

Understanding Watch and Wait



WHAT DOES WATCH AND WAIT MEAN?

There are some forms of lymphoma that are slow growing and doctors may suggest a plan of 'watch and wait' or actively monitoring (sometimes called active surveillance) rather than giving treatment for lymphoma straight away. It refers to a period of time when you have no treatment but attend for regular check-ups. This type of treatment approach is most often used in people who are diagnosed with indolent (slow-growing) lymphoma and have no symptoms or other risk factors that require immediate treatment.

WHAT TYPES OF LYMPHOMA CAN BE TREATED THIS WAY?

Indolent Lymphomas are the main types of lymphoma that have this approach. These include:

- Follicular Lymphoma
- Chronic Lymphocytic Leukaemia (CLL) / Small Lymphocytic Lymphoma (SLL)
- Marginal Zone Lymphomas
- Lymphoplasmacytic Lymphoma (Waldenström's Macroglobulinaemia)
- Mantle Cell Lymphoma – a small amount of people can have an indolent form

MONITORING ON WATCH AND WAIT

The watch and wait approach does not mean nothing is done - the process is still an active one. People are seen regularly by their doctors and are very closely monitored for signs of disease progression. They sometimes have regular blood tests and occasionally imaging (such as PET/CT scans), but they do not receive treatment for the lymphoma itself unless the disease progresses or symptoms appear.

People need to be observant about the presence of disease symptoms, most notably the presence persistent or recurrent fevers, drenching night sweats and unexplained weight loss of 10 percent or more of your body weight, or a rapidly growing lump in one or more areas of the body, which may indicate that active treatment should begin. Most people may go on to need active treatment for their lymphoma. The average time people are on watch and wait varies so it is impossible to say how

long – it may be months or it may be years. However, some people may never require treatment.

WHAT IS THE EVIDENCE FOR WATCH AND WAIT?

There are clinical trials that have shown, in the long term, watch and wait or active monitoring works just as well, if not better than giving chemotherapy treatment at diagnosis. Studies have demonstrated that the long term results are no different between patients with indolent lymphoma who receive treatment immediately and those who wait until treatment is required for symptomatic disease. Evidence also suggests that up to 1 in 5 patients may never need treatment for their lymphoma.

The benefits are that without treatment:

- You will not experience side effects from treatments such as chemotherapy until absolutely necessary
- Effective treatments can be kept in reserve for you until they are needed
- Indolent lymphoma can go through periods when it is more active and periods when it is stable or even shrinks. In some people, the lymphoma may shrink without any treatment (spontaneous regression)
- The lymphoma cells will not become resistant to treatment
- The only hospital visits needed are to the outpatient clinic for check-ups
- Most people enjoy a good quality of life and respond just as well to treatment when it is really needed

More recently, trials have compared watch and wait with the antibody rituximab – a gentler treatment but not completely without risk. These trials have not as yet shown any long-term benefit for giving treatment with rituximab straightaway in patients with no symptoms. Any short-term benefits, for instance in lessening anxiety and improving quality of life, need to be balanced against the risks of the treatment. Also it is not yet known if chemotherapy with rituximab will work as well when rituximab has already been given so ensuring the patient really needs it at the beginning is essential.

Continued overleaf

LIVING WITH WATCH AND WAIT

Watch and Wait may initially cause distress to some people as it may seem a risky or passive approach to a serious disease. It is important that you stay in touch with your hospital team and attend your clinic appointments.

Between check-ups, you should get in touch with your hospital team if you have new symptoms such as, loss of appetite and weight loss, fevers or sweats, worsening tiredness (fatigue), itching, if you notice one or more of your lymph nodes starting to grow more quickly, or if new lymph nodes start to grow. These symptoms might be due to something else, such as an infection, so your Doctor may suggest you wait a week or so to see if things settle down. Even if these are signs of the lymphoma becoming more active, there is rarely any rush to start treatment in a slow-growing lymphoma.

There is no evidence to suggest that you can do anything yourself to keep your lymphoma at bay. However, as you might need treatment in future, you might want to prepare for this by:

- Getting yourself as healthy as possible
- Learning more about your lymphoma so that you will be able to make an informed choice when you do need treatment (this helps some people but might make others more anxious, so it is fine if you don't want to do this).
- Make sure you understand why watch and wait is recommended. If you have any concerns, talk to your doctor.
- Think of your time without treatment as an opportunity to maximise your quality of life. Use it to do things you enjoy, and to get as fit and healthy as you can.
- Express your feelings - you can do this by talking to family and friends, joining a support group or online forum, or by keeping a journal.
- Although watch and wait can be difficult to adjust to at first, many people find it gets easier as time goes on.

Talking to your doctor, specialist nurse, a psychologist or one of our buddies may help. But if you are finding it very hard to cope with being on watch and wait, do make sure you let your doctor know and ask what can be done to help you.

RESOURCES AND SUPPORT

Lymphoma Australia offers a wide variety of resources and support for people with lymphoma and their carers. Please visit our website www.lymphoma.org.au for further information.

RESOURCES AND SUPPORT

Organisation	How can they help?
Lymphoma Australia	<ul style="list-style-type: none"> • Lymphoma Australia offers a wide variety of resources and support for people with lymphoma or CLL and their carers. Please visit our website www.lymphoma.org.au for further information • "Understanding Watchful Waiting" presentation featuring Prof Judith Trotman, Haematologist. View at Lymphoma Australia YouTube channel: http://bit.ly/2OGYQuq • Lymphoma Nurse Support Line: 1800 953 081 or email: nurse@lymphoma.org.au • Online private Facebook group: Lymphoma Down Under http://bit.ly/2mrPA1k
Cancer Council	<ul style="list-style-type: none"> • Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live. Visit www.cancer.org.au or call 13 11 20
Medicare Australia	<ul style="list-style-type: none"> • Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan can give you up to 10 sessions with a registered psychologist either significantly or completely subsidised by Medicare. For more information visit: http://bit.ly/31ahL36
WeCan	<ul style="list-style-type: none"> • WeCan is an Australian supportive care website to help find the information, resources and support services they may need following a diagnosis of cancer. Visit wecan.org.au

SOME QUESTIONS TO ASK YOUR DOCTOR

- Is this the right treatment for me?
- Can I do anything to help myself while I am on watch & wait?
- Why have I been put on watch and wait when some people with my type of lymphoma have started their treatment straight away?
- Will I definitely need treatment one day?
- When will I start other treatment?