

Smart Patients Get Smart Care™

Treatment for CLL: When is the Right Time to Start?

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Speakers



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Treatment For CLL: When Is The Right Time To Start?

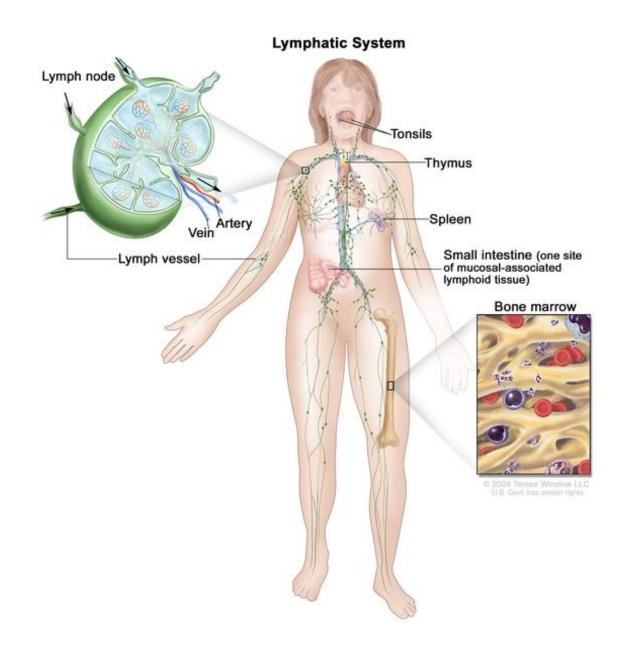
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June 3, 2024

What is CLL/SLL?



- Most common adult leukemia
- Cancer of B-cell lymphocytes which results in ongoing growth and accumulation of abnormal B-lymphocytes
- Primary sites of involvement:
 - Peripheral blood
 - Spleen
 - Lymph nodes
 - Bone marrow
- CLL and SLL are the same type of cancer
 - In CLL, most of the cancer cells are in the blood and bone marrow
 - In SLL, the cancer cells are mainly in the lymph nodes and spleen

Where Are Lymph Nodes Located?

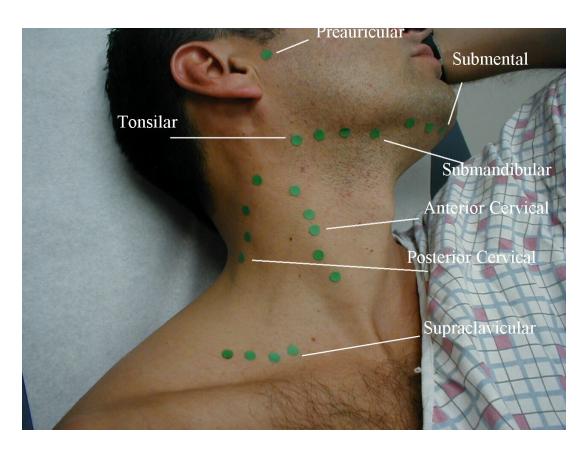




What Do Swollen Lymph Nodes Look Like?



CLL SOCIETY





How Was My CLL Or SLL Diagnosis Determined?



CLL SOCIETY

- Most people do not have any symptoms at the time of diagnosis
- Usually diagnosed when you have a complete blood count (CBC) and there is a high white blood cell count
- Diagnosis by peripheral blood (this is the most common):
 - Flow cytometry detects proteins on the cell surface and can identify a group of cells that have the same combination of proteins on the cell surface



Why Shouldn't My Cancer Be Treated Immediately?



- CLL is not like many other cancers because it usually grows very slowly
- Some people may never need treatment
- Most people will not need any treatment for months to years
- Starting treatment early doesn't lengthen life
- If there are no symptoms and you feel well, it is better to avoid taking a medication that may have side effects or be costly
- There may be better treatments in the future

What is Active Surveillance?



- Active surveillance
 - The period of time after diagnosis before treatment is needed
 - The period of time after treatment when no treatment is needed
- Routine visits with your healthcare provider
 - Physical exam
 - Review of symptoms
 - Lab tests

Is There Anything I Can Do During Active Surveillance?



- Stay up-to-date on vaccinations
- Lifestyle adjustments:
 - Regular exercise
 - Whole food diet, minimize processed foods
 - Maintain emotional health
 - Avoid smoking
- Check vitamin D level and take vitamin D supplement if vitamin D level is low
 - Normal vitamin D levels may be associated with longer life
- Ask if there are any clinical trials available

How Will My Healthcare Provider Determine When It's Time To Start Treatment?



When you have symptoms that interfere with daily life such as:

- Constitutional symptoms:
 - Severe fatigue
 - Drenching night sweats
 - Unintended weight loss of at least 10% of body weight over 6 months
 - Fevers without an infection
- Physical examination findings such as enlarged liver, spleen, or lymph nodes
- Laboratory findings
 - Rapidly rising absolute lymphocyte count (ALC) or low red blood cell or platelet counts.
- Repeated or prolonged infections
- Autoimmune cytopenias (low blood counts) that do not respond well to steroids or other treatment

Shared Decision-Making



- A partnership with your healthcare provider where they help you understand all of the available treatment options, and the likely benefits and harms of each, you help your healthcare provider understand your preferences and what matters most to you, and together you and your healthcare provider select the best course of action for you
- For example, if you are experiencing fatigue, you can explain to your healthcare provider how the fatigue is affecting your life and day-today activities. You and your healthcare provider will work together to try to determine if the fatigue is from the CLL or some other cause such as low thyroid levels or other medical conditions. AIHA can lead to fatigue, and treating AIHA can alleviate symptoms without beginning treatment for CLL or SLL

Shared Decision-Making

Combining Perspectives



CLINICIANS

- Guidelines
- Experience
- Evidence
- · Disease Goals

S D

PATIENTS

- Lifestyle
- Values
- Preferences
- Resources
- Personal goals

Shared Decision-Making



- The two most common treatments for first-line therapy are:
 - BTK inhibitors which are pills taken indefinitely
 - Venetoclax and obinutuzumab which is a year-long treatment
- Discussions about treatment options should include:
 - Expected response to the treatment
 - Potential side effects
 - Logistics
 - Living close to an infusion center
 - Convenience
 - Cost



Can Anything Be Done To Improve My Symptoms?



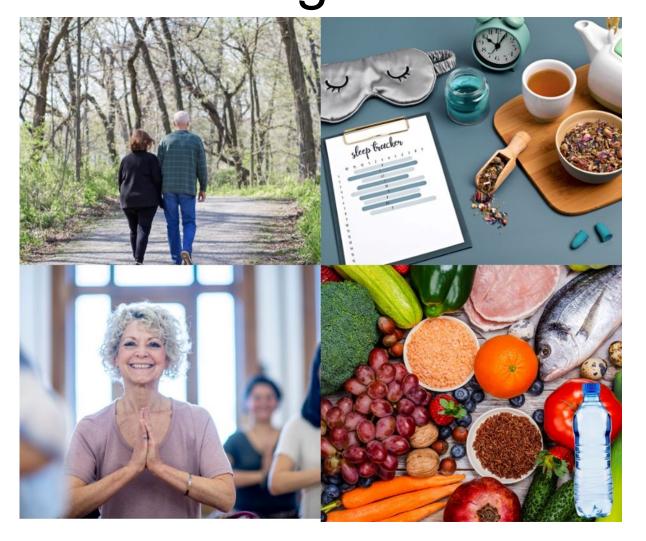
- Consider keeping a symptom journal
- Notify your healthcare provider for:
 - Enlarging lymph nodes
 - Worsening fatigue that disrupts your daily activities
 - Shortness of breath
 - Decreased appetite or feeling full easily
 - Pain
 - Persistent fevers even though you don't have an infection
 - Frequent infections
 - Drenching night sweats

What Is Cancer-Related Fatigue?



- Physical and/or emotional exhaustion related to CLL or its treatment
- Not the type of tiredness that improves with rest or sleep; it is a lack of energy that doesn't improve with rest or sleep and limits usual activities

How Do I Manage Cancer-Related Fatigue?





Sleep Hygiene



- Go to bed and wake up at the same time each day even on weekends and holidays
- Avoid naps after 3 pm
- Take a warm shower or bath about 90 minutes before bed. A hot bath will raise your body temperature, and it is the drop in body temperature that may leave you feeling sleepy.
- Keep your bedroom cool, dark, and gadget/TV-free
- Limit caffeine after 12 pm
- Avoid exercise within 6 hours of bedtime
- Establish relaxation routine

Relaxation Techniques



- Breathing
 - Belly breathing: long, slow, deep breaths
 - 4-7-8 breathing: inhale for 4 seconds, hold your breath for 7 seconds, and exhale for 8 seconds
- Body scan: focus on one part of the body or group of muscles at a time and mentally release any physical tension you feel there
- Guided imagery: think about soothing scenes, places, or experiences to help you relax and focus
- Mindfulness meditation: focus on what you are feeling in the moment and, when your thoughts drift, bring your mind back to focus on the present moment
- Yoga, tai chi, and qigong

Painful Lymph Nodes



- Warm compress
- Rest
- Acetaminophen, after discussion with your healthcare provider

Weight Loss Related To Lack Of Appetite



- Eat small, frequent meals
- Eat foods high in protein and healthy fats
 - Nuts, seeds, trail mix, nut butters (peanut butter, almond butter etc)
 - Full fat Greek yogurt or full-fat cottage cheese
 - Beans, bean dips, and hummus
 - Avocado, guacamole
 - Oats or granola
 - Eggs
 - Fatty fish: salmon, mackerel, sardines, anchovies and bluefin tuna

Night Sweats



- Maintain a cool sleep environment using lightweight, breathable bedding and sleepwear, fans, and a cool, well-ventilated room
- Take a shower before bed
- Consider a cool gel pillow
- Practice relaxation techniques to promote calmness and reduce stress
- Avoid stimulating activities or screen time close to bedtime
- Stay well hydrated throughout the day and strive to maintain a healthy weight

Summary



- CLL is not like many other cancers because it usually grows very slowly
- Some people may never need treatment and most people will not need treatment for months to years
- Your healthcare provider is a partner in your care and, together, you will decide when to start treatment and which treatment is best for you
- People with CLL are at increased risk of infection. Protect yourself by staying up-to-date on immunizations

Links To Additional CLL Society Content



- https://cllsociety.org/recognizing-when-it-is-time-to-treat/
- https://cllsociety.org/2023/04/decision-making-about-treatmentof-cll-sll/
- https://cllsociety.org/cancer-related-fatigue-handout/
- https://cllsociety.org/managing-symptoms/
- https://cllsociety.org/active-surveillance/



Audience Questions & Answers

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Thank You for Attending!

Please take a moment to complete our **post-event survey**, your feedback is important to us



If you're question was not answered, please feel free to email asktheexpert@cllsociety.org

Join us for our next virtual event, **Ask Me Anything:** Featuring Dr. Richard Furman and Jeff Folloder on July 24th

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cllsociety.org/donate-to-cll-society/