

# PATIENT RESOURCE

6th Edition

# CHRONIC LYMPHOCYtic LEUKEMIA

*A Treatment Guide for Patients  
and their Families*

**FREE** take one

*Be a partner  
in your  
care plan*



*For guide to*  
**LEUKEMIA, LYMPHOMA & MULTIPLE MYELOMA**

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**AstraZeneca** 

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6th Edition

# CHRONIC LYMPHOCYTIC LEUKEMIA



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## IN THIS GUIDE

- 3 Introduction & Staging:** Understand the unique aspects of your diagnosis
- 4 Treatment Planning:** Shared decision making is key to managing your treatment
- 5 Living With CLL:** Managing a chronic disease
- 6 Medication Adherence:** The importance of being on time with your treatment
- 7 Personal Perspective:** Research helps Sharon move forward confidently
- 8 Fictional Case Studies:** Exploring multiple treatment paths for CLL

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**Download these helpful worksheets**

Use these worksheets to stay on schedule with your medications and track your laboratory test results. Download and print them at [PatientResource.com/CLL\\_Medication\\_Journal](http://PatientResource.com/CLL_Medication_Journal) and [PatientResource.com/CLL\\_Laboratory\\_Test\\_Tracker](http://PatientResource.com/CLL_Laboratory_Test_Tracker)

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**CALQUENCE**<sup>®</sup>  
(acalabrutinib) 100 mg capsules

"...and if you have the opportunity to *support* somebody else, I would encourage you to do that, because it's really gratifying and *appreciated*."

– Jane | Wife and Caregiver of Cliff,  
a Real CALQUENCE Patient

## **YOU ARE NOT ALONE** with chronic lymphocytic leukemia (CLL)

The **CALQUENCE Connections Facebook Group** is a community for patients—whether currently taking CALQUENCE<sup>®</sup> (acalabrutinib) or soon to begin treatment—and their caregivers to guide and assist each other throughout treatment.

Join the Facebook group today at  
[www.facebook.com/groups/calquenceconnections](https://www.facebook.com/groups/calquenceconnections)  
or scan the QR code with your phone's camera.



### Select Safety Information

CALQUENCE is a prescription oral treatment for adults with chronic lymphocytic leukemia or small lymphocytic lymphoma. May cause serious side effects including: serious infections, bleeding problems, decrease in blood cell count, new cancers, and heart rhythm problems. Some may lead to death. Tell your doctor if you experience infections such as flu-like symptoms; unexpected bleeding such as blood in your stool or urine; or heart rhythm problems such as fast or irregular heartbeat. Use sun protection when outside.

**Please read Brief Summary of Prescribing Information on adjacent page.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](https://www.fda.gov/medwatch) or call 1-800-FDA-1088.

If you cannot afford your medication, AstraZeneca may be able to help. Visit [AstraZeneca-us.com](https://www.astrazeneca-us.com) to find out how.

## PATIENT INFORMATION

# CALQUENCE® (KAL-kwens) (acalabrutinib) capsules

  
**CALQUENCE**  
(acalabrutinib) 100 mg capsules

### What is CALQUENCE?

CALQUENCE is a prescription medicine used to treat adults with:

- Chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).

It is not known if CALQUENCE is safe and effective in children.

### Before taking CALQUENCE, tell your healthcare provider about all of your medical conditions, including if you:

- have had recent surgery or plan to have surgery. Your healthcare provider may stop CALQUENCE for any planned medical, surgical, or dental procedure.
- have bleeding problems.
- have or had heart rhythm problems.
- have an infection.
- have or had liver problems, including hepatitis B virus (HBV) infection.
- are pregnant or plan to become pregnant. CALQUENCE may harm your unborn baby and problems during childbirth (dystocia).
  - If you are able to become pregnant, your healthcare provider may do a pregnancy test before you start treatment with CALQUENCE
  - Females who are able to become pregnant should use effective birth control (contraception) during treatment with CALQUENCE and for at least 1 week after the last dose of CALQUENCE.
- are breastfeeding or plan to breastfeed. It is not known if CALQUENCE passes into your breast milk. Do not breastfeed during treatment with CALQUENCE and for at least 2 weeks after your final dose of CALQUENCE.

**Tell your healthcare provider about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking CALQUENCE with certain other medications may affect how CALQUENCE works and can cause side effects. Especially tell your healthcare provider if you take a blood thinner medicine.

### How should I take CALQUENCE?

- Take CALQUENCE exactly as your healthcare provider tells you to take it.
- Do not change your dose or stop taking CALQUENCE unless your healthcare provider tells you to.
- Your healthcare provider may tell you to decrease your dose, temporarily stop, or completely stop taking CALQUENCE if you develop certain side effects.
- Take CALQUENCE 2 times a day (about 12 hours apart).

(continued)

- Take CALQUENCE with or without food.
- Swallow CALQUENCE capsules whole with a glass of water. Do not open, break, or chew capsules.
- If you need to take an antacid medicine, take it either 2 hours before or 2 hours after you take CALQUENCE.
- If you need to take certain other medicines called acid reducers (H-2 receptor blockers), take CALQUENCE 2 hours before the acid reducer medicine.
- If you miss a dose of CALQUENCE, take it as soon as you remember. If it is more than 3 hours past your usual dosing time, skip the missed dose and take your next dose of CALQUENCE at your regularly scheduled time. Do not take an extra dose to make up for a missed dose.

### What are the possible side effects of CALQUENCE?

#### CALQUENCE may cause serious side effects, including:

- **Serious infections** can happen during treatment with CALQUENCE and may lead to death. Your healthcare provider may prescribe certain medicines if you have an increased risk of getting infections. Tell your healthcare provider right away if you have any signs or symptoms of an infection, including fever, chills, or flu-like symptoms.
- **Bleeding problems (hemorrhage)** can happen during treatment with CALQUENCE and can be serious and may lead to death. Your risk of bleeding may increase if you are also taking a blood thinner medicine. Tell your healthcare provider if you have any signs or symptoms of bleeding, including:
  - blood in your stools or black stools (looks like tar)
  - pink or brown urine
  - unexpected bleeding, or bleeding that is severe or you cannot control
  - vomit blood or vomit that looks like coffee grounds
  - cough up blood or blood clots
  - dizziness
  - weakness
  - confusion
  - changes in your speech
  - headache that lasts a long time
  - bruising or red or purple skin marks
- **Decrease in blood cell counts.**

Decreased blood counts (white blood cells, platelets, and red blood cells) are common with CALQUENCE, but can also be severe. Your healthcare provider should do blood tests to check your blood counts regularly during treatment with CALQUENCE.

(continued)

- **Second primary cancers.** New cancers have happened in people during treatment with CALQUENCE, including cancers of the skin or other organs. Your healthcare provider will check you for skin cancers during treatment with CALQUENCE. Use sun protection when you are outside in sunlight.
- **Heart rhythm problems (atrial fibrillation and atrial flutter)** have happened in people treated with CALQUENCE. Tell your healthcare provider if you have any of the following signs or symptoms:
  - fast or irregular heartbeat
  - dizziness
  - feeling faint
  - chest discomfort
  - shortness of breath

### The most common side effects of CALQUENCE include:

- headache
- diarrhea
- muscle and joint pain
- upper respiratory tract infection
- bruising

These are not all of the possible side effects of CALQUENCE.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

### How should I store CALQUENCE?

- Store CALQUENCE at room temperature between 68°F to 77°F (20°C to 25°C).

### Keep CALQUENCE and all medicines out of the reach of children.

### General information about the safe and effective use of CALQUENCE.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use CALQUENCE for a condition for which it was not prescribed. Do not give CALQUENCE to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for more information about CALQUENCE that is written for health professionals.

### What are the ingredients in CALQUENCE?

**Active ingredient:** acalabrutinib

**Inactive ingredients:** silicified microcrystalline cellulose, pregelatinized starch, magnesium stearate, and sodium starch glycolate.

Capsule shell contains: gelatin, titanium dioxide, yellow iron oxide, FD&C Blue 2, and black ink.

For more information, go to [www.CALQUENCE.com](http://www.CALQUENCE.com) or call 1-800-236-9933.

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# Understand the unique aspects of your diagnosis

**R**ecceiving a **chronic lymphocytic leukemia** (CLL) diagnosis is life-changing. Although it is a condition that is managed, not cured, it may ease your mind to know that advances in CLL treatment are being made at a rapid pace. This progress is life-changing, too, but in a much more encouraging way. More personalized treatment options are allowing many people to manage this type of blood cancer while still living life on their terms.

CLL is a type of leukemia that begins in the blood and bone marrow (the soft, spongy center of some bones). It develops from a type of white blood cell known as a lymphocyte. Lymphocytes make up lymphoid tissue, which is found in the lymph nodes, thymus, spleen, tonsils and other parts of the body. They are a part of the immune system.

When mature lymphocytes change and multiply uncontrollably, growing at a faster rate than usual and not dying when they should, they build up and circulate in the bloodstream and can spread to other parts of the body. These abnormal lymphocytes accumulate in the blood, bone marrow, lymph nodes and spleen. They interfere with the normal production of healthy cells, including red blood cells that carry oxygen, white blood cells that fight infection and platelets that help blood to clot. Patients with CLL often have larger-than-normal lymph nodes that can appear as lumps in the neck, armpits or groin regions.

## GET YOUR FACTS

Understanding the details of your diagnosis enables you to take an active role in your care. Because of the fast pace at which CLL research and advances are happening, consider choosing a hematologist with expertise in treating CLL.

Your diagnosing physician should be able to give you a referral. If a CLL specialist is not nearby and traveling is not an option, look for a CLL specialist to consult with your doctor and offer a second opinion to confirm the suggested treatment plan or add other options to consider. Connect with CLL support groups and learn how other people with CLL found their physicians. Advocacy groups, such as the CLL Society, are another resource. CLL Society's program, Expert Access™, offers a free consultation to patients seeking a second opinion ([cllsociety.org/programs-and-support/expert-access](http://cllsociety.org/programs-and-support/expert-access)).

## TEST RESULTS GUIDE YOUR TREATMENT

Your doctor will perform a physical examination to check for pain, enlarged lymph nodes and size irregularities in your spleen and other organs, as well as blood tests and genomic testing.

Blood tests are used to measure blood cell counts so your doctor can assess your risk for infections and to check that your liver and kidneys are working properly before starting treatment. Genomic testing, also called molecular profiling, tests a small sample of tissue, blood or other fluid to identify specific gene abnormalities or mutations, proteins and changes in chromosomes. These tests help

distinguish CLL from other forms of leukemia, determine the subtype (B-cell CLL or T-cell prolymphocytic leukemia), check for specific markers that may help predict whether the disease will progress, and select treatment.

Genomic testing may also be used to find the following:

1. *TP53* gene mutation status
2. Immunoglobulin heavy chain variable (*IGHV*) status
3. Serum B2-microglobulin concentration
4. Deletion of chromosomes 11q, 13q or 17p
5. An extra copy of chromosome 12 (trisomy)
6. *NOTCH1*, *SF3B1* or *MYD88* mutations

The tests may include the following:

- Fluorescence in situ hybridization (FISH) to examine genes or chromosomes
- Flow cytometry to look for markers
- Immunohistochemistry to verify a CLL diagnosis
- Next-generation sequencing to test multiple genes
- Karyotyping to look for abnormal chromosomes or structures

As the disease progresses, the status of your molecular test results may change. Tests will be re-run before changing the treatment strategy.

The Modified Rai Staging System and the Chronic Lymphocytic Leukemia International Prognostic Index (CLL-IPI) further assist your doctor (see Tables 1 and 2). Modified Rai offers information about how CLL may progress. CLL-IPI incorporates the Rai stage and predicts the risk of disease recurrence and overall survival.

Your doctor will also consider the clinical stage, your age and other criteria to help determine the most effective treatment. ■

**TABLE 1**  
**MODIFIED RAI STAGING SYSTEM**

Stage	Risk	Description
Stage 0	Low	Lymphocytosis only (the blood contains a significant number of lymphocytes).
Stage I	Intermediate	+ Adenopathy (the blood contains a significant number of lymphocytes, and lymph nodes are enlarged).
Stage II	Intermediate	+ Enlarged spleen and/or liver (the blood contains a significant number of lymphocytes, the spleen and/or liver is enlarged, and the lymph nodes may or may not be enlarged).
Stage III	High	Lymphocytosis + Hgb < 11g/dL (the blood contains a significant number of lymphocytes, and the hemoglobin is less than 11 grams per deciliter).
Stage IV	High	Lymphocytosis + Plt < 100,000/ $\mu$ L (the blood contains a significant number of lymphocytes, and the platelet count is less than 100,000 microliters).

In addition to this staging system, some oncologists may also use the Chronic Lymphocytic Leukemia International Prognostic Index (CLL-IPI) to predict the risk of disease recurrence and overall survival. Your doctor, after evaluating your physical examination and diagnostic test results, takes into account your *TP53* status, *IGHV* mutation status, serum B2-microglobulin concentration, clinical stage and age.

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

**TABLE 2**  
**CHRONIC LYMPHOCYTIC LEUKEMIA INTERNATIONAL PROGNOSTIC INDEX (CLL-IPI)**

The CLL-IPI assigns weighted values for each of the following risk factors.

Risk factors	Points
<i>TP53</i> mutation	4
<i>IGHV</i> unmutated	2
Serum B2-microglobulin more than 3.5 mg/L	2
Rai Stages I-IV	--
Age older than 65 years	1

# Shared decision making is key to managing your treatment

**D**eveloping a solid patient-doctor relationship is vital to the success of your CLL treatment. You will be a key partner in your care plan, and it is important to be comfortable asking questions, sharing information and advocating for yourself. As you work closely with your medical team on a treatment strategy, discuss the options that are available to you, potential side effects of each and the goal you hope to achieve.

Ideally, the goal of any cancer treatment is to cure. With CLL, however, “cure” can mean different things. It could be reaching remission with no signs or symptoms of cancer, or it could be managing the disease as you would a chronic condition.

The treatment approach for CLL is different than for most types of cancer. It typically does not begin until symptoms or test results indicate it is necessary. When that time comes, your doctor will ask for your input about how certain types of treatment may fit in with your perception of your quality of life. For example, some therapies are given as infusions at a medical office while others are oral therapies taken at home. Helping you manage your CLL in a way that enables you to continue enjoying life is a priority.

## TREATMENT OPTIONS

Depending on your test results, you may have one or more of the treatments discussed here. Keep in mind that as the disease changes, so will your treatment. Consistent monitoring and honest communication will help ensure your condition continues to be managed most effectively. Your input will help determine when to begin treatment and when it may be time to consider a different treatment strategy.

**Active surveillance**, sometimes referred to as watch and wait, is often recommended for low-stage or low-risk CLL. Research shows that treating early does not result in a better

outcome, and it enables people to avoid treatment-related side effects until it is necessary, which can sometimes be years. Although you may feel you are not being proactive about your condition, keeping follow-up appointments and alerting your medical team immediately if you experience any symptoms are important responsibilities. See *Living with CLL* on page 5 for suggestions on how to manage the stress that often accompanies active surveillance.

Any of these symptoms may indicate the CLL is progressing. It is important that you alert your doctor if you are experiencing any of the following:

- Unexplained weight loss
- Severe fatigue
- Fevers above 100.4 °F without evidence of infection
- Drenching night sweats
- Spleen or lymph node enlargement
- Shaking; chills
- Chest pain or shortness of breath
- Excessive bleeding or bruising; clotting issues
- Bloody or cloudy urine
- Diarrhea lasting more than two days without improvement; bloody or black stool
- Signs of dehydration: excessive thirst, dry mouth, little or no urination, dark-colored urine, severe weakness, dizziness or lightheadedness
- Severe abdominal or rectal pain
- Heart palpitations

**Clinical trials** may be the best first treatment option for your specific diagnosis, even if symptoms do not yet indicate you need treatment. Clinical trials are studies that evaluate whether a new treatment, such as a drug or vaccine, drug combination, surgical procedure, type of radiation therapy or a combination of therapies, is more effective or better in some way than the current standard of care.

**Targeted therapy**, commonly the first treatment given for CLL, is a personalized strategy that enables your doctor to use the results from your genomic (molecular) testing to target specific genes and proteins that are causing cancer cells to grow and multiply. This option allows your medical team to control the disease while limiting damage to healthy cells, which may result in fewer side effects. Some targeted therapy drugs are oral medications given in pill form, and others are given intravenously (IV). Some may be used alone or in combination with other therapies.

Using one type of targeted therapy does not eliminate the option of using another if that type fails or becomes less effective, or if a relapse occurs. This flexibility is appealing to both doctors and patients. Additionally, one therapy may require time off work because of the many office visits at the beginning, but it is only taken for a specific amount of time. Another therapy may be more convenient because it is taken at home, yet it must be taken indefinitely. Talk with your doctor about which targeted therapy might be a better fit for you.

Following are the types of targeted therapy:

- Tyrosine kinase inhibitors (TKIs) block certain substances that control how cells grow and divide. One type, called a Bruton’s tyrosine kinase (BTK) inhibitor, blocks the BTK protein, which may promote the growth of abnormal B-cells.
- BCL-2 inhibitors block the BCL-2 protein, which is found in leukemia cells.
- Monoclonal antibodies are laboratory-made immune system proteins that attach to a specific target on cancer cells or other cells that may help cancer grow. The antibodies are then able to kill the cancer cells, block their growth or keep them from spreading.

## TERMS TO KNOW

**Complete remission:** All signs and symptoms of cancer have disappeared, but cancer may still be in the body.

**Partial remission:** Leukemia levels are significantly reduced, but there is still evidence of some leukemia cells.

**Minimal residual disease (MRD):** A term used to describe a very small number of cancer cells that remain in the body during or after treatment. Specialists use highly sensitive laboratory tests to find one cancer cell among one million normal cells. This information helps your doctor to plan further treatment and monitor you to determine whether the treatment is working or if cancer has returned.

**Corticosteroids** are anti-inflammatory drugs that appear to help cause the death of cancerous white blood cells. They may be given with other drug therapies.

**Chemoimmunotherapy** combines chemotherapy with immunotherapy, a treatment that stimulates or restores the ability of the immune system to fight cancer. It may be used for CLL that does not have the 17p deletion and *TP53* mutation.

**Radiation therapy** may be used to shrink an enlarged spleen or swollen lymph nodes, relieve certain symptoms or assist in the conditioning phase of a stem cell transplant.

An **allogeneic stem cell transplant**, which uses stem cells from a volunteer donor, may be used to treat CLL. The goal of transplantation is for your blood counts to return to safe levels and/or remission. (Flip over this guide to see *Stem Cell Transplantation*, page 16.)

**Chemotherapy** may be used in some instances and combined with other therapies. It may be given in high doses before a stem cell transplant in a process known as conditioning.

**Surgery** may be used to remove an enlarged spleen (splenectomy).

#### RELAPSED AND REFRACTORY CLL

CLL may return in different ways.

**Relapsed (or recurrent) CLL** is cancer that has come back, usually after a period of time during which it cannot be detected. If this occurs, your doctor will begin a new cycle of diagnostic tests, which may include another biopsy and laboratory tests. Your doctor will confirm whether the cancer is recurrent and whether it has transformed into a more aggressive subtype, which will affect your treatment plan.

**Refractory CLL** is cancer that does not respond to or improve with treatment. Your

#### SOME DRUG THERAPIES FOR CLL

*These therapies may be used alone or in combination. For some possible combination therapies your doctor might suggest, go to [PatientResource.com/CLL\\_Treatment](http://PatientResource.com/CLL_Treatment)*

- ▶ acalabrutinib (Calquence)
- ▶ bendamustine (Bendeka)
- ▶ chlorambucil (Leukeran)
- ▶ cyclophosphamide
- ▶ dexamethasone
- ▶ doxorubicin hydrochloride (Adriamycin)
- ▶ duvelisib (Copiktra)
- ▶ fludarabine phosphate (Fludara)
- ▶ ibrutinib (Imbruvica)
- ▶ idelalisib (Zydelig)
- ▶ methylprednisolone
- ▶ obinutuzumab (Gazyva)
- ▶ ofatumumab (Arzerra)
- ▶ prednisone
- ▶ rituximab (Rituxan)
- ▶ rituximab and hyaluronidase human (Rituxan Hycela)
- ▶ venetoclax (Venclexta)

As of 10/7/22

doctor will consider the options you have already tried and your overall health before recommending another plan. If your doctor does not specialize in CLL, get a second opinion to ensure you learn about all your options, including clinical trials. ■

## Living with CLL

➔ **Managing a chronic disease means taking actions to keep yourself as healthy as possible. Consider these recommendations.**

**Lead a healthy lifestyle.** Focus on making positive choices in many areas of your life, such as being active, following a healthy diet and surrounding yourself with support. Research shows exercising and following a nutritious diet offers many health benefits, including helping you be better prepared for future health issues.

**Lower your risk of infection.** People with CLL often have weakened immune systems, which may make them more susceptible to developing infections. Infections while you are already managing CLL can become serious, making it important to detect and treat infections as soon as they start. Your doctor will talk with you about the signs to watch for and what to do if they occur.

You are encouraged to stay up to date with vaccinations, which may include those for the flu, pneumonia, shingles and COVID-19. Ask your doctor about an additional layer of protection against COVID-19 for immunocompromised individuals, which includes people who have CLL at any stage.

Also, stay vigilant about your health screenings for other cancers, such as mammograms, colonoscopies, skin exams, Pap smears, HPV testing, prostate-specific antigen (PSA) blood tests and any additional testing your doctor recommends.

**Take advantage of supportive care.** Most cancer treatments have side effects, and they can be more intense with combination therapies. Keep in mind that people respond differently, even to the same diagnosis and type of treatment. To help you maintain the best quality of life possible, your health care team will rely on a group of services known as supportive care. Also referred to as palliative care, supportive care addresses physical and emotional side effects along with the practical, spiritual, financial and family-related challenges associated with cancer. Counseling about nutrition; fitness; mental health; spirituality; physical/occupational therapy; speech therapy; complementary medicine and other areas is also available.

Severe side effects are not common but can occur with certain types of treatment. Ask whether you are at risk, how you can identify the signs and what to do if they occur. Prompt treatment may help prevent more serious complications.

Late effects are side effects that do not begin immediately during treatment. They may appear weeks, months or even years after treatment begins. They may go away over time or be permanent. They often depend on the type of treatment and the length of time it was given, as well as your age, gender and overall health.

**Consider telehealth options.** Telehealth is accessing medical care from a distance through technology. It is not designed to replace in-person visits but may be a convenient option for certain types of visits, especially if you are in remission, taking oral-based therapies or receiving maintenance therapy.

**Stay on course.** Commit to taking your treatments and going to your appointments. Appointments are important for monitoring treatment, addressing side effects or issues, and detecting a recurrence or second cancer early. A second cancer is a completely different or new type of cancer diagnosis.

During your regularly scheduled appointments, you will have exams and lab tests to look for physical signs of CLL and to measure how well the CLL is responding to current treatment. When your treatment is no longer working or is not as effective as it once was, your doctor may try another therapy.

**Manage your scanxiety.** Whether you are in active surveillance or monitoring your treatment, you may feel anxious before scans or other tests and while waiting for results. It may help to ask when to expect results, how you will receive them, and who will deliver them to you. Then, occupy yourself with things you enjoy, such as watching a movie, calling a friend, going for a walk or meditating. If you need additional relief, talk with your doctor about medications that may help. Above all, give yourself a break. It is normal to have feelings like these.

# The importance of being on time with your treatment

**T**aking the right drug in the right dose at the right time – every time – for as long as prescribed is medication adherence. Adherence is extremely important to get the most benefit from a drug. Whether you are taking oral therapy (pills) or getting intravenous (IV) treatments, you are responsible for taking your treatment just as your doctor intends. Though it may sound simple, it requires serious effort to make it happen.

Taking your medication correctly is important in the fight against cancer because it can influence the effectiveness of the treatment. Most therapies are designed to maintain a specific level of medication in your system for a certain time based on your symptoms, overall health and other factors.

An increasing number of CLL drug treatments are now available as pills. The advantages over IV treatments include the comfort and convenience of taking your medicine at home without traveling to a hospital or doctor's office, less risk of side effects and a greater sense of control over your own care.

However, if your medications are not tak-

en exactly as prescribed, the consequences can be serious, even life-threatening. Track each dose, including missed doses or appointments, and detail any side effects.

Even with the best of intentions, it is easy to forget how important it is to stay on the proper medication schedule. Sometimes life gets in the way, or you may simply not understand the effects of missing a dose. Unintentional noncompliance or non-adherence is the missing, skipping or stopping of your medications without understanding the harmful effects of those choices.

Non-adherence can lead to unnecessary side effects, physician visits, hospitalizations and even cancer progression.

Following are suggestions for maintaining long-term medication adherence:

- Ask your pharmacist to explain how to take your medicine and discuss possible drug interactions.
- Keep a treatment diary that includes when you take the pills, and write down any missed or skipped doses. Share your diary with your doctor so trends can be addressed right away.
- Set up reminders for taking your medicine and scheduling refills. A reminder can be an alarm on your clock or phone.
- Try weekly pill organizers to keep track of and organize your medications.
- Understand that treating CLL will require diligence and consistency for the rest of your life. It is common for many people to experience treatment fatigue. Discuss this with your doctor.
- Contact your doctor if side effects or symptoms become too challenging. ■

## Frequently Asked Questions

**Q** Can I stop taking my medications if I haven't felt symptoms for several months?

**A** No. Not having any symptoms indicates the therapy is working. Treating CLL focuses on controlling or maintaining the progression of the disease, which means the medication helps prevent it from worsening or recurring.

**Q** Side effects from treatment feel worse than the symptoms of CLL. Can I stop the medication to get some relief?

**A** Talk with your doctor about other therapies. Advances in CLL have led to many treatment options with side effects that you may tolerate better.

**Q** I cannot afford my treatment. Is it ok if I cut my dose in half to save money?

**A** Cutting a dosage is never a good idea. Your treatment should be taken the way it is prescribed so it is most effective for you. Many financial and advocacy resources are available that may be able to help. Ask a member of your health care team to connect you with those resources.



**Q** Can I take more medication than I've been prescribed? If the original dose works, a higher dose may work even better.

**A** This is sometimes called "intentional over-adherence." Although it might seem to make sense, the dose you've been prescribed is designed to be the most effective for you. Higher doses may lead to increased side effects, which may make the health care team believe you cannot tolerate the drug. It may also lead to unnecessary diagnostic tests.

**Q** I keep forgetting when or if I've taken my medication. What can I do?

**A** It can help to keep a diary of when you take your medication. Download and make copies of *My CLL Medication Journal* at [www.PatientResource.com/CLL\\_Medication\\_Journal](http://www.PatientResource.com/CLL_Medication_Journal)

### PATIENT ASSISTANCE RESOURCES For more resources, flip over this guide and see pages 23-24.

- ▶ **myAbbVie Assist:** [www.abbvie.com/patients/patient-assistance](http://www.abbvie.com/patients/patient-assistance)
- ▶ **Arzerra Oncology Access Program:** [us.arzerra.com](http://us.arzerra.com)
- ▶ **AstraZeneca Access 360:** [www.myaccess360.com/patient](http://www.myaccess360.com/patient)
- ▶ **Bendeka Teva CORE:** [www.tevacore.com/patient-assistance](http://www.tevacore.com/patient-assistance)
- ▶ **Calquence Access 360:** [www.myaccess360.com/patient/calquence-acalabrutinib/patient-affordability](http://www.myaccess360.com/patient/calquence-acalabrutinib/patient-affordability)
- ▶ **Copiktra Secura Care:** [copiktra.com/patient-assistance](http://copiktra.com/patient-assistance)
- ▶ **Gazyva Access Solutions:** [www.gazyva.com/first-line-cll/financial-support/ways-to-save.html](http://www.gazyva.com/first-line-cll/financial-support/ways-to-save.html)
- ▶ **Genentech Access Solutions:** [www.genentech-access.com/patient](http://www.genentech-access.com/patient)
- ▶ **Gilead's Advancing Access:** [www.gileadadvancingaccess.com](http://www.gileadadvancingaccess.com)
- ▶ **GSK For You:** [www.gskforyou.com](http://www.gskforyou.com)
- ▶ **Imbruvica By Your Side Patient Support:** [www.imbruvica.com/imbruvica-by-your-side](http://www.imbruvica.com/imbruvica-by-your-side)
- ▶ **Novartis Patient Assistance NOW Oncology:** [patient.novartisoncology.com/financial-assistance/pano](http://patient.novartisoncology.com/financial-assistance/pano)
- ▶ **Rituxan Access Solutions:** [www.genentech-access.com/patient/brands/rituxan-nhl-cll](http://www.genentech-access.com/patient/brands/rituxan-nhl-cll)
- ▶ **Rituxan Hycela Access Solutions:** [genentech-access.com/patient/brands/rituxan-hycela](http://genentech-access.com/patient/brands/rituxan-hycela)
- ▶ **Secura Care Patient Support Program:** [securabio.com/patient-support-programs](http://securabio.com/patient-support-programs)
- ▶ **Teva CORE:** [www.tevacore.com/patient-assistance](http://www.tevacore.com/patient-assistance)
- ▶ **Venclexta Access Solutions:** [genentech-access.com/patient/brands/venclexta](http://genentech-access.com/patient/brands/venclexta)
- ▶ **Zydelig AccessConnect:** [www.zydeligaccessconnect.com/patient](http://www.zydeligaccessconnect.com/patient)

*Sharon didn't let a diagnosis of chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) at 72 slow her down. Taking a practical approach, with the combined support of her husband Rob and a trusted oncologist, helps her enjoy an active, happy life. Since beginning treatment in 2021, she has traveled from her home in the Midwest to Colorado, Texas, California and Paris, France. She hopes her experiences will offer insight and encouragement to other people facing CLL.*



## *Research and trust help this survivor move forward confidently*

### ➤ **Night sweats, disrupted sleep, general fatigue**

and a lump on my neck were the symptoms. I also felt a little down. I wasn't sure whether to blame it on COVID-19, just getting older or something else, so I saw my doctor. Blood work showed my white blood cell count was way out of range. He suspected I had a form of leukemia. He asked a pathologist to run a flow cytometry test to confirm it. The diagnosis was chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL).

My doctor made an oncology referral, but I chose to see the oncologist who treated my breast cancer six years before. I was comfortable with him and trusted him. He suggested we "wait and see" for a bit. I talked with a friend at church who had CLL and saw the same oncologist. She had been "waiting and seeing" for a couple of years. For me, that approach lasted just a couple of months. I began to have more lumps, a CT scan showed that my spleen was enlarged, and my blood work indicated it was time to treat.

My oncologist recommended a type of oral medication. In his opinion, it would result in the best outcome. And, it wouldn't make me lose my hair, which made me happy. Being able to take pills instead of having to get infusions was wonderful. I am grateful that medical science came up with this option.

Had I not been comfortable with his treatment plan or if it wasn't effective, I would have sought a second opinion. Fortunately, my numbers starting dropping like a rock right away. The night sweats subsided, I'm no longer fatigued and I sleep much better now. I bruise easily, and I have occasional bone pain in my limbs but it's not extreme. At first, I followed up with blood work monthly, and now I go every couple of months. In that first year, I was also sent for three CT scans. Now, I let my body tell me how it's doing, and my oncologist pays attention to the numbers.

Rob and I are very self-sufficient. We try not to worry about things we can't control. We both worked in the medical field. I ran a medical office, and he was in pharmaceuticals. I think having background knowledge of how things work in that world and a familiarity with the language helped us better understand the diagnosis and treatment process.

I don't really talk too much with friends about having CLL. I looked into support groups on Facebook, but my family is really my support system. We have two children and five grandchildren who we try to see regularly, and Rob helps me however he can. He is always reassuring and works on being sensitive to how I'm feeling. He avoids adding extra responsibilities to my plate. I love it when Rob cooks! We have always been supportive of each other's health issues and work well as a team.

It helps to lead a healthy lifestyle when you have CLL. We try to eat a fairly healthy diet. We don't eat as many desserts as we used to, but I enjoy fruits and vegetables.

I exercise in different ways depending on the season. I walk regularly until it gets too hot outside. I take a chair exercise class at church, and sometimes I swim.

To help lower my risk of infection, Rob runs more errands than I do. I wear a mask when I go out. I also received infusions of monoclonal antibodies to help boost my immunity and prevent me from getting COVID-19. I have felt really good since getting them, even well enough to take vacations.

I'd always wanted to see Paris, so Rob and I went with four other friends. We cruised up the Seine, toured many interesting sites along the Seine, visited the beaches at Normandy and enjoyed excellent food. It was probably my favorite vacation. ■

### ➤ **Advice from Sharon and Rob**

- ▶ Don't panic. Instead, educate yourself by talking to your doctor and researching reputable websites. Knowing what to expect always helps.
- ▶ Find a good doctor you trust. Ask questions. Your comfort level is important.
- ▶ CLL can take many forms and lead you down many roads. Though it seems strange, "wait and see" might be the right treatment for you until it's not. Trust your doctor, and go with it.
- ▶ Talking to others who have CLL can help ease your anxiety.
- ▶ Stay as positive as you can. It is easy to go into a deep depression when you hear you have cancer. It is devastating, I know, but excessive worry will affect your health and make things worse.
- ▶ Try to de-stress. Meditate, take a walk in nature or find strength in your faith. Do whatever you can to calm yourself.
- ▶ Know that there are advances in medical science all the time.

# Exploring multiple treatment paths for CLL

➔ Following are two sample scenarios of patients whose chronic lymphocytic leukemia diagnoses led them down different treatment paths. The patients are not real.

## FICTIONAL CASE STUDY # 1

**James**, age 71 (*James is not a real patient.*) / **Diagnosis:** Chronic Lymphocytic Leukemia

➔ **James has been more fatigued than usual** and he feels a bump on his neck that isn't going away, so he calls his doctor. Blood test results show elevated levels of white blood cells and low levels of red blood cells. His doctor refers him to a hematologist.

The hematologist reviews James' blood work and orders additional tests. Results confirm it is chronic lymphocytic leukemia (CLL). This doctor refers him to a CLL specialist.

The specialist orders more blood work to closely examine the leukemia cells and a CT to check for organ enlargement. Tests show James has a deletion of the long arm of chromosome 13, a *TP53* gene mutation and an enlarged spleen.

He discusses a couple of treatment options with James. One is a Bruton's tyrosine kinase (BTK) inhibitor that is taken daily by mouth until the treatment stops working. The other option is a BCL-2 inhibitor. It requires a lot of initial lab work and follow-up appointments, but this treatment will end after 12 months.

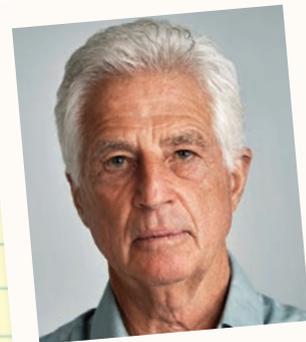
After discussing his options with his wife, James decides it is easier to start with the BTK inhibitor because he doesn't mind taking a pill every day.

James' blood counts return to near normal and his spleen shrinks in size. He has minimal side effects and feels better. After 57 months, his symptoms gradually return, his red blood cells and platelets decrease, and his white blood cells increase.

His specialist recommends switching to the BCL-2 inhibitor and combining it with a monoclonal antibody (mAb).

James starts the mAb right away. After a few weeks, he begins the BCL-2 inhibitor. For the first five weeks, his wife takes him to the cancer clinic as they adjust his dose of the BCL-2 inhibitor. Once he gets to his stable dose, he only has minor side effects and tolerates the drug well.

A year later, James finishes the BCL-2 inhibitor treatment, and nothing further is needed at this time. The doctor explains that although James has reached as close to remission as he can get, his CLL is not cured. He will rely on James to continue follow-up appointments and blood work to monitor his CLL. Together they will continue to manage the CLL as a chronic illness.



## FICTIONAL CASE STUDY # 2

**Neera**, age 60 (*Neera is not a real patient.*) / **Diagnosis:** Chronic Lymphocytic Leukemia

➔ **Neera's upper left part of her abdomen hurts** and when she eats, she feels full quickly, which is causing her to lose weight. Concerned about her symptoms, she sees her doctor, who does a physical exam and orders blood tests and a CT. Results show her white blood cell count is high and her spleen is enlarged. Her doctor suspects she has a type of leukemia, so he refers her to a hematologist.

The hematologist runs additional tests to look for chromosome changes and other genetic abnormalities in the leukemia cells. Results indicate Neera has a high number of lymphocytes circulating in her blood and her red blood cells are low. The tests confirm she has high-risk Stage III chronic lymphocytic leukemia (CLL).

Because her CLL is active and aggressive, her doctor suggests a BTK inhibitor. She starts with this targeted therapy and her symptoms improve, but gradually her symptoms return. Testing reveals she has developed resistance to the drug. Her doctor switches Neera to a BCL-2 inhibitor, which she takes for a year. This controls her CLL for a few years before having another relapse. Her doctor now recommends a clinical trial that is testing CAR T-cell therapy. He connects her with the clinical trials coordinator who finds a trial for Neera, and she decides to join it.

The trial doctor ensures Neera understands that, like most cancer treatments, CAR T-cell therapy has side effects. He explains the potential serious side effects, which include infection, cytokine

release syndrome, tumor lysis syndrome and neurotoxicity.

Neera's blood is drawn and her T-cells are removed. They are sent to a lab where chimeric antigen receptors (CARs) are added to help them attack cancer cells. They are then multiplied into the millions.

As Neera waits for the CAR T-cells to be ready, she has chemotherapy to deplete her immune system so the new CAR T-cells have a fresh environment in which to grow. After she completes the chemotherapy, the CAR T-cells are infused back into her body. She stays at a nearby hospital for several weeks so she can be monitored for any serious side effects.

While she is in the hospital, she feels nauseated. Her urine is dark and her kidneys are failing. All are signs of tumor lysis syndrome. The trial nurses and doctors treat her, and blood work is ordered to check her electrolyte levels and kidney damage. The treatment is able to reverse the symptoms, and Neera continues to be monitored for a few more weeks before going home.

She continues with follow-up testing, and recent tests show Neera has had a complete response to the treatment.



P A T I E N T  
R E S O U R C E

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*Where information equals hope*