will monitor you closely.

#### Rituximab

- May cause mild fever, chills, tiredness, or headache.
- Allergic-type reactions can happen, such as rash, itching, or shortness of breath.

- Can temporarily lower your white blood cell count, which can slightly increase infection risk.
- Vaccinations may work less well while you are on rituximab.

**Important:** Can cause a reaction during the first infusion which may include fever, chills, rash, itching or chest pain. This is more common if you have lots of lymphoma in your body. It is usually easy to manage, and your nurses will be keeping a close watch over you.

### **BTK inhibitors (e.g. ibrutinib, acalabrutinib, zanubrutinib)**

Common effects:

- easy bruising or bleeding,
- diarrhoea,
- muscle or joint aches,
- tiredness,
- headache.

Some people can develop heart rhythm changes or high blood pressure, so regular monitoring is important.

**Important:** May increase bleeding risk, especially if taken with some pain relievers or supplements.

### **Obinutuzumab**

Similar to rituximab – see above

- Often given together with other medicines, so your team will watch for side effects from each.

### **Venetoclax**

Works by switching off the “stay alive” signal in lymphoma cells, which can cause them to break down quickly at the start of treatment.

Because of this, treatment starts slowly with careful blood tests to prevent a rare problem called tumour lysis syndrome, which is when too many cells break down at once.

Other common effects include :

- tiredness,
- nausea,
- diarrhoea, which often improve with time.

**Important:** Your doctor will tailor doses and check blood tests often to keep you safe. Always contact your treating team if you feel unwell, have a fever, or notice unusual bruising or bleeding.

To learn more about side-effects of treatment please visit our website [Side effects of treatment - Lymphoma Australia](#)

**Important:** There is always risk of an allergic reaction to any treatment. This risk is low, but ask your doctor what symptoms and signs you should look out for when starting any new treatment.

### What does the research say?

Large studies help us understand what happens during W&W and how it compares to early treatment.

A study by the Australasian Lymphoma Alliance found that people on W&W had similar overall survival to those treated early. No deaths were related to having started on W&W. About 3 out of 10 people (30%) on W&W did not need any treatment even after 10 years.

Another long-term study compared early treatment with a medicine called rituximab to watch and wait. This study included people with:

- advanced follicular lymphoma **and**
- few or no symptoms **and**
- only small areas of lymphoma in their body.

Some patients did report feeling more in control of their lymphoma when they started treatment early, which helped reduce their anxiety and stress levels. However, overall survival did not change.

About 6 to 7 out of 10 people who had rituximab needed no more treatment for around 15 years. This compared with about 3 to 4 out of 10 people on watch and wait **who didn't need treatment at all during the same timeframe.** People in both groups lived for about the same length of time (or are still living).

The study didn't go into details about side-effects, but some people did stop treatment early and left the clinical trial.

### Questions to ask your specialist

1. Why do you believe watch and wait is the best option for me?
2. Are there safe treatment options I could consider now?
3. How will you decide when it is time to start treatment?
4. What symptoms should I look out for?
5. Who should I contact if I notice any changes?

### Living with W&W

At first, it can feel strange or worrying to know you have lymphoma – a cancer but are not being treated. This is a normal reaction. But W&W is a safe and evidence-based approach for early, symptom-free indolent lymphoma.

#### Comment from patient on Watch & Wait

"I was shocked when my doctor said we would wait... but over time I have realised I am still living a full life, just with extra check-ups."

### When to see your doctor

See your GP or specialist if you notice:

- Loss of appetite or weight loss
- Fevers or night sweats
- New lumps, fatigue, bruising, or repeated infections
- **Always report any new or worsening symptoms.**

Also, ask your GP about a Mental Health Care Plan for counselling through Medicare. This can help you with new strategies to manage the added stress, anxiety or fear of a lymphoma diagnosis, watch and wait, treatment or other concerns you may have.



### Tips for living well

- Eat well and stay active – ask your GP for a referral to a dietitian or exercise physiologist



- [Learn about your subtype](#) – knowledge helps you feel more confident
- Connect with others – join support groups such as [Lymphoma Down Under on Facebook](#).
- Focus on what matters most – spend time doing what you love, let go of unnecessary stress.
- Be kind to yourself – it gets easier over time
- Let others help – family and friends often want to support you

### Key takeaway

Watch and wait is a safe and proven approach for many people with slow-growing lymphoma. It gives you time, freedom, and the right treatment when you need it. Newer treatment options based on recent clinical trials may mean other options may be suitable.

**Ask your doctor about the best options for you.**

### When to see your doctor

See your GP or specialist if you notice:

- Loss of appetite or weight loss
- Fevers or night sweats
- New lumps, ongoing tiredness (fatigue), bruising, or repeated infections
- Always report any new or worsening symptoms.
- Ask your GP about a Mental Health Care Plan for counselling through Medicare

### 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 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](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).

