

Treatment Only When You Need It

Watch and wait (also called active surveillance) involves closely monitoring a patient's condition without beginning any treatment until symptoms appear or change. Some blood cancers can be managed successfully for years using watch and wait as the treatment plan. Other terms for watch and wait include "watchful waiting" and "active monitoring," but all refer to the same disease management strategy.

A patient has two options for treatment: standard of care or a clinical trial. It is important to talk to your healthcare team about the best treatment option.

Watch and wait is the standard of care for patients in the early stages of indolent (slow-growing) or chronic forms of blood cancers, including:

- Chronic lymphocytic leukemia (CLL)/Small lymphocytic lymphoma (SLL)
- Some subtypes of non-Hodgkin lymphoma (NHL)
- Smoldering myeloma, also called asymptomatic myeloma
- Low-risk myelodysplastic syndrome (MDS)

Current research indicates early treatment for some diagnoses is not beneficial and does not improve the patient's quality of life or increase overall survival.

Many patients may remain on watch and wait for years after diagnosis, and some may never need treatment. For example, approximately one in three patients diagnosed with CLL will never require treatment for CLL.¹ Early exposure to treatment also unnecessarily puts patients at risk for short and long-term side effects.

Watch and wait may expand your treatment options. Healthcare professionals are learning more about blood cancers through ongoing research and clinical trials. When treatment becomes necessary, there may be better options available to you than what are available now.

Watch and wait may be the best treatment plan for you. Most patients are able to continue with their normal routine and activities during this time. Through close monitoring with your healthcare team, you will receive treatment when you need it.

¹Source: Shadman M. (2023). Diagnosis and treatment of chronic lymphocytic leukemia: A Review. *JAMA*, 329(11), 918–932. <https://doi.org/10.1001/jama.2023.1946>



WHAT ARE THE BENEFITS OF WATCH AND WAIT?

- Maintain quality of life
- Avoid side effects
- Avoid treatment complications
- Less risk of drug resistance
- Potential access to more treatment options
- Time to find a specialist and establish a relationship with your healthcare team
- Possible financial benefits from not needing to pay for treatment

COPING DURING WATCH AND WAIT

After a cancer diagnosis, it is normal to feel scared, worried, or overwhelmed. You may be anxious to start treatment immediately. Waiting may make you feel uncomfortable. Remember, however, that you may not need or even benefit from immediate treatment. Do not think of watch and wait as doing nothing. Through regular checkups and tests, your healthcare team will closely monitor your health and check for disease progression so you can start treatment as soon as you need it.

Focus on the benefits your treatment plan provides. Try not to let a treatment plan of watch and wait become “watch and worry.” For some patients, anxiety increases as the time for checkups with their hematologist-oncologist comes closer. Over time, many patients on watch and wait become more

comfortable with the process. During watch and wait, you will likely be able to continue with your normal routine and activities. Some patients report feeling fatigued, while others report no symptoms at all.

WHAT HAPPENS DURING WATCH AND WAIT

You will visit your hematologist-oncologist regularly to monitor whether your disease remains stable or starts to progress. Your healthcare team will use blood tests and physical exams to help decide when it is time to start treatment.

Your partnership with your healthcare team is key during watch and wait. If you notice any changes between appointments, alert your healthcare team immediately. Open and ongoing communication will help ensure you receive the best care. Ask who will be the main point of contact on your healthcare team and the best way to reach them, such as email, phone or patient portal.

WHAT ELSE CAN I DO DURING WATCH AND WAIT?

Although you will not receive treatment during watch and wait, there are still things you can do to improve your health and well-being.

- Learn as much as you can about your diagnosis. For more information, visit www.LLS.org/booklets to view all the disease and treatment booklets.
- Find a hematologist-oncologist who specializes in your diagnosis and establish yourself as a patient.
- Do not skip any doctor appointments or tests, even if you are feeling well.
- Continue to see your primary care provider (PCP) and follow all recommended cancer and disease screenings, even those unrelated to the blood cancer diagnosis.
- Maintain health insurance coverage if at all possible.
- Improve your health with nutrition, exercise and other good practices, such as not smoking and cutting back on alcohol. For more information, visit www.LLS.org/booklets to view *Healthy Behaviors*.
- Discuss immunizations with your healthcare team. Stay up-to-date on immunizations with COVID-19 boosters and yearly flu shots.
- Take care of your mental health. Join a support group or connect with a fellow patient following watch and wait to help you work through your feelings and answer questions.

If you notice any changes in your well-being, reach out to your healthcare team. Do not wait until your regular checkup.

Your healthcare team may advise you to begin treatment if you have:

- Lymph nodes that are getting larger in the neck, armpits or groin
- Weakness or feeling tired
- Shortness of breath
- Feeling of fullness from an enlarged spleen or liver
- A relatively rapid increase in the number of lymphocytes in the blood
- Easy bruising or bleeding (caused by low platelet count)
- Worsening anemia (low red blood cell count)
- Frequent infections or illness
- Bone or other organs that have become affected by cancer
- Fevers when there is no infection*
- Heavy night sweats*
- Unexplained weight loss*
- A loss of overall well-being

*These are known as "B symptoms." They require urgent follow-up care.

Questions To Ask Your Healthcare Team

- Is watch and wait the best treatment plan for me?
- What will my monitoring schedule be, and what tests will be included?
- What signs or symptoms will indicate that I need to begin treatment?
- What symptoms do I need to tell the healthcare team about immediately?
- What can I do during the watch and wait period to stay healthy and feel well?
- Where can I learn more about my diagnosis and watch and wait?
- How can I connect with other patients or find a support group?

GET ONE-ON-ONE SUPPORT

The Leukemia & Lymphoma Society's **Information Specialists**, highly trained oncology social workers and nurses, can provide information and support and connect you to our **Clinical Trial Support Center** and **Registered Dietitians**.

- Call **800.955.4572** Mon.-Fri. 9 a.m. to 9 p.m. (ET)
- Visit www.LLS.org/PatientSupport