

Preparing for Your Doctor's Visit

A WORKSHEET FOR PEOPLE WITH CHRONIC LYMPHOCYTIC LEUKEMIA



If you have Chronic Lymphocytic Leukemia (CLL), this worksheet can help you talk with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

ASK YOUR HEALTH CARE TEAM

- Talk with your doctor and confirm that the specialists on your health care team have experience treating CLL.
- Ask about the next steps in your treatment and what tests you will need.
- Ask about symptoms and side effects and which ones you need to know about and report to your team. Ask about side effect management.
- Ask questions until you understand what is being said. You can ask for information in a different language or a drawing if you need it.
- Ask about the latest information from clinical trials.
- Talk to your health care team about how you are feeling. Ask about a counselor or mental health services if you are feeling overwhelmed or anxious.

TIPS FOR TAKING CONTROL

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor.
- Be proactive. Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- If your health care team has recommended observation or “watch and wait,” talk with them about what this means. Ask about next steps and treatment options.
- Be your own advocate. If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- Write down your questions before each doctor's visit. Keep a journal to take notes and track your progress over time. This can include information about tests and lab work.
- Learn the words that doctors use to talk about CLL. This can help you better understand your test results and treatment options.

Below are some of the symptoms and side effects people with CLL may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.

	Rarely	Sometimes	All the Time
Fatigue, feeling very tired, or shortness of breath			
General pain, or pain in the upper left abdomen (swollen spleen)			
Frequent infections (like chronic UTIs, sinus, or chest infections)			
Feeling anxious, overwhelmed, or depressed			
Bruising, nose bleeds, excessive bleeding, or capillaries			
Enlarged or swollen lymph nodes			
Fever or chills			
Weight loss, diarrhea, constipation, edema, or bloating			
Loss of sexual desire or problems with intimacy			
Others:			

How often are cancer or side effects interfering with your life?	Rarely	Sometimes	All the Time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities I normally enjoy, such a traveling			
Confidence/self-image			
Difficulty thinking/brain fog			
Social relationships			
Sexual relationships			
Eating and/or exercise			
Difficulty sleeping/insomnia			
Others:			

THINK ABOUT TREATMENT AND PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. Possible goals may be to: live as long and as well as possible, contribute to progress by taking part in research, make it to a special event/milestone, or find cutting edge treatments. Let your health care team know about your treatment and personal goals. Remember that your goals may change over time.

Physical Health and Well-being	<i>What is most important for you to be able to do?</i>
Family and Social Relationships	<i>What's going on in the lives of others that is important to you?</i>
Work/School	<i>Do you want to continue working? Can you adjust your schedule or responsibilities?</i>
Community/ Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/ involved in your community?</i>
Other	<i>What else is important to you?</i>

PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know.

Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

- Can you explain my test results to me?
- When should I start treatment? What happens if I don't start treatment now?
- Are there any genetic risk factors or biomarkers that I should be aware of?"
- How long will I be on the treatment? What are the common side effects?
- The symptoms and side effects that are affecting me the most are: [discuss your answers from page 1].
 - They are interfering with my life in these ways: [discuss your answers from the top of page 2].
 - What can we do to manage them?
- My top goals for treatment are: [fill in your answers from the bottom of page 2].
 - Is the treatment that I am currently on the best treatment for me to meet these goals?
- What other treatments are available to me? What are the pros and cons of each option? Are there any new treatments or clinical trials that may be right for me?
- What are my treatment options if I relapse?
- How can I manage treatment costs? Is there a financial navigator that I can talk with?

GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).

- Make a list of things you need (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using MyLifeLine.org to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support.
- You can also ask for a mentor or to be matched with another person with CLL.
- If you search for information online, make sure that you are using trusted websites. Turn to the back page of this publication to see a listing of trusted organizations.
- CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have CLL.

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your health care team and your pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing the financial issues and costs.
- Reach out to your health insurance company to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment is far away, ask if there are assistance programs that can help cover your travel costs.

The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: www.CancerSupportCommunity.org/cost

CLL Information & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/cll

American Cancer Society • 800-227-2345 • www.cancer.org

American Society of Clinical Oncology (ASCO) • 571-483-1780 • www.cancer.net/cll

CLL Society • www.cllsociety.org

Imerman Angels • imermanangels.org

Leukemia & Lymphoma Society • 800-955-4572 • www.lls.org

Patient Power • www.powerfulpatients.org/health_center/chronic-lymphocytic-leukemia

Financial Support Resources

Cancer and Careers (CAC) • www.cancerandcareers.org

CancerCare • 800-813-4673 • www.cancercare.org/financial_assistance

Leukemia & Lymphoma Society • 800-955-4572 • www.lls.org/financial-support

Partnership for Prescription Assistance • www.pparx.org

Patient Access Network Foundation • 866-316-7263 • www.panfoundation.org/assistance-programs

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Open to Options® — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/policy-advocacy/become-advocate.

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For more information and additional resources, please visit the CSC Leukemia page at www.CancerSupportCommunity.org/cll.

Share your experience and make your voice heard. Join the Cancer Experience Registry and participate in the special community of people facing chronic lymphocytic leukemia at www.CancerExperienceRegistry.org.

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