



Active surveillance is an approach used in chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL) when the cancer is not causing significant health problems or bothersome symptoms and treatment is not yet needed. However, during this time the disease is being very closely monitored by your healthcare team. Other phrases used to describe this approach include “Watch and Wait” or “Active Observation.” While it more commonly refers to the period of time after diagnosis before any treatment is necessary, active surveillance also describes the time period(s) of remission after certain treatments have been completed but ongoing close monitoring is still necessary.

## SHOULDN'T ALL CANCERS BE TREATED RIGHT AWAY?

It depends on the type of cancer. Many individuals with CLL and SLL can go years without requiring treatment, and up to one-third of those diagnosed with the disease will never need treatment. Research studies have repeatedly shown that starting treatment early before symptoms worsen does not result in a longer lifespan or better outcomes. Additionally, medications to treat the cancer can cause significant side effects. This is another reason to avoid treatment as long as possible until the cancer becomes more active. Treatments for CLL and SLL will be just as effective if they are not taken until significant symptoms are present.

## WHAT KIND OF CLOSE MONITORING OCCURS DURING ACTIVE SURVEILLANCE?

Even when you are not receiving any medication for your CLL or SLL, you will still see your specialist regularly. The frequency of check-ups will depend on findings from laboratory testing, your physical exam, and how well you feel. At each appointment, your healthcare team will check for new or worsening symptoms and be looking for trends in your laboratory values. It is important to note that usually no one single abnormal lab value will signal that treatment is necessary right away, but rather your healthcare provider is watching for upward or downward trends over time. Some symptoms can indicate the cancer may be progressing. These symptoms are referred to as B-symptoms and include:

- Unexplained weight loss of more than 10% of total body weight in the previous 6 months.
- Severe fatigue that makes it difficult to work or perform usual daily activities.
- Fevers higher than 100.4°F lasting for at least 2 weeks without any other signs of infection.
- Drenching night sweats (soaking the bed sheets) for more than a month without evidence of infection.

Other symptoms your healthcare provider will be monitoring for tend to occur later in the course of the

disease and are called secondary symptoms. These secondary symptoms may include:

- Repeat infections that are caused by low levels of healthy white blood cells.
- Red, flat, pinpoint spots under the skin called petechiae.
- Easy bleeding or excessive bruising that occurs when the cancerous cells in the bone marrow crowd out the number of cells that are needed to help with blood clotting (called platelets).
- Shortness of breath or light-headedness that occurs when the cancer reduces the number of cells that are needed to carry oxygen to tissues (called red blood cells).

Some people may experience other symptoms related to their disease, such as joint and muscle aches, swollen lymph nodes, and anxiety. On the other hand, some may have no visible symptoms and may wonder how they can feel well, but still have cancer. In either case, close monitoring is necessary.

## WHAT CAN BE DONE TO MANAGE MY OVERALL HEALTH DURING ACTIVE SURVEILLANCE?

- **Frontload your knowledge as much as possible.** This is a very good time to visit the CLL Society's website to learn about the disease and the available treatment options. Make sure you understand why active surveillance is recommended for those with CLL and SLL. Read all you can on the subject and continue to have discussions with your healthcare team when you have questions.
- **Build your care team.** It is important to find a healthcare provider whose expertise is in CLL. This is especially important when it comes time to select which treatment will be best for you. If you are seeing a local oncologist who does not specialize in the disease, they can coordinate the bulk of your care and monitoring, but they should be willing to work with the CLL expert when needed. It is also important to have a primary care provider who can oversee and manage all preventative care. Also, establish



care with a dermatologist who can perform annual skin cancer screenings, since those with CLL and SLL are at higher risk of developing skin cancer.

- **Establish your support system.** Lean into family and friends for logistical support. This can include assistance with transportation to appointments, picking up medications, and general help with day-to-day activities when you are not feeling well.
- **Take care of your physical health.** Work with your primary care provider to ensure you are on track with receiving all recommended preventative health screenings. Since those with CLL and SLL are at a higher risk for developing secondary cancers, it is critical to schedule regular annual health screenings. This should include an annual full-body skin exam (preferably by a dermatologist), colon cancer screening, well-women check-ups/mammograms, and prostate cancer screening for men.
- **Join a support group.** You are not alone. CLL Society has many support groups all across the country that meet once a month. These groups are led by trained facilitators and are made up of people who have been (or who currently are) in a similar situation. CLL Society support groups not only serve as a place of support where you can safely ask questions, but they also provide education and are a place to learn more about the disease. It is important that you have the support you need throughout your cancer journey.
- **Take care of your mental health.** Since the period of active surveillance can be full of anxiety and worry, it is important to express these feelings with your healthcare provider so they can help you navigate these normal emotions and recommend resources that are available to you.
- **Protect yourself from infection.** Everyone diagnosed with CLL and SLL is considered immunocompromised due to having a cancer of the immune system. This is the case even if you have never undergone any type of treatment. Being immunocompromised means you can contract infections more easily, may have more severe forms of any given illness, and may have a more difficult time fighting off infections after you have become sick. Active surveillance is the best time to make sure you are up to date on all recommended vaccinations, but make sure you are not receiving any “live” vaccines. Additionally, it is important to

take extra measures to avoid contact with those who are ill, wash your hands frequently, avoid indoor crowded settings, and consider wearing a well-fitted N95 mask when you are going to be in contact with others outside of your household. Notify your healthcare team quickly should you have signs of infection, especially if you have a fever.

- **Eat a well-rounded diet and exercise as tolerated.** There is no data to support any special diets that help to slow or control the cancer. To achieve optimal health, it is important to eat a diet that is rich in nutrients.
- **Protect your skin.** Wear sunscreen and protective clothing when outside and avoid prolonged sun exposure.

## ARE THERE ANY HELPFUL TIPS FOR COPING EMOTIONALLY DURING ACTIVE SURVEILLANCE?

Yes. It is completely normal to feel anxious and confused during this time. One of the most important things to remember is that active surveillance is a form of treatment, and your healthcare provider does have a plan of action to closely monitor your disease for signs and symptoms that may or may not progress over time. Here are some things you can do to help process things emotionally during active surveillance:

- Utilize the time that you are not on medication as an opportunity to take steps to improve your overall mental and physical wellness by purposely doing things you enjoy that improve your overall quality of life.
- Practice mindfulness by trying to remain focused on the present and the things you can control, rather than unknowns and what may or may not happen in the future.
- Express your feelings either outwardly by talking to family and friends that you trust, or inwardly by keeping a journal.
- Remind yourself that nearly one-third of those diagnosed with CLL and SLL never require treatment. And if treatment is needed at some point, there are excellent therapies available to treat the disease.
- Try to remain hopeful as much as you can. Although active surveillance can be difficult to adjust to at first, many people with CLL and SLL report that it does get easier to cope over time.