

FRANKLY SPEAKING ABOUT CANCER

Coping with Chronic Lymphocytic Leukemia (CLL)



When you have chronic lymphocytic leukemia (CLL), everyday can bring a new challenge. You may be dealing with a range of different emotions such as feeling scared, anxious, or angry. But, you can take an active role in your care and move forward.

This fact sheet covers how to cope with CLL and offers ways on how to regain control, get support, and help you maintain the best possible quality of life. For information

on the diagnosis and current treatment for CLL, see our *Frankly Speaking about Cancer: Chronic Lymphocytic Leukemia* booklet: www.CancerSupportCommunity.com/CLL.


CANCER SUPPORT
COMMUNITY.



Coping with Watchful Waiting

CLL is different from other cancers because in many cases, people living with CLL do not need treatment right away. Unlike many other cancers, CLL often does not benefit from early treatment. Instead, watchful waiting (also called “active surveillance” or “watch and wait”) may be the safest approach for your care. Your health care team may take this approach if there are minimal changes in your blood counts and no symptoms. With watchful waiting, you see a doctor regularly but don’t begin treatment until needed. Waiting to treat your cancer can be difficult to deal with, causing you stress and anxiety about what the future holds. It can be frustrating to feel like you’re not doing anything to fight the cancer. You can regain control of your care by taking the active steps listed below to help you cope with watchful waiting.

TIPS FOR COPING WITH WATCHFUL WAITING

- ✓ Ask your health care team questions until you understand why watchful waiting is a good choice for you. Remember that you, too, are a key member of your team, so speak up if you have questions or concerns.
- ✓ Ask your health care team about all of the treatment options that are available to you. It is important that you understand them so you and your health care team can make decisions together about the best choices for you.
- ✓ Learn and recognize any signs or symptoms that you should tell your health care team about right away.
- ✓ Accept that you do not have control over some aspects of your cancer.

- ✓ Keep written notes about signs or symptoms you notice and any other questions you have. Take notes during your conversations with your health care team. You may find it useful to bring someone with you to your medical appointments.
- ✓ Know that you will be more anxious when it gets close to your doctor’s appointments. Be gentle with yourself when you are feeling stressed.
- ✓ Yoga, breathing relaxation exercises, and doing activities you enjoy can help you relax.
- ✓ Focus on what gives you pleasure now, instead of worrying about the future. Make time for what you really want. Pamper yourself in small ways — take a warm bath, read a good book, or buy yourself a small gift.
- ✓ Know that it’s normal to have fears, but practice letting them go. Try to picture them floating away, leaving as you breathe out, being washed away, or being vaporized.

Sources of Support

Look for support from friends and your community. Talk with others who have been there. It may be difficult to express your feelings of fear or uncertainty, but it may help you let go of those thoughts.

FAMILY AND FRIENDS

They may not know how to help you, so make suggestions. For example, maybe they could lend a hand with household chores, give rides to medical appointments, or manage financial paperwork. Websites, such as **www.MyLifeLine.org**, can help you and your loved ones connect and organize a schedule.



SUPPORT GROUPS

Blood cancer support groups near you or online will allow you to talk about your feelings. Other people who have had the same experiences may give you ideas that can help you. Some groups are made up only of people with cancer, while others include spouses, family members, or friends.

COUNSELING

If you are feeling sad, nervous, or having other types of feelings that concern you, consider speaking to a counselor or therapist. These individuals are trained to provide personal attention and help deal with these types of emotional feelings.

HELP WITH FINANCES

If you are concerned about the cost of treatment for CLL, ask your doctor to refer you to an oncology social worker, financial counselor, patient advocate, or to a nonprofit organization for help. To get started, download and use our *Tips for Managing and Budgeting Your Cancer Costs* tool: www.CancerSupportCommunity.org/cost.

Take Control of Your Health

Because CLL is a chronic illness, you may feel like your health is out of your control. But there are things you can control that will keep you healthier:

- If you smoke, get help to stop
- Exercise regularly, as long as it is approved by your health care team
- Eat healthy foods
- Limit alcohol
- Maintain a healthy weight
- Avoid people who are sick
- Wash hands frequently and thoroughly
- Talk to your doctor about getting the flu shot or pneumococcal vaccine
- Talk to your doctor about age appropriate cancer screenings
- Maintain a regular sleep schedule
- Manage your stress

Caregivers

CLL affects not only those with the disease, but also the people who care for them.

Caregiving for a person with CLL can be stressful and frustrating. Some caregivers assist with finances, insurance, household chores, rides, or making appointments. Caring for someone who has cancer is not easy. People who do so need support and help. To learn more about CLL and caregiving, visit www.CancerSupportCommunity.org/caregivers.

CLL Resources

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

CancerCare • 800-813-4673 • www.cancercare.org/diagnosis/chronic_lymphocytic_leukemia

CLL Society • www.cllsociety.org

For a more extensive list of CLL resources, see our CLL booklet: www.CancerSupportCommunity.org/CLL

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 platform 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, at www.CancerSupportCommunity.org/FindLocation.

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/become-advocate.

FRANKLY SPEAKING ABOUT CANCER: CHRONIC LYMPHOCYTIC LEUKEMIA PARTNERS:



FRANKLY SPEAKING ABOUT CANCER: CHRONIC LYMPHOCYTIC LEUKEMIA WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



The Cancer Support Community and its partners provide 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.

This fact sheet 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.

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