

FRANKLY SPEAKING ABOUT CANCER

Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma



If you or a loved one has chronic lymphocytic leukemia (CLL)/small lymphocytic lymphoma (SLL), you may be feeling overwhelmed. You may have a lot to process and many doctor visits. It can seem like your health care team is speaking another language. Whether you have decisions to make about your treatment or not, it helps to know what to expect with this diagnosis.

This booklet gives an overview of a CLL/SLL diagnosis, treatment, and how to cope. We hope this will help you learn more about your options, know what questions to ask, and start to feel empowered to take control of your life.


CANCER SUPPORT
COMMUNITY.



TALKING ABOUT CLL/SLL

You will hear many words used to talk about CLL and SLL. Some key ones to know are:

ANEMIA: (*uh-NEE-mee-uh*) A low number of red blood cells.

BLOOD CANCER: (*blud KAN-ser*) Cancer that begins in blood-forming tissue, such as the bone marrow, or in the cells of the immune system.

CHRONIC: (*KRAH-nik*) This type of leukemia develops slowly. Symptoms do not appear right away. A diagnosis may be made at a regular check-up or through a blood test.

LEUKEMIA: (*loo-KEE-mee-uh*) Cancer of the blood cells that makes them unable to fight infection. It also causes the cells to grow out of control and crowd out healthy cells.

LYMPHOCYTIC: (*LIM-foh-SIH-tik*) Referring to lymphocytes, a type of white blood cell.

MARROW: (*MAYR-oh*) The soft middle of many large bones. Blood cells are made in the bone marrow.

What is Leukemia?

Leukemia is cancer of the blood cells. It forms in tissue such as bone marrow and causes blood cells to be produced and enter the bloodstream. It starts most often in white blood cells, which are strong infection fighters. The blood cells grow and divide abnormally, producing large numbers of white blood cells that do not function properly.

What is CLL?

Chronic lymphocytic leukemia (CLL) is a cancer that begins in B lymphocytes or B cells. These are a type of white blood cell. B lymphocytes are part of the immune system and make antibodies to attack bacteria, viruses, and toxins.

CLL is one of the most common types of leukemia in adults. It most often occurs after age 40. About 9 out of 10 people with CLL are over age 50. The average age at diagnosis is 71 years. It's very rare in children. There are about 21,000 new cases of CLL in the United States each year. The risk is slightly higher in men than in women.

What is SLL?

Small lymphocytic lymphoma (SLL) is a cancer that affects the lymphocytes. CLL and SLL are the same disease. But in CLL, cancer cells are found mostly in the blood and bone marrow. In SLL cancer cells are found mostly in the lymph nodes. CLL and SLL are often referred to as CLL/SLL. CLL/SLL is also a type of non-Hodgkin lymphoma.

Diagnosis and Staging

Your results will help determine what treatment is best for you. Your doctor will want to see you and order blood tests if they suspect you have CLL.

EXAM

Your doctor will do a physical exam and ask many questions. Describe how you have been feeling and any changes you have noticed.

LAB TESTS

The following lab tests are used at the time of diagnosis and for monitoring CLL over time:

- **Complete blood count (CBC)** is first done to see if you have lower-than-normal levels of red cells and platelets. The CBC also counts the number and type of white blood cells present. For information on normal results for CBC tests, visit www.CancerSupportCommunity.org/CBC.
- **Flow cytometry** (flow test) to see if the cancer cells have specific antigens or proteins on their cell surface. This is critical for diagnosing CLL.
- **Fluorescence in situ hybridization (FISH)** to see if the cancer cells have abnormal chromosomes or genes. In CLL, this test looks for the shortening of chromosome 17, also called “del(17p).” and other genetic abnormalities. This can help predict how quickly CLL may progress. It also helps determine what treatment is best for you.
- **IGVH** (immunoglobulin heavy chain variable region mutation) analysis to test for genetic mutations. This test can help predict how quickly CLL may progress. It also helps determine what treatment is best for you.

- **Next generation DNA sequencing** looks for specific changes (or mutations) to the cancer cell’s genes (such as a mutation in the TP53 gene), which may predict your response to treatment.

CLL STAGING

In addition to the tests mentioned above, the stage of CLL you have helps the doctor determine which treatment options are best for you.

The Rai staging system is used to divide patients into three groups: low, intermediate, and high risk CLL.

- **Low-Risk CLL:** Too many lymphocytes in the blood
- **Intermediate-Risk CLL:** Too many lymphocytes in the blood and either the lymph nodes, liver, or spleen are enlarged
- **High-Risk CLL:** Too many lymphocytes in the blood, either too few red blood cells (anemia) or too few platelets

SIGNS TO START TREATMENT

If you have Low- or Intermediate-Risk CLL, treatment may not be needed now. Signs to start treatment include:

- Symptoms of active CLL, such as drenching night sweats
- Severe fatigue
- Fever without proof of infection
- Unplanned weight loss
- Low red blood cell or platelet counts

Contact your doctor if you notice any of these signs.

Choosing Your Treatment Team

The best cancer treatments can be very complicated and change all the time with new discoveries. You want a health care team you trust to take the best care of you. You also want a doctor and team that you can communicate with well. Your team may include many people including:

- **Medical oncologist/hematologist:** Look for a doctor who specializes in blood cancers.
- **Oncology nurses, oncology nurse practitioners, and physician assistants.**
- **Social worker:** Can help you and your family find resources to cope with cancer and its treatment and paying for care.
- **Patient navigator/advocate:** A person who helps patients through the care system, from diagnosis through treatment and recovery.

GETTING A “SECOND OPINION”

Are your questions about treatment getting answered? Do you feel comfortable with your care team? Do you see a doctor who specializes in CLL? You can ask for a “second opinion” with a “hematologist-oncologist” who specializes in CLL. If your doctor treats all cancers, ask about how many CLL patients they treat each

year and if they stay current on the newest CLL treatments. Consider getting treatment or a second opinion at a major cancer center or university hospital. Talking with a second doctor can help you understand your disease and how to better treat it, or reassure you that the first treatment recommended is best. Let your doctor know if you want a second opinion.

Treatment Planning

After being diagnosed with CLL, your doctor will tell you which treatments are best for you or if you should wait before starting treatment. Your doctor may ask you what you want to do. This is called treatment planning. You may make choices at the start of treatment and again along the way.

When you talk to your doctor about your treatment options (including the option to wait to start treatment), ask about the goals of each option and how each option might affect the goals you have for your life. Think about what you want to be able to do. Do you want to continue working? How will your treatment affect your family and social relationships? Will you be able to do the things you enjoy? If the doctor recommends that the CLL does not need to be treated at this time, what are the concerns you might have about this option (see treatment section below).

Open to Options® If you are facing a cancer treatment decision, Cancer Support Community’s Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



TIPS FOR TREATMENT PLANNING:

- 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.
- 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 “watch and wait,” talk with them about what this means. Ask about next steps and treatment options.
- 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 track your side effects and results over time.
- Learn the words that doctors use to talk about CLL. This can help you better understand your test results and treatment options.
- Use CSC’s *Preparing for your Doctor’s Visit: A Worksheet for People with CLL*, available at www.CancerSupportCommunity.org/CLL.

Treatment

There are a number of treatments that work well for CLL. Though most current treatments do not cure CLL, they do help manage it. While some people with CLL can live for years without treatment, most people will need to be treated on and off for years.

Treatment depends on:

- The stage of the disease
- Your age and overall health
- Red blood cell, white blood cell, and platelet blood counts
- Symptoms such as fever, chills, or weight loss
- Larger than normal liver, spleen, or lymph nodes
- Genetic mutations such as TP53 or 17p deletion
- Results from additional molecular testing using the lab tests listed in the Diagnosis section on page 3
- Whether the CLL has come back after responding to another treatment

“WATCH AND WAIT”

If you have a slow-growing CLL, you may not need treatment right away. Instead, watchful waiting (also called “active surveillance”) may be the safest approach for your care. With watchful waiting, you see a doctor regularly but don’t begin treatment until needed. Studies have shown that when there is no indication to start treatment, watchful waiting allows the patient to continue their lifestyle without causing their disease to progress more rapidly. Studies do not show any benefit to starting treatment before there is a need. Watchful waiting delays treatment related side effects, while still allowing your treatment to begin when needed (when symptoms occur or if the CLL cells increase in number).

Some people find waiting to treat cancer to be difficult to deal with, causing stress and anxiety. See our *Coping with CLL* booklet for more on coping with watch and wait.

www.CancerSupportCommunity.org/CLL

IMMUNOTHERAPY

Sometimes immunotherapy is used on its own. This treatment improves the body's natural defenses against leukemia. One type is a substance called a monoclonal antibody. It is given by IV and binds to leukemia cells, killing them or helping the immune system destroy them. **These are the latest types of immunotherapies as of August 2020.** For the most updated information, please visit www.CancerSupportCommunity.org/CLL. Not all people get all side effects. Be sure to tell your health care team about the side effects you have.

GENERIC (AND BRAND) NAMES	COMMON SIDE EFFECTS
MONOCLONAL ANTIBODIES TARGETING CD 20	<p>Rare but serious side effects for all these drugs may include:</p> <ul style="list-style-type: none"> • Hepatitis B reactivation (the drug does not cause hepatitis B, but if the person was previously infected, it may retrigger) • Mental status changes (i.e., confusion, dizziness, memory or vision problems, etc.) • Tumor lysis syndrome (which can cause kidney failure) • Brain infection
<ul style="list-style-type: none"> • obinutuzumab (Gazyva®) <i>Given by IV into vein.</i> 	<ul style="list-style-type: none"> • Low blood counts • Infection • Infusion reaction (itching, hives within 24 hours of 1st infusion) • Low blood sugar • High level of potassium in blood <p>Rare but serious side effects for all these drugs may include:</p> <ul style="list-style-type: none"> • Severe infusion reactions (hypotension, shortness of breath, possible hospitalization)
<ul style="list-style-type: none"> • ofatumumab (Arzerra®) <i>Given by IV into vein.</i> 	<ul style="list-style-type: none"> • 1-2% • Low blood counts • Severe infusion reaction (within 30-120 minutes of infusion)
<ul style="list-style-type: none"> • rituximab (Rituxan®) and its biosimilars, like rituximab-abbs (Truxima®) <i>Given by IV into vein.</i> 	<ul style="list-style-type: none"> • Fever and chills (flu like symptoms) <p>Additional rare but serious side effects may include:</p> <ul style="list-style-type: none"> • Heart pain or irregular heartbeats • Severe infusion reaction (within 30-120 minutes) • Severe skin and mouth reactions
<ul style="list-style-type: none"> • rituximab and hyaluronidase human (Rituxan Hycela®) <i>Given by injection.</i> 	<ul style="list-style-type: none"> • Low blood counts • Serious infections • Fever • Nausea <p>Additional rare but serious side effects may include:</p> <ul style="list-style-type: none"> • Severe skin and mouth reactions • Heart problems

CHEMOIMMUNOTHERAPY

In CLL, chemotherapy is almost always combined with immunotherapy, which increases how well it works. Chemotherapy by itself is rarely used to treat CLL. **These are the latest types of chemoimmunotherapies as of August 2020.** For the most updated information, please visit www.CancerSupportCommunity.org/CLL.

Chemotherapy kills fast-growing leukemia cells but can also harm fast-growing healthy cells, causing side effects. With chemoimmunotherapy, you could experience both immunotherapy and/or chemotherapy side effects. However, most people do not experience all side effects. Be sure to tell your health care team about the side effects you have.

GENERIC (AND BRAND) NAMES

COMMON SIDE EFFECTS

FCR COMBINATION

- fludarabine (Fludara®)
- cyclophosphamide (Cytoxan®)

Given by IV into vein with the immunotherapy, rituximab. Used most often with patients younger than 70 in good overall health.

- Low blood counts
- Nausea and vomiting
- Infection
- Fever

Rare but serious side effects may include:

- Tumor lysis syndrome (which can cause kidney failure)

- chlorambucil (Leukeran®)

Given by mouth as a tablet with the immunotherapy, obinutuzumab. Used most often with patients 70+ or patients with other serious health issues.

- Nausea and vomiting
- Abnormal levels on blood tests measuring liver function (these return to normal once treatment is stopped)
- Mouth sores

Rare but serious side effects may include:

- Skin rash (a severe skin reaction)

- bendamustine (Bendeka®, Treanda®)

Given by IV into vein with the immunotherapy, rituximab. Used most often with patients 70+ or patients with other serious health issues.

- Low blood counts
- Infection
- Anemia
- Bleeding and bruising

Rare but serious side effects may include:

- Tumor lysis syndrome (which can cause kidney failure)
- Infertility
- Skin rash (a severe skin reaction)

TARGETED THERAPY

Targeted therapies treat the cancer cells with less harm to normal cells. These drugs often can control CLL, so people do not need to start chemotherapy right away. **These are the latest types of targeted therapies as of August 2020.** For the most updated information, please visit www.CancerSupportCommunity.org/CLL. Not all people get all side effects. Be sure to tell your health care team about the side effects you have.

TYPE OF IMMUNOTHERAPY	GENERIC (AND BRAND) NAMES	COMMON SIDE EFFECTS
BTK INHIBITOR <i>Taken as a pill</i>	<ul style="list-style-type: none"> • ibrutinib (Imbruvica®) <i>Used for CLL patients with and without 17p deletion. May be used in combination with the immunotherapy, rituximab.</i> • acalabrutinib (Calquence®) 	<ul style="list-style-type: none"> • Diarrhea • Low blood counts • Fatigue • Pain in muscles and joints • Swelling • Upper respiratory tract infection • Nausea • Headache • Bruising <p>Rare but serious side effects may include:</p> <ul style="list-style-type: none"> • Irregular heart beat • Serious infections • Bleeding and high blood pressure
PI3K INHIBITORS <i>Taken as a pill</i>	<ul style="list-style-type: none"> • idelalisib (Zydelig®) <i>Used for CLL patients whose cancer has returned.</i> • duvelisib (Copiktra®) <i>Used for CLL patients whose cancer has returned after or has not responded to two other therapies.</i> 	<ul style="list-style-type: none"> • Low blood counts • Fever • Diarrhea • Rash • Fatigue • Cough • Nausea • Respiratory infection and pneumonia • Muscle and joint pain <p>Rare but serious side effects may include:</p> <ul style="list-style-type: none"> • Liver problems • Severe diarrhea (colitis) • Lung problems (pneumonitis) • Severe infections • Severe skin reactions
BCL-2 INHIBITOR <i>Taken as a pill</i>	<ul style="list-style-type: none"> • venetoclax (Venclexta®) <i>Used for CLL patients as a first treatment in combination with immunotherapy or when cancer has returned after treatment. Some patients may need to be monitored for a few days at the hospital.</i> 	<ul style="list-style-type: none"> • Low blood cell counts • Diarrhea • Nausea <p>Rare but serious side effects may include:</p> <ul style="list-style-type: none"> • Tumor lysis syndrome (which can cause kidney failure)

TAKING TARGETED THERAPY



Targeted therapies for CLL are pills you can take at home. It is important to follow the directions for when to take the pills and not to forget to take them. For your therapy to work well, you must take them exactly as directed. Otherwise, they may not work properly.

Tips for making sure your targeted therapy works well:

- Take all pills on schedule. Things that can help:
 - Set reminders for every dose on your phone, watch, or travel alarm.
 - Use a pill calendar or a pill organizer that shows you when pills need to be taken and whether you have taken them
 - Store pills where you will see them every day
- Follow your doctor or pharmacist's instructions on what to do if you miss a dose
- Ask your doctor or pharmacist about whether you need to avoid certain foods, take your pills with food, or take them on an empty stomach.

STEM CELL TRANSPLANT



Stem cell transplant (SCT) is not often used to treat CLL. This is because today's standard treatments work so well. When used for CLL, SCT is most often used in younger patients with an aggressive form of CLL that does not respond to targeted therapy.

In a SCT, patients get an infusion of healthy blood-forming cells (stem cells). CLL patients get stem cells from a matched donor. This is called an allogenic (or "allo") stem cell transplant. You get chemotherapy and/or radiation to make room for the donor stem cells. An allo transplant can

KEY THINGS TO KNOW:

- Clinical trials for CLL are done to test new treatments, combinations of treatments, or different ways of doing stem cell transplant.
- A doctor experienced in treating CLL should be able to recommend specific trials.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover "standard" treatment costs. Be sure to ask what costs you may incur.

See the resources on the back page for help finding clinical trials that might be right for you.

help treat CLL because the donor cells recognize cancer cells as something foreign, and will attack any remaining cancer cells in your body. This is called "graft-versus-tumor" (GVT) effect.

Side effects of stem cell transplants include infections, bleeding, and other side effects of the large doses of chemotherapy or radiation given. Stem cell transplants from donated stem cells can also lead to Graft-Versus-Host Disease (GVHD). For more information on stem cell transplant, visit www.CancerSupportCommunity.org/SCT.

CLINICAL TRIALS

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or

learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments.

One treatment used for other blood cancers that is being tested in clinical trials for CLL is called chimeric antigen receptor (CAR) T cell therapy. This therapy uses a person's own immune cells (T cells) to identify and attack cancer cells.

In CAR T cell therapy, T cells are taken from a patient's blood and sent to a lab. There, the cells are modified so they can better find and attack cancer cells. The modified T cells are re-injected into the patient to fight cancer. For more information on CAR T Cell Therapy, visit www.CancerSupportCommunity.org/CART or the CAR T section at www.CLLSociety.org.

Managing Side Effects

After you start treatment, keep track of how you feel. Write down when you notice a problem, how long it lasts, and if there is anything that makes it better. It is important to let your health care team know. There may be medicine or other ways to manage side effects that will help you feel better. Consider using our *Preparing for Your Doctor's Visit* worksheet, available at www.CancerSupportCommunity.org/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.

Here are two examples of important side effects reported by CLL patients:

INFECTIONS

People with CLL have a higher risk of infection. Antibiotics are often used to treat them.

If you keep getting infections, injections of immunoglobulin (gamma globulin) or drugs to increase white cells may help. Be sure you are up to date with flu, pneumococcal, and VZV vaccines. Avoid "live" vaccines.

FATIGUE

Cancer-related fatigue is a feeling of tiredness that doesn't go away. Some people also have muscle weakness or difficulty concentrating. It may be caused by the cancer, by treatment, or other health problems. If you have cancer-related fatigue, your doctor will try to find and treat what is causing your fatigue.

For more information on coping with side effects, visit www.CancerSupportCommunity.org/cancer-treatment-side-effects.

Cost and Expenses

The treatment for CLL and follow-up appointments can be costly. Keeping up with these costs might be overwhelming. Many families facing cancer say that financial worries about cancer costs are a big source of stress, and they don't know where to turn.

However, there are resources that can help. (Visit www.CancerSupportCommunity.org/Cost. See resources on the back page for more information.)

QUESTIONS TO ASK YOUR HEALTH CARE TEAM

1. What stage is the CLL?
2. How fast-growing does the CLL appear to be?
3. Do I need to start treatment now? If not, how will we know when to start treatment?
4. Does the CLL test positive for any biomarkers [such as a TP53 or del(17p)] that help make treatment decisions?
5. If I need to start treatment now, what are my treatments options?
6. Which treatment do you recommend for me and why?
7. What is the goal of each of my treatment options? What are the risks?
8. How, where, and how often will I receive this treatment?
9. How long will I need to be on this treatment?
10. How will we know if this treatment is working?
11. How will this treatment impact my everyday life? Will I need to miss work/school?
12. How much will this treatment cost me? Will it be covered by my insurance? Is there a social worker or financial counselor that I could meet with?
13. Are there any clinical trials that would be right for me? How do I find out more about them?
14. Do I need to go to an academic medical center for my treatment?
15. What side effects should I expect (short and long term)? What can we do to manage them?
16. Which side effects or symptoms do I need to report to my health care team?
17. Whom should I call if I have questions or problems during office hours? After hours and weekends?
18. How can I find a counselor or mental health services?
19. How can I maintain my health and wellness when dealing with CLL?
20. Am I up-to-date on flu, pneumococcal, and VZV vaccines? Are there any “live” vaccines I should avoid?

Coping with Cancer

Cancer stirs up many feelings. It affects people who have it, their families, and loved ones. It is normal to feel sad, worried, shocked, stressed, or even panicked. The feelings may be mild or more serious. Remember that cancer can affect anyone. No one deserves cancer. And everyone with cancer deserves good care.

TIPS FOR COPING

- Ask your health care team questions until you understand why watchful waiting or your current treatment is a good choice for you.
- Know if there are signs or symptoms that you should tell your care team about right away.
- Control what you can. If you smoke, get help to stop. Exercise regularly, as long as it is approved by your care team. Eat healthy foods and maintain a healthy weight.
- 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.

FINDING THE SUPPORT YOU NEED

- Share your feelings with friends, family members, a counselor, or a clergy person.
- A counselor or a therapist can help you cope with anxiety. Other things that can help are yoga, breathing, and relaxation exercises.
- Ask for help from friends and your community. The Cancer Support Community's **MyLifeLine.org** is a great way to coordinate this online.
- Contact the patient groups on the back page to find local and online support groups, helplines, and other ways to seek support from people who have CLL.

- Ask your health care team about resources for social, emotional, and practical support. Let them know about your concerns. Before each visit, fill out our *Preparing for Your Doctor's Visit* worksheet, available at www.CancerSupportCommunity.org/CLL.
- If you search for information online, make sure you are using trusted websites. Turn to the back page to see a listing of trusted patient groups. For more information, see our *Coping with CLL* booklet at www.CancerSupportCommunity.org/CLL.

CAREGIVERS

Caregivers help or arrange help for people who are ill or disabled. This can take different forms. It might involve physical care or emotional support. Some caregivers assist with money matters, insurance, household chores, rides, or making appointments. Caregivers may or may not live with the person. Caring for someone who has cancer is not easy. People who do so need support and help from their family, friends, and health care team.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time.

Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit www.CancerSupportCommunity.org/Caregivers.

SUPPORT FOR CLL 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. You may feel angry, guilty, alone, afraid, or sad. If you are caring for a person with CLL:

FIND SUPPORT

Share your feelings with others. Look for caregiver support groups, either in person or online. Ask the patient's cancer center if they have a support program for caregivers.

LOOK FOR EXTRA HELP

Ask friends and family if they can help. If they offer, give them specific tasks. If you can afford it, consider hiring people to help care for the person with CLL. Or have them help with chores, childcare, or errands.



TAKE CARE OF YOURSELF

Just as the person with CLL needs to pay attention to their diet, exercise, and sleep, so do you. If you smoke, find a smoking cessation program. Limit alcohol.



TAKE BREAKS

Carve out time for yourself. Spend time with people important to you, and take time for activities you enjoy. Don't feel guilty about making time for yourself — it is important for your own health.



LEARN ABOUT THE FAMILY AND MEDICAL LEAVE ACT (FMLA)

You may qualify to take up to 12 weeks of unpaid, job-protected leave to care for a seriously ill family member.



LEARN ABOUT FINANCIAL ASSISTANCE

You may have high out-of-pocket costs from parking, transportation, and food as part of your caregiving duties. Ask the hospital where the person with cancer is receiving treatment if they can provide help with financial counseling for caregivers.





Lynn's Story

Coping with Watch and Wait

Four years after her diagnosis with chronic lymphocytic leukemia (CLL), Lynn started treatment. CLL grows slowly, so doctors often “watch and wait” before treating. To Lynn, like many others, it felt like “watch and worry.” It didn’t help that she had to defend the approach to others. Friends insisted that, in her position, they would “demand treatment.”

Connecting with CSC helped Lynn cope. With three locations within 20 minutes of her house, Lynn took advantage of all that CSC has to offer. Yoga, mindfulness, journaling, and educational seminars – she was there. CLL is relatively rare, so she joined a general support group for cancer survivors.

Slowly, Lynn grew to accept the situation. “It took me a while to get there. Initially, at each doctor’s visit, even though I was feeling good, I thought, ‘this visit will be the time they say I need to start treatment.’”

When that time came, Lynn started a targeted therapy. The side effects have been manageable, but she regularly experiences fatigue. “They say fatigue isn’t part of the disease, but it is. I watch my body and sleep late if needed. A short power nap can take the edge off.”

Lynn offers this advice to others: “Don’t read or believe everything you see on the internet. Surround yourself with positive people. Join a support group. Breathe. Everything’s going to be okay.”

CLL Resources

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

American Cancer Society • 800-227-2345 • www.cancer.org/cancer/chronic-lymphocytic-leukemia.html

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

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

CLL Society • www.cllsociety.org

Imerman Angels • 866-463-7626 • www.imermanangels.org

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

Lymphoma Research Foundation • www.lymphoma.org/aboutlymphoma/ctl

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

CLL Clinical Trials Information

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

CLL Society Clinical Trial News • www.cllsociety.org/news-clinical-trials

Leukemia & Lymphoma Society's Clinical Trial Support Center

800-955-4572 • www.lls.org/support/information-specialists/clinical-trial-support-center-ctsc

National Cancer Institute • 800-422-6237 • Trials.cancer.gov

National Institute of Health's Clinical Trial Search • ClinicalTrials.gov

Financial Resources

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

Provides tips for managing and budgeting your cancer costs, information on how to get insurance coverage, and more.

Cancer and Careers (CAC) • 646-929-8032 • www.cancerandcareers.org

Provide education on thriving in your workplace to people with cancer.

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

Provides assistance to underinsured patients. Patients or a member of their medical team can apply online or over the phone.

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

Offers assistance to patients who need specific help with insurance, insurance coverage, job retention, debt crisis matters, and other practical matters affecting people with cancer.

Triage Cancer • 424-258-4628 • www.triagecancer.org

Provides education on the practical and legal issues related to cancer.

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 at www.CancerSupportCommunity.org/FindLocation.

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/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 booklet 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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