



A PATIENTS GUIDE TO
WATCH & WAIT

AN APPROACH FOR INDOLENT
LYMPHOMAS AND CHRONIC
LYMPHOCYTIC LEUKEMIA (CLL)



LYMPHOMA
CANADA



WHAT IS WATCH & WAIT?

Many people newly diagnosed with certain lymphomas or CLL do not need immediate anti-cancer treatment. These specific “indolent” (slow-growing) lymphomas or CLL, often progress slowly and may not cause any problems for a period of time. Instead, patients will be regularly monitored by their hematologist or oncologist for months or years until the cancer changes and treatment is considered necessary.

This approach is called ‘watch and wait’ or ‘watchful waiting’ or ‘active surveillance’.



Watch - because you will have regular appointments to monitor your symptoms and health.



Wait - because you will not start treatment until you experience signs or symptoms that would indicate your need to start therapy.

This watch and wait approach can also be started again once a patient has been treated for their lymphoma or CLL, where their oncologist will begin to monitor them for a potential return of their cancer. This is also referred to as observation in remission.

Clinical trials have compared watch and wait with giving chemotherapy treatment immediately. Related to disease outcomes and safety, these studies have shown that people who are monitored through this approach do as well or better than those given treatment immediately.

WHAT SUBTYPES OF LYMPHOMA ARE THE WATCH AND WAIT APPROACH RECOMMENDED FOR?

Watch and wait is used as an approach in patients with certain lymphoma subtypes or CLL. There are a number of characteristics that your oncologist will review before recommending if you need treatment or can undergo the watch and wait approach. A major decision factor is the type of lymphoma you have been diagnosed with. There are over 80 lymphoma subtypes, each with their own clinical course. The watch and wait approach is recommended for certain lymphoma subtypes where patients may not be experiencing signs and symptoms that would indicate the need for treatment.

Lymphomas can be categorized into aggressive subtypes or indolent “slow-growing” subtypes. Because the cancer growth rate is generally slower in indolent lymphomas, patients may not experience symptoms at diagnosis. Indolent lymphomas are long-lasting cancers and though they may respond well to treatment, they are largely incurable. Therefore, patients may experience cycles of remission (disease-free) and relapse (return of lymphoma).

The goal of the watch and wait approach in indolent lymphomas is to delay the need to start treatment when treatment will likely not improve your disease outcome; instead, it can lead to harmful or toxic side effects. The watch and wait approach does not mean that there is no treatment option for you or that your doctor is refusing to treat you, but rather that there is no benefit to starting treatment before it is needed. The watch and wait approach is generally not used in aggressive lymphomas which often require treatment right away.

There are several types of indolent lymphomas, some of which include:

- + Follicular lymphoma:** Follicular lymphoma is the most common type of indolent non-Hodgkin lymphomas (NHLs) (20-30%). Follicular lymphoma grows slowly in most cases and causes few symptoms in the early stages. The most common sign of follicular lymphoma is painless swelling in the lymph nodes of the neck, armpit or groin. Sometimes more than one group of nodes is affected. Often treatment is not required until symptoms develop.
- + Lymphoplasmacytic Lymphoma (LPL):** LPL is a rare form of B cell lymphoma, making up 1% to 2% of all NHL cases. Waldenstrom Macroglobulinemia (WM) is a type of LPL where there is an overproduction of a certain type of protein called IgM. Symptoms are not usually obvious in the early stages of the disease and the disease is often found by chance when getting a routine blood test or an examination for another reason.
- + Marginal zone lymphomas:** Marginal zone lymphomas account for approximately 10% of all NHL cases and are categorized into three main groups: mucosa-associated lymphatic tissue lymphoma (MALT), splenic marginal zone lymphoma (SMZL) and nodal marginal zone lymphoma (NMZL). Some marginal zone lymphomas can either be indolent (slow-growing) and can follow the watch and wait approach, while others may be aggressive.
- + Mantle cell lymphoma (can be indolent or aggressive):** Mantle cell lymphoma is rare and may follow an indolent or slow-growing course but usually is an aggressive disease and is treated as an aggressive lymphoma. The most common symptom is a painless swelling in the neck, armpit or groin, caused by enlarged lymph nodes.

- + Chronic lymphocytic leukemia/small lymphocytic leukemia:** Chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL) are really two forms of the same disease. The same kind of cell has become cancerous in both. The difference is where the cancer cells are found. CLL usually progresses slowly. In many cases, it causes few, if any problems in its early stages. Many people have CLL that is slow-growing and they may have stable disease for years with few or no symptoms. Common symptoms include fatigue, swollen lymph nodes or spleen, infections, weight loss and night sweats.
- + Cutaneous T-Cell Lymphoma:** Lymphoma in the skin is known as cutaneous lymphoma. Cutaneous lymphomas can appear as small, raised, red patches on the skin, often on the breasts, buttocks, skin folds and face. Patients often have several years of eczema-like skin conditions before the diagnosis is finally established.
- + Nodular lymphocyte depleted Hodgkin lymphoma (NLPHL):** Nodular lymphocyte predominant HL is rare, affecting 5-10% of patients diagnosed with HL. This subtype is often found in the neck lymph nodes, is usually diagnosed at an early stage, and it is typically not very aggressive (it grows slowly).

If you do not know your lymphoma subtype, ask your doctor for this information and discuss whether the watch and wait approach may be an option for you. To learn more about lymphoma subtypes, visit the Lymphoma Canada website: <https://www.lymphoma.ca/lymphoma-subtype/>.

WHY HAS MY DOCTOR RECOMMENDED THIS APPROACH FOR ME?

Watch and wait is the recommended care for those who are diagnosed with indolent lymphoma or CLL, feel well, have small lymph nodes that are not causing problems or growing rapidly, have acceptable blood tests, and have no significant problems with their liver, kidneys or other organs. Undergoing the watch and wait approach means that your oncologist has reviewed your health status and test results and has confirmed there is no benefit in starting treatment before it is needed. It does not mean that there is no treatment available for your lymphoma or that your doctor does not want to treat you. Being on active monitoring also does not necessarily increase the risk that your lymphoma will transform (change) to a faster-growing or more aggressive type.

The advantages of watch and wait are:

- + You avoid immediate treatment side effects, and maintain a good quality of life;
- + Treatment can be as effective if it is started when symptoms begin or there's evidence of advancing disease. Treating before your lymphoma is causing problems will not make you live longer;
- + Other treatment options may become available when it is eventually time to treat;
- + There is a small chance that the disease will never need treatment, and may even spontaneously go into remission (approximately 5-10% of follicular lymphoma cases on watchful waiting).

The average time people are on watch and wait varies so it is impossible to say how long each patient will be monitored this way – it may be months, or it may even be years. Some patients may never require treatment as their disease remains stable and they have manageable symptoms or do not experience any symptoms.



HOW WILL I KNOW IF I NEED TREATMENT?

During the watch and wait period, you will meet regularly with your oncologist to monitor changes in your disease and overall health. Your appointments will likely be every 3-6 months if your lymphoma is not progressing. At these appointments, your doctor will examine you, do blood tests and may perform other tests like imaging scans. They will also ask how you are feeling and about any symptoms you have. At the time you start the watch and wait program, you should be actively monitoring and recording your symptoms between appointments to share with your healthcare team. If there are any new and/or urgent symptoms, contact your oncologist immediately, however, do not delay accessing emergency medical care as needed for urgent and potentially life-threatening symptoms.

The results of exams and blood tests over time, as well as the signs or symptoms you may be experiencing, will help your doctor determine if you need treatment and the type of treatment you should have.

It is important to understand that a new symptom or change in symptoms does not necessarily mean your lymphoma has gotten worse. Lymph nodes for example can swell for a number of different reasons apart from your lymphoma progressing. Your doctor will determine whether further testing is required.

Treatment is usually only started if you show signs and symptoms of disease progression, which may include:

- + B symptoms:
 - Unintentional weight loss that is more than 10% of body weight in the previous 6 months;
 - Unexplained fevers higher than 38°C for two or more weeks without evidence of infection;
 - Drenching night sweats for more than one month without evidence of infection;
 - Significant fatigue (inability to work or perform usual activities)
- + Progression of the tumour(s) in lymph nodes and/or in the spleen (i.e. enlargement or increased number of infected lymph nodes);
- + Large masses or organ involvement;
- + Changes in blood cell counts over time that do not respond to medication.

There are different signs and symptoms that may indicate your lymphoma or CLL is progressing depending on your lymphoma subtype. For example, Waldenstrom Macroglobulinemia patients may need to additionally monitor for hyperviscosity syndrome (thickening of the blood) which can cause lethargy, headache, disturbance of vision or hearing, abnormal bleeding, or heart or kidney problems. Symptoms can also be very specific. For example, a treatment indication for CLL patients could be a rapid increase in lymphocyte count. Therefore, it is important to discuss with your doctor the signs and symptoms to watch out for specific to your subtype, as well as the tests you will need.

Record the additional symptoms that you need to look out for in the chart on the following page.

ADDITIONAL SYMPTOMS

SIGN OR SYMPTOM	WHEN AND HOW TO REPORT TO HEALTHCARE TEAM

WHY IS IT IMPORTANT TO STAY IN TOUCH?

If you are on watch and wait, it is important that you stay in touch with your oncologist and attend your clinic appointments. Do not skip your doctors' appointments as your doctor uses this valuable time to ask questions and monitor your health for any changes. It is important to remember your upcoming appointments.

You can use the appointment calendar found below to help you remember your upcoming appointments and if you have any upcoming tests or procedures.

APPOINTMENT CALENDAR

DATE	LOCATION AND TYPE OF APPOINTMENT	NOTES FROM APPOINTMENT
<i>Jan. 1, 2022</i>	<i>Hospital; in-person follow-up and blood test</i>	<i>No new changes reported by doctor; waiting for blood test results</i>

Between check-ups, you should contact your oncologist if:

+ you have new symptoms such as:

- loss of appetite and weight loss
- fevers or drenching sweats
- worsening fatigue
- widespread itching, without any skin problems
- abdominal pain or discomfort due to pressure or bloating
- shortness of breath or chronic cough

+ you notice:

- one or more lymph nodes starting to grow more quickly
- new lymph nodes start to swell

These symptoms might be due to something else, such as an infection, so your oncologist may suggest you wait a week or so to see if things settle down. If the symptoms are not related to lymphoma, they may resolve or require other treatment. If they are lymphoma-related, your oncologist will discuss treatment options with you. In all these cases you are now in the “close monitoring” stage because treatment may be required.

It may be helpful to keep a journal of your symptoms to share with your medical team at your appointments. It is important that you discuss with your oncologist the preferred contact method for you to speak with them about the symptom(s) you are experiencing as well as how frequently you should contact them (i.e. phone call, e-mail, upcoming clinic appointment, etc.). You will need to also confirm with your doctor what symptoms are emergency or urgent symptoms that could require you to receive immediate medical care through a hospital. **Please see the symptom tracker at the end of this guide to help track your symptoms.**

WHAT CAN I DO TO HELP MYSELF?

There is no evidence to suggest that you can do anything yourself to keep your lymphoma or CLL from progressing. However, as you might need treatment in the future, you should prepare for this by getting yourself as healthy as possible. This might mean making changes to your lifestyle, such as:

- + Eating a healthy diet and trying to maintain a healthy weight
- + Not smoking
- + Limiting your alcohol intake
- + Doing regular exercise – this will also help with fatigue

If you find the watchful waiting period is causing significant anxiety, you might also want to think about:

- + Reducing your stress and anxiety levels and improving your physical and mental wellbeing such as through meditation techniques, complementary therapy (i.e. massage), and self-help resources;
- + Connecting with others that can relate to your situation, or speaking with a professional support counsellor or psychologist;
- + Finding time for the things you enjoy doing, such as your hobbies, travelling or seeing family and friends ;
- + Consider speaking to your employer about any changes you may need to make to your working hours or responsibilities to focus on you and your health;
- + Continuing to educate yourself about your lymphoma subtype so that you will be able to make an informed choice if and when you do need treatment (treatment options and advancements are improving with increased research).

WATCH & WORRY

The watch and wait approach can be challenging for patients to accept following a diagnosis. The last thing many patients want to do is wait and would prefer to take action. However, it is important to remember that lymphoma is not like other cancers, and this is why the watch and wait approach is unique. With other cancers, treatment often begins shortly after diagnosis (depending on the staging) to improve disease outcomes. However, as indolent lymphomas are slow-growing, it can take months to years for your cancer to progress to the point of needing treatment, and research has shown there is no benefit in beginning treatment earlier than needed. It is preferable to closely monitor your lymphoma instead of receiving unnecessary treatments that could cause potentially toxic side effects.

With other cancers, we have been taught that early detection is important, in order to “catch the cancer at an early stage, in order to have best results of treatment”. For many indolent lymphoma and CLL patients, a common concern is: If we don’t treat this right away, is there a risk that my cancer will spread (and my stage increase), so shouldn’t we treat it before it spreads? Unlike other cancers, the results of treatment of indolent lymphoma and CLL can be just as good, regardless of what stage it has reached when treatment is started.

Living with lymphoma or CLL during the watch and wait approach can cause different emotional responses. Some patients are relieved that they do not need to begin treatment, while others find it difficult to wait for their lymphoma to progress. It is important to discuss your concerns and emotions with your healthcare team so that they can answer the questions you need to feel confident in the decision to proceed with watch and wait. They may also be able to provide you with resources or connect you with support programs that can help you cope emotionally with your diagnosis and throughout the watch and wait approach. There may also be the opportunity to speak with someone who has been through the watch and wait approach themselves that can offer valuable advice and guidance.



QUESTIONS TO ASK YOUR HEALTHCARE TEAM

1

Is watch and wait the best treatment approach for me based on my lymphoma subtype and health status?

2

What will my monitoring schedule look like for the first year, and what tests will be included? Will my monitoring schedule ever change?

3

What signs or symptoms do I need to look for that may indicate that I need to begin treatment?

4

What symptoms do I need to tell the healthcare team about immediately and how do I go about communicating this? When should I seek immediate medical care?

5

What can I do during the watch and wait period to stay healthy and feel well?

6

Where can I learn more about my diagnosis and watch and wait?

TRACK YOUR SYMPTOMS

It is important to track your symptoms throughout your Watch and Wait program. You can do this by keeping a diary or using the written symptom tracker below. Be sure to include as much detail as you can. You can also use Lymphoma Canada's Watch & Wait online tracker that will allow you to track symptoms over time and download and share symptom reports. You can access the tracker through the web or mobile app at www.cllwatchandwait.ca

The following symptom log should be used to track signs and symptoms that arise between check-ups with your oncologist, so you can contact your doctor as soon as they occur. This tracker can also be shared with your medical team at your appointments.

Important Signs/Symptoms to Track:

- + loss of appetite and weight loss
- + fevers or drenching sweats
- + worsening fatigue
- + abdominal pain
- + widespread itching, without any skin problems
- + one or more of your lymph nodes starting to grow more quickly
- + new lymph nodes start to swell

DOCTOR OR HEALTH CARE CONTACT INFORMATION

NAME	PHONE NUMBER OR EMAIL

WHEN AND HOW TO CONTACT YOUR HEALTH CARE TEAM

Blank area for notes or instructions regarding when and how to contact the health care team.

ARE YOU STILL EXPERIENCING THE SYMPTOM?	COMMUNICATION WITH HEALTHCARE TEAM
<i>No, one night only.</i>	<i>Yes, discussed at recent appointment on Jan 6, 2021. Determined non-urgent. Continue to monitor.</i>



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