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

<table>
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<th>FINANCIAL CONCERNS OF CLL PATIENTS</th>
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<td>7 out of 10 reported that no one from their health care team talked to them about the cost of their care</td>
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<td>1 out of 3 spend over $250 in monthly out-of-pocket cost to cover cancer care</td>
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<td>1 out of 3 were moderately to very seriously concerned about health insurance or money worries</td>
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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 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.

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.
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.

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.

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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 OptionsTM – 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.
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:

- Pharmacyscctics
- Janssen
- 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.

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