

TREATMENT UPDATE:

# Chronic Lymphocytic Leukemia (CLL)

**CANCERCARE  
CONNECT®  
BOOKLET SERIES**



**CANCER*care***®

[WWW.CANCERCARE.ORG](http://WWW.CANCERCARE.ORG)



CANCER*care*®

The CancerCare Connect Booklet® Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects and coping with cancer.

To order free copies of this booklet, please use the online order form on our website, [www.cancercare.org](http://www.cancercare.org).

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers and world-leading cancer experts.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at [www.cancercare.org/donate](http://www.cancercare.org/donate). You may also mail a check, payable to CancerCare, to CancerCare, Attn: Donations, 275 Seventh Avenue, New York, NY 10001.

Thank you.

CancerCare®  
National Office  
275 Seventh Avenue  
New York, NY 10001

Toll-free 800-813-HOPE (4673)  
Fax 212-712-8495  
Email [info@cancercare.org](mailto:info@cancercare.org)  
Web [www.cancercare.org](http://www.cancercare.org)

The content of this booklet is independent, non-promotional and free of commercial influence and bias.

# Treatment Update: Chronic Lymphocytic Leukemia (CLL)

## TABLE OF CONTENTS

Introduction.....	2
Treatment Options.....	2
Treatment Approaches Being Studied.....	6
Treatment Side Effects.....	8
General Side Effects.....	10
Communicating With Your Health Care Team.....	14
CancerCare’s Free Support Services and Programs.....	17
Frequently Asked Questions.....	18
Resources.....	21

## EDITOR

### **Lindsey E. Roeker, MD**

*Hematology/Medical Oncology Fellow, Department of Medicine,  
Memorial Sloan Kettering Cancer Center*

© 2020 CancerCare®. All rights reserved. 10/20

All people depicted in the photographs in this booklet are models, used for illustrative purposes only.

*Each year in the United States, over 20,000 people are diagnosed with chronic lymphocytic leukemia (CLL), a cancer of the blood and bone marrow.*

Because of new treatment options, long-term survival and quality of life continue to improve for people diagnosed with this type of cancer.

In CLL, the body produces too many lymphocytes, a type of white blood cell that helps fight infection. The stage of CLL is determined by:

- The enlargement of the lymph nodes, liver or spleen.
- Low blood counts, including anemia (too few red blood cells) or thrombocytopenia (too few platelets).

## Treatment Options

Treatment options for CLL depend on several factors, including the stage of the cancer, whether or not it is causing symptoms and the person's overall health. People with early-stage CLL who are not exhibiting symptoms typically don't receive treatment. Instead, their condition is monitored by their health care team through blood tests and physical exam, as well as a review of any CLL-related symptoms. This monitoring is often referred to as "active surveillance."

If treatment is recommended, you and your doctor will discuss the approach that is right for you, based on your individual circumstances.

## Targeted Therapy

Targeted therapies focus on binding to specific molecules that are important for cancer cell survival and growth. Targeted therapy treatments are meant to spare healthy tissues and cause fewer side effects than chemotherapy.

Targeted therapies used to treat CLL include:

- **Kinase inhibitors.** Kinase proteins send signals to the cell's control center to help tumor cells grow. Kinase inhibitors block these proteins.
  - **Ibrutinib** (Imbruvica) and acalabrutinib (Calquence) inhibit the function of a type of kinase called Bruton's tyrosine kinase (BTK). Ibrutinib is approved by the U.S. Food and Drug Administration (FDA) as a first-line (initial) treatment for CLL and can be used in combination with immunotherapy (rituximab or obinutuzumab). It is also approved as a treatment for CLL that has recurred.
  - **Idelalisib** (Zydelig) acts as a phosphoinositide 3-kinase (PI3K) inhibitor and can be combined with the immunotherapy rituximab in the treatment of CLL.
  - **Duvelisib** (Copiktra) is used in treatment of people with relapsed (recurring) or refractory (not responding to treatment) CLL after at least two prior therapies. Duvelisib blocks two kinase proteins called PI3K-delta and PI3K-gamma.

- **BCL-2 inhibitors.** These drugs target the B-cell lymphoma 2 (BCL-2) protein, leading to the death of CLL cells. They are approved by the FDA as a first-line therapy for CLL, in combination with the immunotherapy obinutuzumab. They are also approved as a treatment for CLL that has recurred, with or without the immunotherapy rituximab.
- **Immunomodulatory agents.** Lenalidomide (Revlimid) helps the bone marrow produce healthy blood cells while killing abnormal cells. It has been shown to be an effective approach after initial treatment with chemotherapy.

## Chemotherapy

Chemotherapy drugs, given intravenously (through a needle into a vein) or in pill form, can kill cancer cells. Chemotherapy has long been an effective treatment for CLL, and continues to be an important treatment option for some people.

The types of chemotherapy most often given to treat CLL are:

- **Purine analogs**, including fludarabine (Fludara), pentostatin (Nipent) and cladribine (Leustatin). Purine analogs are “antimetabolites” that interfere with DNA production and halt the growth of cancer cells.
- **Alkylating agents**, including chlorambucil (Leukeran) and cyclophosphamide (Cytoxan). These drugs are often used in combination with a purine analog.
- **Bendamustine** (Treanda), an alkylating agent that has some of the same properties as purine analogs.

Chemotherapy treatment often combines two or more drugs, as this seems to be a more effective approach than administering one drug alone (monotherapy). An often-used combination is called FCR, from the initials of the drugs it contains: fludarabine, cyclophosphamide and rituximab (rituximab is not a chemotherapy; it belongs to a group of drugs called monoclonal antibodies).

## Immunotherapy

Our immune system works constantly to keep us healthy. It recognizes and fights against danger, such as infections, viruses and growing cancer cells. In general terms, immunotherapy activates our own immune system.

Immunotherapy is an important treatment option for people with CLL and can be used in combination with chemotherapy or targeted therapy. The most commonly used immunotherapies for CLL are monoclonal antibodies. Anticancer monoclonal antibodies are made in the laboratory and then administered intravenously to target cancer cells. Monoclonal antibodies used in combination with chemotherapy in the treatment of CLL include obinutuzumab (Gazyva), ofatumumab (Arzerra) and rituximab (Rituxan).



# Treatment Approaches Being Studied

There are a number of new approaches being studied for the treatment of CLL, including:

- Research is being conducted on “next-generation” versions of the targeted therapies ibrutinib and idelalisib. These drugs will work in the same way, with modifications intended to make them more effective, with fewer side effects.
- A phase III trial is evaluating the effectiveness of treating CLL with the targeted therapy ibrutinib plus the immunotherapy obinutuzumab, with or without the targeted therapy venetoclax.
- The phase II CLARITY trial showed a combination of the targeted therapies ibrutinib and venetoclax to be promising in the treatment of relapsed or refractory CLL.
- CAR T-cell therapy, a type of immunotherapy, is being evaluated as an option for treating CLL. CAR T-cell therapy follows certain steps, which include drawing blood, separating out and genetically modifying the T-cells, multiplying those cells in a laboratory and infusing them back into the patient, where they attack cancer cells.





# The Importance of Clinical Trials

**Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.**

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new valuable treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit
- You can stop taking part in a clinical trial at any time for any reason.

# Treatment Side Effects

All cancer treatments can cause side effects. It's important that you report any side effects you experience to your health care team so they can help you manage them. Report them right away—don't wait for your next appointment. Doing so may improve your quality of life and allow you to maintain your treatment plan. It's important to remember that not all people experience all side effects, and people may experience side effects not listed here.

## Side Effects of Targeted Therapy

Targeted therapy doesn't have the same effect on the body as do chemotherapy drugs, but it can still cause side effects. Each targeted therapy treatment has unique side effects. It's important to have a discussion with your health care team to understand what these potential side effects are, how to reduce the risk of their occurring and how to minimize their impact should you experience them. It is also important to let your health care team know if you are going to have surgery or any other type of procedure, as these drugs may need to be temporarily stopped. In general, if you're experiencing any new or bothersome symptoms while taking a targeted therapy, it is best to let your doctor know.

## Side Effects of Chemotherapy

The side effects of chemotherapy depend on the type and dose of drugs given and the length of time they are used, and can include:

- Fatigue
- Nausea or vomiting
- Hair loss
- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding (from having a low platelet count)
- Changes in memory or thinking
- Peripheral neuropathy (numbness or tingling in hands and feet)

## Side Effects of Immunotherapy

The immunotherapy used in combination with chemotherapy or targeted therapy for the treatment of CLL travels through the bloodstream, helping to prompt an immune response. Because it can trigger an attack on healthy cells as well as cancer cells, certain side effects may be experienced, including fatigue, decreased appetite and digestive tract symptoms. The management of these potential side effects is discussed in the next section of this booklet.



# General Side Effects

Some side effects may occur across treatment approaches; this section provides tips and guidance on how to manage these side effects should they occur.

## Managing Digestive Tract Symptoms

### *Nausea and vomiting*

- Avoid food with strong odors, as well as overly sweet, greasy, fried or highly seasoned food.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.
- Do not lie down within two hours after eating.

### *Diarrhea*

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose fiber-dense foods such as whole grains, fruits and vegetables, all of which help form stools.
- Avoid food high in refined sugar and those sweetened with sugar alcohols such as sorbitol and mannitol.

## *Loss of appetite*

- Eating small meals throughout the day is an easy way to take in more protein and calories, which will help maintain your weight. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna or trail mix.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

## *Constipation*

- As hydration is important, make sure to drink plenty of fluids. Also, limit your intake of caffeine and alcoholic beverages, as they can cause dehydration.
- Include foods high in fiber in your daily diet, such as fruit (especially pears and prunes), vegetables and cereals. If your health care team approves, you may want to add synthetic fiber to your diet, such as Metamucil, Citrucel or FiberCon.
- Be as physically active as you can, after checking with your doctor on the level of physical activity that is right for you.
- If your doctor has prescribed a “bowel regimen,” make sure to follow it exactly.

## Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking a medication, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking a smaller dose is right for you.

There are a number of other tips for reducing fatigue:

- Take several short naps or breaks during the day.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis and depression. So be sure to ask your doctor if he or she thinks any of these conditions may be contributing to your fatigue.

## Managing Pain

To help your doctor prescribe the best medication, it's useful to give an accurate report of your pain. Keep a journal that includes information on:

- Where the pain occurs
- When the pain occurs
- How long it lasts
- How strong it is on a scale of 1 to 10, with 1 being the least amount of pain and 10 the most intense
- What makes the pain feel better and what makes it feel more intense

There are a number of options for pain relief, including prescription and over-the-counter medications. It's important to talk to a member of your health care team before taking any over-the-counter medication, to determine if they are safe and will not interfere with your treatments.

Physical therapy, acupuncture and massage may also be of help in managing your pain. Consult with a member of your health care team before beginning any of these activities.



# Communicating With Your Health Care Team

As you manage your CLL, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurse practitioners, physician assistants, nurses, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

**Start a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with cancer and treatment. You can separate your journal or notebook into different sections to help keep it organized.

**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, ask your most important questions first and be as specific as possible.

**Bring someone with you to your appointments.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. They may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.



**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. You can also ask the person who accompanies you to take notes for you. If you have a mobile device, ask if you can use it to take notes. Keeping notes will help you review the information later.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

**Incorporate other health care professionals into your team.** Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your CLL treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have or any pain you are experiencing so that they can consult with your primary care physician or specialists as needed.

Remember, there is no such thing as over-communication.



# CancerCare's Free Support Services and Programs

**It can be very difficult to receive a diagnosis of CLL, and adjusting to the necessary changes in your life can be challenging.**

CancerCare® can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.

# Frequently Asked Questions

### **Q: What reasons would warrant the move from active surveillance to treatment for my CLL?**

A: Many people living with CLL can stay on active surveillance for a long period of time, even years. There are well-established criteria for beginning treatment, including the experience of certain symptoms, such as:

- Severe fatigue
- Significant unintended weight loss
- Excessive sweating
- Pain coming from the spleen
- Enlarged or uncomfortable lymph nodes
- Certain changes in blood counts

It is essential that you visit your doctor regularly for blood tests and to alert them to any symptoms you might be having.

### **Q: Am I more susceptible to infections when being treated for CLL?**

A: People with CLL have an increased risk of infection, both from the disease itself and its treatment. When white blood cells are abnormally low (a condition called neutropenia), an infection may progress rapidly and become serious. For this reason, it's important that people being treated for CLL immediately report fevers or other signs of infection to their health care team.

During treatment, you should avoid contact with those who have symptoms of a cold and should stay away from crowded places during cold and flu season.

### **Q: Should I get a flu shot while being treated for CLL?**

A: The Centers for Disease Control and Prevention (CDC) recommends seasonal flu shots for people being treated for any form of cancer, including CLL. Flu shots are safe for people with compromised immune systems, as they they're made from an inactivated virus. The nasal mist form of the flu vaccine should not be taken, as it's made from a live virus. It's also important that family members and close companions of those receiving any type of cancer treatment get flu shots to prevent catching and passing on the flu.

On a related note, ask your doctor or a member of your health care team if you should continue to receive the vaccines recommended for your age and specific situation, such as those for pneumonia, shingles and herpes zoster.

### **Q: Is stem cell transplantation a treatment option for CLL?**

A: A stem cell transplant is a procedure in which diseased bone marrow (the spongy tissue inside bones where blood cells are made) is replaced with healthy bone marrow. It is not a common treatment approach for CLL, as there are a number of effective drugs available that avoid the risk associated with a stem cell transplant. Stem cell transplantation may be recommended in certain circumstances; for example, in cases where the CLL has not responded to other treatment approaches.

If stem cell transplantation is chosen as a treatment for CLL, the stem cells are harvested (removed) from a donor (often a close relative, such as a brother or sister) and subsequently delivered to the patient. The stem cells are then "infused" (transplanted) into the body, where they travel to the bones and begin rebuilding bone marrow.

# Notes

# Resources

## **CancerCare®**

800-813-HOPE (800-813-4673)  
[www.cancercares.org](http://www.cancercares.org)

## **American Cancer Society**

800-227-2345  
[www.cancer.org](http://www.cancer.org)

## **Cancer.Net**

Patient information from  
the American Society of  
Clinical Oncology  
888-651-3038  
[www.cancer.net](http://www.cancer.net)

## **National Cancer Institute**

800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

## **Cancer Support Community**

888-793-9355  
[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## **National Coalition for Cancer Survivorship**

877-622-7937  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

## **CLINICAL TRIALS WEBSITES**

### **EmergingMed**

[www.emergingmed.com](http://www.emergingmed.com)

### **National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)

## **BLOOD CANCER ORGANIZATIONS**

### **Be The Match®**

800-627-7692  
[www.bethematch.org](http://www.bethematch.org)

### **Blood & Marrow Transplant Information Network**

800-597-7674  
[www.bmtinfonet.org](http://www.bmtinfonet.org)

### **CLL Society**

[www.clisociety.org](http://www.clisociety.org)

### **The Leukemia & Lymphoma Society**

800-955-4572  
[www.lls.org](http://www.lls.org)

### **National Bone Marrow Transplant Link**

800-546-5268  
[www.nbmtlink.org](http://www.nbmtlink.org)

### **Medicine Assistance Tool**

[www.medicineassistancetool.org](http://www.medicineassistancetool.org)

This activity is supported by Pharmacyclics LLC, an AbbVie Company and Janssen Biotech, Inc., administered by Janssen Scientific Affairs, LLC.



**CANCER***care*<sup>®</sup>

Help and Hope

---

**WWW.CANCERCARE.ORG**  
**800-813-HOPE (4673)**