Communicating with your oncology care team

A guide to getting the most out of your appointments

A diagnosis of chronic lymphocytic leukemia (CLL) can be overwhelming. One of the most important things you can do from the start is to build a good relationship with your oncology care team. This guide will help you formulate important questions to get the most out of your appointments.

Building rapport

> *The right doctor makes all the difference in the world.* *Nancy, patient with CLL*

Having a good relationship with your medical team—and finding a team that's the right fit—is critical. Consider asking questions about your doctor's practice and communication style.

Questions to ask your oncology care team

- As a patient, what is the best way for me to communicate with my doctor between appointments—email, phone, or patient portal?
- What is the role of each person on the oncology team, and are they available to answer questions if my doctor is busy?
- In addition to medical care, does your practice provide other kinds of patient support (eg, help with insurance questions)?

Living life with CLL

> *I won't get back to the way I was before, but I am very open to embracing each new chapter with this journey.* *Penny, patient with CLL*

A CLL diagnosis changes everything—but life continues, and there are lots of ways to get the most out of each day. Your care team can give you a better sense of what to expect.

Questions to ask your oncology care team

- Will CLL affect my daily life, and if so, how?
- Will I be able to pursue hobbies and travel?
- Does CLL have an effect on intimacy?
- When I'm on treatment, can I drink alcohol or take over-the-counter medicines?
- How do I care for my mental health and deal with stress?



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Exercise and wellness

> *I have learned about the disease and what I can do to help in every way… through nutrition, exercise, and mind.* *Caroline, caregiver of a patient with CLL*

Exercise and wellness can play an important role in your life, even when you're living with CLL. Ask your oncologist about activities that are safe and appropriate.

Questions to ask your oncology care team

- Are there specific exercise recommendations for people with cancer?
- Will there be limits to the types of physical activities I can pursue?
- Will I need to make any changes to my diet?

Symptoms

It is possible to experience disease-related symptoms such as fatigue and weight loss. Your care team will give you a better sense of what to look out for and may provide tips for symptom management.

Questions to ask your oncology care team

- What symptoms can I expect, if any?
- Are there ways to address them?



Treatment options

There are different treatment paths for CLL, and it is the job of your care team to help you understand what may be the best fit. Coming prepared with specific questions will help you navigate these conversations.

Questions to ask your oncology care team

- What is watch and wait/active surveillance, and what triggers treatment?
- What kind of testing is available to me, and how might it affect my treatment plan?
- Am I at risk for CLL that progresses quickly?
- How long might each type of treatment last, and how will I know if it's working?
- What are the pros and cons of different types of treatments, and how will they impact my quality of life?
- Could any existing health issues have an impact on my treatment plan?
- Will I take one type of medication on its own or multiple treatments together? What are the pros and cons of each approach?
- What types of side effects should I expect with different types of treatment, and are there ways to manage them?
- Are there side effects that require immediate medical attention?

> *My inspiration actually comes from other CLL patients. I see what they've gone through and how they survive.* *Larry, patient with CLL*

Caregiving

> *Be as open as you possibly can to the ideas, concerns, questions, and information that the patient and the doctor are sharing with you. It's so important for a patient to know that someone has their back.* *Caregiver to Larry, patient with CLL*

It can be hard to know how to best support a loved one with a cancer diagnosis. An oncology care team may be able to help you navigate that role.

Questions to ask the oncology care team

- What is my role during and between appointments?
- How do I keep myself informed about CLL and new treatment developments?
- Are there specific support resources for caregivers?
- How do I know when to let my loved one make independent decisions about their care, as opposed to guiding those decisions myself?
- Are there any limitations on the activities that my loved one and I enjoy doing together?

Resources

> *Knowledge is power. The more you know, the better off you are.* *Wendy, patient with CLL*

There are excellent resources for people living with CLL, including research and advocacy organizations. Your doctor and their office staff may be able to help you learn about and connect with these groups.

Questions to ask your oncology care team

- What are reliable sources, online and otherwise, for learning about my disease and treatment options?
- Are there resources that may help me afford my medication, and is there someone in your practice who can help?
- What is an advocacy group?
- Why might it be valuable to attend a medical conference?
- Are you aware of in-person or online caregiver support groups that I might join?

Top 5 questions for your oncology care team

- How often will we interact, and what's the best way for us to communicate between appointments?
- Will CLL impact my daily life, and if so, how?
- What is watch and wait/active surveillance, and what triggers treatment?
- What are the pros and cons of different types of treatments?
- What kind of testing is available to me, and how might it affect my treatment plan?



Helpful tips from patients for getting the most out of your appointments

> *Ask the doctor if you can record the session with a cell phone… So when you get home, you can go back and say, 'Oh yeah, that's what they said about that.'* Wendy, patient with CLL

> *I submit questions on the patient portal, but I also… print them out and give them to the receptionists when I arrive. It's like a meeting agenda.* Jacques, patient with CLL

> *I bring a spreadsheet of all of my lab results to my appointments. My doctor can then chart it and know exactly what my history is.* Larry, patient with CLL

> *I can't tell you the number of times I've walked out of an appointment and thought, 'Oh my gosh, I forgot to ask about... ' So I try to keep a record of the things that I really want to talk about and make sure those questions get answered before I leave.* Penny, patient with CLL

Glossary

- **Active surveillance:**
  Also called *watch and wait.* Closely watching a patient's condition but refraining from treatment unless symptoms and/or tests reveal that the disease has progressed.
- **B cell:**
  Type of white blood cell that produces antibodies. Also called *B lymphocyte.*
- **Bone marrow:**
  Spongy tissue found in the center of most bones. Red and white blood cells and platelets are produced in the bone marrow.
- **Chemoimmunotherapy:**
  Combination of immunotherapy (a treatment that enhances the ability of the immune system to fight cancer) and chemotherapy (a treatment that kills or slows the growth of cancer cells).
- **Chemotherapy:**
  Treatment that stops the growth of cancer cells. It can be administered by injection, infusion, or by mouth, alone or alongside other treatments.
- **Chronic lymphocytic leukemia (CLL):**
  A cancer characterized by the presence of too many immature white blood cells in the bone marrow and blood. This cancer is considered to be the same disease as small lymphocytic lymphoma (SLL).
- **Lymphocyte:**
  Type of white blood cell found in the lymph tissue and blood. Lymphocytes are part of the immune system.
- **Small lymphocytic lymphoma (SLL):**
  Cancer characterized by the presence of too many immature white blood cells in the lymph nodes. This cancer is considered to be the same disease as chronic lymphocytic leukemia (CLL).
- **Targeted therapy:**
  Cancer treatment that targets specific cancer cells while causing less harm to normal cells.
- **White blood cell:**
  Immune cell that is produced in the bone marrow and found in lymph tissue and blood.

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Oncology Care Team
Contact Information

Notes