

CLL: Improving Communication with Your Patients

Patients with chronic lymphocytic leukemia (CLL) are often overwhelmed by their diagnosis and treatment options. **Over a third of CLL patients report greater anxiety, depression, and fatigue than the general population.** Many patients report concerns with navigating care and their quality of life.

This handout offers valuable tips to help improve communication.

MANAGING FINANCIAL CONCERNS RELATED TO CANCER

FINANCIAL CONCERNS OF CLL PATIENTS

7 out of 10 reported that no one from their health care team talked to them about the cost of their care	1 out of 3 spend over \$250 in monthly out-of-pocket cost to cover cancer care	1 out of 3 were moderately to very seriously concerned about health insurance or money worries
---	---	---

According to the CSC Registry Report, one-third of patients report intrusive thoughts about financial concerns related to their cancer. **However, 70% of patients report that no one on their health care team asked them about their health care costs.** In a 2020 CSC study, financial burden correlated with patients' postponing treatment and care for their CLL.

It is important for health care providers to ask questions about patient's financial concerns when discussing the cost of treatment and treatment decisions. If your hospital has a financial counselor, refer your patient to them. Here are some questions to ask your patients to initiate the conversation about the cost of care:

- Do you have concerns about the cost of your treatment?
- Are you at risk for losing your insurance or do you expect any upcoming changes in your insurance?
- Have you been connected with a financial counselor or navigator that can help answer your financial questions?

- Do you understand your health insurance coverage?
- Do you have prescription drug coverage?
- Prior to your diagnosis, did you have any financial concerns?
- Do you have concerns about costs indirectly related to your care (transportation, childcare, nutritional support etc)?

QUALITY OF LIFE IMPACT

CLL is a **chronic disease** that can impact your patients' functioning whether it's spiritually, physically, emotionally, or socially over long periods of time. Patients have reported feelings of isolation and additional impacts as a result of their cancer. Ask your patients if CLL or treatment interferes with their ability to:

- Work (lost income, challenges of disability insurance)
- Sleep
- Think clearly
- Stay emotionally healthy
- Be social/enjoy hobbies
- Maintain close relationships/be present in family life
- Be intimate with partner
- Exercise/be physically active
- Function in other ways

QUESTIONS TO ASK YOUR PATIENTS

- How is your emotional health? How are you coping with the diagnosis and treatment?
- What is worrying you most?
- With whom are you able to share these concerns?
- How have your symptoms changed since the last visit?
- How is the cancer and/or related treatments affecting your life?
- What side effects are you experiencing? What are you doing to manage them? How are you coping with fatigue?
- Are you experiencing isolation as a result of your symptoms or side effects?
- What questions do you have about your cancer or treatment?
- If patient is on oral medication: how and when are you taking your prescribed medication? What do you do if you miss a dose?

CSC's new discussion tool can help patients with chronic lymphocytic leukemia prepare to ask questions and clarify their concerns. Check it out at www.CancerSupportCommunity.org/CLL.

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:			

TREATMENT GOALS

Treatment of CLL can aim to:

- Prolong survival and delay disease progression
- Put the patient into complete remission
- Optimize quality of life

Share these goals with your patients and have them reflect back to you to ensure comprehension. Discussing treatment goals can also help better understand your patients' goals for treatment.

How to Ensure the Patient's Treatment Aligns with Their Personal Goals

- 1 Understand, consider, and respect individual patient goals.
- 2 Educate patients about ALL options for treatment with benefits and risks for each one. Allow patients to ask questions after discussing each treatment. Hearing them all at once may be overwhelming and they may forget questions.

- Watch & Wait
- Targeted Therapy
- Immunotherapy
- Stem Cell Transplant
- Chemoimmunotherapy
- Clinical Trials
- Palliative Care

- 3 Encourage patients to take notes and have a family member or friend with them.
- 4 Understand the emotional, physical, and financial concerns that may impact decision-making.

DISCUSSING WATCH & WAIT WITH PATIENTS

Depending on the stage of CLL, active surveillance (watch & wait) may be the best management option for the patient. **23% of patients reported feeling uncomfortable or anxious with this option.** It is important to explain to your patient why this is the best

option for them. Sometimes, patients' loved ones might be confused or upset to hear that the doctors aren't treating the patient. Educating the patient on this treatment option can help them explain and ask for the support they need from their loved ones.

Patients have reported their health care team labelling the cancer as "good cancer" when watch and wait is the best treatment option of choice. Instead of labeling the cancer as "good," discuss the decision for the treatment and normalize this treatment decision. Follow these tips when discussing the cancer with your patient:

- Provide additional ways patients can be active in their treatment while they watch and wait.
- Share signs for your patients to monitor as a way to be active in their treatment.
- Listen to your patients' concerns.
- Provide referrals.

WEIGHING TREATMENT OPTIONS

Most CLL patients say they want to work with their health care team to map out their treatment plan. Making decisions about cancer treatment can be overwhelming and patients need support and guidance. Providing resources, such as Open to Options, at the first appointment to patients can provide needed support.

CSC's free decision support advising program Open to Options™ – can help. A trained specialist works with individuals to develop a personal list of questions and concerns. This list can then be shared with health care providers before or at medical visits. To set up appointment, call 1-888-793-9355.



WAYS PATIENTS CAN BE ACTIVE PARTICIPANTS IN TREATMENT

Diet and exercise were reported as the two top concerns of patients with CLL. Diet and exercise can be helpful ways for patients to feel empowered to take control of their health. Although diet and exercise can be a simple and direct way for patients to be active in their treatment, many patients lack the knowledge and understanding of what their diet and exercise should look like while living with cancer.

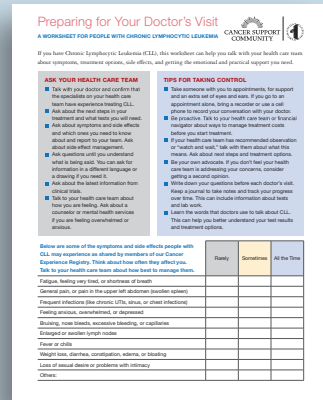
Connecting your patient with resources is a great way to help empower your patients to participate in their health. Here are some ways you can support your patient:

- Provide referrals to a Registered Dietitian (RD) or an Oncology Registered Dietitian (O-RD).
- Refer your patient to a local Cancer Support Community/Gilda's Club to find support, workshops, and nutrition & exercise classes.
- Provide CSC's "Frankly Speaking About Cancer: Eating Well During Cancer Treatment" booklet to help them find helpful recipes and tips.
- Provide resources on integrative services, such as massage therapy or reiki, if your institution offers them.



CLL RESOURCES

CSC provides resources and tools that can help you improve communication and shared decision making in your everyday practice. *Frankly Speaking About Cancer: Chronic Lymphocytic Leukemia* is CSC's highly acclaimed cancer education series that provides accurate medical and psychosocial information and support resources. It includes free print materials (booklet, coping booklet, and discussion tool), an online program, and patient education workshop. To download or order these materials, visit www.CancerSupportCommunity.org/CLL or call our Helpline at 888-793-9355.



CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org.

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, 9 am– 9 pm ET. If you have questions specifically related to COVID, the Helpline can help.

Open to Options®— Preparing for your next appointment? 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.

Frankly Speaking About Cancer®— Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

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. www.CancerSupportCommunity.org/FindLocation.

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

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. Connect with other caregivers by joining the Caregiver Support online discussion board. Sign up at www.MyLifeLine.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/become-advocate

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



PHARMACEUTICAL COMPANIES
OF **Johnson & Johnson**

This book is available to download and print yourself at www.CancerSupportCommunity.org/CLL. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

© September 2021. Cancer Support Community. All rights reserved.