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.**

What does watch and wait mean?

If you have a slow growing (also called indolent) lymphoma, watch and wait (W&W) may be the best option for you. This means that, while you will not be having treatment for your lymphoma at this point in time, you will be monitored closely.

This treatment option is given when you have an indolent lymphoma and no (or very minor) symptoms of the disease. You will still need to attend the outpatient department for appointments with your specialist haematologist or oncologist. This way your treating team can make sure your disease is stable and that you are not becoming unwell, while still ensuring you have the best quality of life.

Watch and wait is a bit misleading, because it sounds like nothing is happening. Better names for this include "active surveillance" or "active monitoring".

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

If you have any of the following lymphomas and no symptoms, your treating team may suggest W&W for you:

- Follicular Lymphoma (FL).
- Chronic Lymphocytic Leukemia (CLL) or Small Lymphocytic Lymphoma (SLL).
- Marginal Zone Lymphoma (MZL).
- Lymphoplasmacytic Lymphoma – also known as Waldenström's Macroglobulinemia (WM).
- Mantle Cell Lymphoma (MCL) – This is usually an aggressive subtype, but a small number of people with MCL will have an indolent form and may be suitable for W&W.
- Nodular Lymphocyte Proliferative Hodgkin's Lymphoma (NLPHL) – not all people with NLPHL will be offered W&W, but if yours is slow growing and you have no symptoms, it may be an option for you.

Monitoring while on W&W

As mentioned above, being on W&W does not mean nothing is happening. You will still be actively monitored by your treating team. You will be seen regularly by your haematologist or oncologist and have regular blood tests. You may also have scans such as a CT scan or PET scan. This way your team can see if the lymphoma is growing, or if other parts of your body are being affected by the lymphoma. You will also be able to report if you have any symptoms that are worrying you.

If you do start to have symptoms, it may indicate that your lymphoma is starting to grow faster. If this happens, your doctor may consider taking you off W&W and starting you on active treatment.

It is important that you report all symptoms to your treating team. Some of the symptoms you may experience if your lymphoma is growing include:

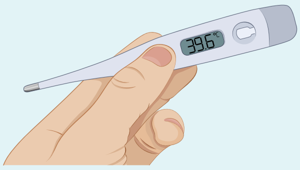
- Fevers that don't go away, or keep coming back.
- Drenching night sweats - where your clothing and bedding become saturated.
- Unexplained weight loss.
- A new lump that has come up quickly.
- Unusual bleeding, bruising or rash.
- Dizziness or shortness of breath.
- Infections that are difficult to get rid of, or keep coming back.
- 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.

But isn't it better to start treatment straight away?

The simple answer to this question is "No". Not if your lymphoma is slow growing and you don't have symptoms.

Clinical trials have shown that there are many more benefits to waiting to start treatment, than there are for starting treatment early for people with these types of lymphoma. There are no long term benefits to patients that start treatment early, compared to those who start on W&W.

Evidence suggests that about 1 out of every 5 people who start on W&W never need treatment for their lymphoma or CLL. This means if everyone starts on treatment straight away, 1 in 5 would have all the risks and side effects of the treatment, when they would otherwise have lived a long and healthy life without it.

> Many people on W&W do eventually need to start active treatment, but some people live their whole life, never needing active treatment for their indolent lymphoma.

What are the benefits of W&W?

Most indolent lymphomas and CLL cannot be cured with any known treatments. They are diseases you will live with for the rest of your life. Waiting to start treatment will not shorten your life, but will improve the quality of your life by minimising hospital visits and side effects. Many people live full and healthy lives while on W&W.

There are many benefits to starting on W&W while still being cared for by a specialist team. Some of these benefits include:

- There are no unwanted side effects from treatments such as chemotherapy until absolutely necessary.
- Effective treatments can be kept in reserve for when your lymphoma is most likely to respond to them and have the most effect.
- Your lymphoma cells will not become resistant to treatments (this can happen when there is an initial response, but then the lymphoma cells create another barrier to stop the treatment from working). Starting treatment during an indolent phase when you have no symptoms may mean treatment will not work as effectively if the lymphoma or CLL becomes more aggressive later.
- Your lymphoma may improve (though not go away) on its own without need for toxic treatments – Indolent lymphomas can go through periods when they are active or sleeping (Treatment works best on actively growing disease).
- You can minimise hospital visits by only needing to go to the specialist outpatient clinic.

- Most people enjoy a good quality of life and respond just as well to treatment later when it is actually needed.

Questions you may like to ask your specialist haematologist or oncologist

- Why do you believe watch and wait is the best option for me?
- Are there any active treatments that would be safe and effective for me right now?
- There are others with my subtype of lymphoma or CLL who are having treatment, why the difference in treatment?
- Will I need to have treatment in the future?
- When and how should I contact you?

Living with W&W

Watch and Wait may cause anxiety or distress at first. It can seem like a passive or even risky approach when you know you have cancer. But it is important to know that W&W is the safest option in early, asymptomatic, indolent lymphoma. New developments in medical technology and clinical trials, mean that this may change, but currently the safest option is to W&W.

It can help to have someone to talk to. Family and friends can be a great support for some people, but there is other support available too. Please talk to your local doctor (also called a general practitioner or GP), or your specialist team about what support is available to you, to help you live well, and cope with your diagnosis of lymphoma or CLL during the W&W.

You can also contact our Lymphoma Care Nurses on 1800 953 081 or nurse@lymphoma.org.au.

Tips on living well while on W&W

There is no known, natural way to cure lymphoma or CLL, or to prevent them from progressing later down the track. We don't know why some people go on to need treatment while others never will. But there are things you can do to improve your quality of life, and prepare your body for any future treatments.

Some things you can do:

- Get yourself fit and healthy – Eat well and exercise regularly. This can help with your mood, activity levels and prepare your body if you do ever need active treatment. If you're not sure how to do this, or want some help, talk to your GP about seeing a dietician, physiotherapist or exercise physiologist to help get you started.
- Learn as much about your lymphoma subtype as possible. This can help you feel more confident when talking to your health care team – knowledge is power.

- Join a support group or social media group (such as Lymphoma Down Under on Facebook), with people who have been through, or are going through lymphoma treatment or W&W.
- Use W&W as an opportunity to think about what is really important to you, to make a list and start doing the things you've always wanted to do.
- Find a healthy way to express or talk about your feelings, write a book, start a journal, paint a picture – or your house, join a club or find a good councillor – whatever works for you.
- Go easy on yourself – it can be difficult to adjust to life, knowing you have a type of cancer and are on W&W. Most people say it gets easier as you get used to the doctors' appointments and continue to feel well.
- Let your family and friends know what you need. Most people want to help, but many don't know how. Letting them know what you need helps you and them.
- Connect with a life coach https://www.lymphoma.org.au/support-for-you/coaching-support-for-you/.

When to see your doctor

You will have regular appointments with your specialist haematologist or oncologist. But it is also a good idea to have a good local GP that you can see in between your specialist appointments. If you don't already have one, please find one. Make sure they are someone you feel comfortable with, and who listens to your concerns. You are never stuck with one doctor. If you feel you are not being listened to, you can ask for a second opinion or find a new doctor. You can then have all your medical records moved to the new doctor so they have your medical history.

There are some signs and symptoms that may suggest your lymphoma or CLL is growing or changing. If you experience any of the following symptoms, please arrange to see your specialist medical team.

- Loss of appetite (not wanting to eat)
- Losing weight without trying
- Fevers that don't go away or keep coming back
- Drenching night sweats – that soak your clothes and bedding
- A new lump or swollen lymph node
- Unexplained tiredness (fatigue)
- Unusual bleeding, bruising or rash
- Infections that don't go away or keep coming back
- Get B-symptoms (see picture on page 2)

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 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.

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.

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