Taking an active role in your care means understanding your needs and sharing them with the people who are part of your care team. Use this worksheet to help you get what you want by working with the loved ones and doctors who make up your team.1,2

START WITH YOU

Take some time to reflect on your needs, values, and preferences when it comes to living with CLL. Answer the questions below to get started.3,4

• Who is on your care team?
  Ex: Care partner, adult children, friends, neighbors

• What matters to you?
  Ex: Spending time with loved ones, doing activities you enjoy, feeling in control

• What are your communication goals?
  Ex: Understanding my choices, learning all I can, advocating for my care

• What impacts your treatment decision?
  Ex: Cost, side effects, how treatment is given or taken

CONNECT WITH YOUR CARE PARTNER

Your care partner can help advocate for you. Once you understand your needs, share them with your care partner and talk about how the rest of your care team can help. Answer the questions below to get started.

• What do you need from your care partner?
  Ex: Help with errands and appointments, a shoulder to lean on, help connecting with the rest of your care team

• What role would you like your care partner to take during doctor visits?
  Ex: Note-taking, moral support, active participant

• What activities can you do together?
  Ex: Going to the movies, playing board games, taking walks

• How can the rest of your care team help you both?
  Ex: Rides to appointments, help with yard work, meals
Now that you’ve shared your needs with your care partner, it’s time to consider another important member of your care team—your doctor. So, go to your next appointment with everything you need to have a productive conversation with your doctor. Use this side of the worksheet to help you get started.

**QUESTIONS YOU MAY WANT TO ASK**

- What stage is my disease?
- How will I know if my CLL is getting worse or it’s time to start treatment?
- What specific CLL mutations or deletions do I have, if any?
- Which chemotherapy or nonchemotherapy option might be right for me?
- Are any of these treatments oral or given through an IV?
- What can I do to support my overall health?

**COMMUNICATION TIPS TO CONSIDER**

- **START STRONG**: Bring up your most important question or concern first so your doctor has time to address it.  
- **RAISE YOUR HAND**: You may not know every medical term your doctor uses—that’s OK. Ask your doctor to explain.
- **TELL IT LIKE IT IS**: Share your symptoms, needs, concerns, fears, and preferences with your doctor.
- **DON’T GET STUCK ON A “SOLVE”**: Talk to your care partner about stress. You don’t have to solve every problem on the spot. But getting things out in the open may help you both.

3. Referenced with permission from the NCCN Guidelines for Patients®: Chronic Lymphocytic Leukemia V.2019. © NCCN Foundation®. 2019. All rights reserved. Accessed May 1, 2019. To view the most recent and complete version of the guideline, go online to NCCN.org/patients. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.