QUESTIONS YOU *MUST* ASK YOUR CARE TEAM TODAY! p. 24

Healthmonitor®

Guide to living with CLL

CHRONIC LYMPHOCYTIC LEUKEMIA

Tips to thrive from patients like you

Don't let cancer hold you back!

- ☑ Learn your treatment options
- ☑ Boost your energy levels
- ☑ Fend off common side effects

"CLL saved me!"

Lacey Buchorn got a new lease on life—and is cancer-free!—thanks to a new treatment for chronic lymphocytic leukemia

COMPLIMENTS OF YOUR HEALTHCARE PROVIDER

FREE take-home copy

Guide to living with

CLL

CHRONIC LYMPHOCYTIC LEUKEMIA

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The basics

You & your healthcare team

True inspiration

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Feel your best

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COVER PHOTO BY ADAM KEALING

Looking forward to *tomorrow*

With new treatment strategies coming out all the time, a chronic lymphocytic leukemia (CLL) diagnosis no longer has to hold you back.

When Kenny S. finally retired from his job as a middle school math teacher at the age of 65, he had two goals: 1) go get a full physical and 2) start making travel plans.

"I wanted to make sure all the pieces were working correctly before I set off on my world travels," Kenny jokes. "I didn't expect anything more than maybe a high cholesterol or blood pressure reading."

But Kenny got much more than expected—his bloodwork came back with an abnormally high white blood cell count. His doctor called him back in to check for an infection, but when none was found he referred Kenny to a hematologist oncologist.

"Just the referral was concerning, of course," Kenny recalls. "He did some other tests and finally told me, 'You have leukemia.' I've never been more shocked in my life. Cancer!? I didn't even have symptoms!"

Kenny technically had chronic lymphocytic leukemia (CLL), a cancer of the white blood cells (keep reading to learn more). "I had definitely never heard of it, but my hematologist reassured me that today there were a lot of different ways to treat it. When I asked him if I needed to make final plans he immediately said no—that I could live a normal, healthy life for many years as long as I stayed on top of things, got my numbers checked regularly and stuck with my treatments when I needed them.

Kenny's doctor recommended he start with one of the new targeted therapies that have recently been approved to treat CLL.

"No chemo for me, and that was great news," says Kenny. Even better? The treatment worked, getting his blood cell count back into a normal range.

"Just a few months after my diagnosis, my condition was so stable I asked my doctor if it was safe to start making travel plans," Kenny says. "He told me, 'Book the tickets, just don't forget to send me a postcard!'

"There's nothing scarier than a cancer diagnosis, but I consider it just a small bump on my retirement journey. I've already purchased my plane tickets to Rome and when that's done...well, then it's time to take on the rest of the world, CLL be damned!"

If, like Kenny, you received an unexpected CLL diagnosis, take heart: There's every reason to believe you, too, will find a treatment that gets the condition under control. Read on to learn more about CLL, including your treatment options and how to feel your best every day.

What is CLL?

With about 20,000 new cases diagnosed each year, CLL is the most common type of leukemia—cancer of the blood and bone marrow—in adults. Lymphocytic leukemia specifically affects a type of white blood cell called a lymphocyte, which is produced in bone marrow and helps fight off infection. The condition is called chronic (rather than acute) when it progresses slowly.

CLL is caused by an "acquired mutation"—that means it's not something you're born with but rather something that develops when the DNA in a lymphocyte is damaged. ▶

As the damaged lymphocytes multiply, they start to crowd out healthy blood cells.

Who is at risk?

A few factors seem to increase a person's risk of CLL, the most significant being advancing age. CLL occurs most often after age 50, with 71 being the median age at diagnosis. Having a family history of the disease—say, a parent or sibling who has been affected—is also linked to a higher risk, as is exposure to certain insecticides and herbicides. Although doctors don't know why, CLL seems to be slightly more prevalent in men than women, and is more common in white people than other races.

What are the symptoms?

Many people are diagnosed with CLL without having shown any signs. That's because symptoms—fatigue, weakness and shortness of breath even during normal physical activity—tend to develop gradually. Patients may also have enlarged lymph nodes, particularly in the neck, or pain in their upper-left abdomen, which is related to an enlarged spleen and/or liver. Low-grade fevers and frequent infections are also common. Other symptoms include night sweats, chills and unexplained weight loss.

How is it diagnosed?

An accurate and precise diagnosis is key when it comes to CLL since it helps doctors determine how far the disease has progressed and how best to treat it. A number of tests are used:

- ***Blood tests:*** A complete blood count will reveal the number of red cells, white cells and platelets in your blood. CLL often is revealed by abnormally high levels of white cells. While red blood cell and platelet levels may be low, they are often only slightly below average in the early stages of CLL.

- ***Immunophenotyping:*** Also called flow cytometry, this test looks for markers on cancerous cells to determine the type of lymphocytes in the blood and whether they are a result of CLL or another blood disorder.

- ***Bone marrow tests:*** While not always necessary, a bone marrow aspiration and biopsy may be recommended to help rule out other diseases. In addition, doctors can use the results to determine how far the CLL has progressed, which can help guide treatment decisions. The tests may have to be repeated during treatment to determine its effectiveness.

- ***Fluorescence in situ hybridization:*** Known as FISH, this test helps pinpoint the type of genetic mutation involved in CLL, which can help doctors determine the most suitable treatment plan. It uses DNA probes that bind to specific areas within cells and light up, revealing the location of abnormalities, such as 17p deletion.

What's next?

Treatment varies from person to person, and many patients will need to try more than one as CLL progresses. And while relapses may occur, doctors have more options than ever that can help patients like Kenny live life to its fullest! Turn to p. 8 to learn more.

Meet your healthcare team

Partnering with many of these healthcare professionals will help ensure your CLL treatment is on the right track.

- **Hematologist/hematologist oncologist**—a hematologist specializes in the treatment of blood disorders; a hematologist/oncologist specializes specifically in blood cancers
- **Medical oncologist**—a doctor who uses medicines, including chemotherapy, to treat cancer
- **Radiation oncologist**—a doctor who uses radiation therapy to treat cancer
- **Surgical oncologist**—a doctor who uses surgery to treat cancer
- **Oncology nurse practitioner**—a specialized nurse who works closely with your oncologist
- **Oncology nurse navigator**—a specialized nurse who assists with medical, psychosocial and financial needs
- **Registered dietitian**—a professional who can counsel on the best diet to bolster health
- **Psychiatrist/psychologist**—a mental health professional who can provide counseling and support; a psychiatrist may also prescribe medication
- **Social worker**—a professional who can offer support for social issues and financial concerns

Take back control from CLL

Read on to learn the different treatment options for chronic lymphocytic leukemia and work with your healthcare team to find which one may work best for you.

With the wealth of options now available for the treatment of CLL, you have a special responsibility: to work as closely as possible with your care team to develop a plan targeted to your specific case. The right fit will do much to manage the disease, slow the growth of CLL cells and even promote periods of remission.

Because your personalized care plan will depend on the severity of your CLL, your doctor will use your test results (see p. 6 to learn more about tests) to classify your condition as early, intermediate or advanced. Keep reading for the approaches your care team may suggest, and keep something very important in mind: Your treatment will be ever-evolving as your CLL progresses (or doesn't) over time—that's why regular monitoring is so important.

Early-stage therapy

Watch and wait. Since CLL is so slow-growing, many patients don't need treatment right away—especially since some therapies' potential side effects outweigh the benefits when the disease is in its early stages. What's more, studies show early treatment offers no long-term advantages for patients. That's why doctors prefer watchful waiting, with regular exams and testing to monitor the disease's progression.

Intermediate- and advanced-stage therapies

Chemotherapy. Chemo destroys fast-growing cells throughout the body, whether cancerous or not. The drugs may be given orally, intravenously or via an injection and are often dosed in cycles, with a rest period between treatments. Your physician may use a single chemotherapy drug or a combination depending on your CLL.

Targeted drug therapy. Typically given orally, this type of treatment can target the specific abnormality that contributes to a CLL cell's growth. Because it is specialized, it helps preserve healthy cells while killing off cancerous ones and is generally associated with fewer side effects than treatments such as chemotherapy. The specific drug used will depend on your CLL, and your doctor will perform tests to determine the right one for you. There are three kinds of targeted therapies:

- ***Kinase inhibitors.*** These drugs work by blocking particular kinases, or enzymes, found in CLL cells, thus halting their growth. Medications include ibrutinib and idelalisib.
- ***BCL2 inhibitors.*** B-cell lymphoma 2 (BCL2) proteins control cell growth and death, and when they are mutated, as in CLL, normal cell death is delayed, leading to an overgrowth of cancerous cells. Drugs like venetoclax are formulated to target these proteins and kill CLL cells. They are approved for use in patients who've already received at least one other form of treatment.
- ***Monoclonal antibodies.*** These drugs seek out and attach to specific proteins found on CLL cells, helping block their growth. They include alemtuzumab, rituximab and ofatumumab.

Radiation. This treatment uses high-energy X-rays to destroy cancer. Since CLL cells circulate throughout the body rather than form tumors, radiation is not a common treatment; nonetheless, it may sometimes be used to ease symptoms, such as enlarged lymph nodes.

Surgery. CLL cells can collect in the spleen, causing it to become enlarged. That can lead to both discomfort and reduced blood cell counts, further weakening your immune system. In such (rare) cases, surgery to remove the spleen, known as a splenectomy, may be recommended.

Stem cell transplant. This is used more commonly in younger patients who have not responded to other treatments and those with advanced-stage disease. After receiving a strong course of chemotherapy, doctors infuse healthy stem cells into your blood, which develop a new immune system that may help produce a cancer-free bone marrow.

Relapsed and refractory CLL

The term "relapsed" refers to when your CLL stops responding to a previously effective therapy after six or more months. Refractory CLL is when therapy does not lead to remission or your CLL worsens within six months of the last treatment. Treatment for relapsed or refractory CLL follows the same guidelines as first-line options, with physicians relying on certain drugs, such as venetoclax and rituximab, that have proven to be particularly effective in these cases.

Feeling your best

CLL therapy often results in side effects that vary depending on the treatment given. Luckily, most are temporary. It's important to talk with your doctor about any side effects you may experience as there are coping mechanisms that can help. You may also find it helpful to connect with others who have CLL. (Learn more about support groups via the Leukemia & Lymphoma Society at *lls.org*.) You'll also want to work with your care team to design a diet and exercise plan that helps you stay as healthy and active as possible.

“CLL saved my life!”

When Lacey Buchorn was diagnosed with chronic lymphocytic leukemia 12 years ago, she wasn’t sure what her future would hold. But today, thanks to finding the right treatment, she’s living the happy, active life she’d always hoped for—*and* her cancer is undetectable! —BY AMY CAPETTA

“I am actually in better shape today than I was before I was diagnosed with cancer!” says Lacey.

PHOTO BY ADAM KEALING

If you’re looking for Lacey Buchorn you’ll have to lace up a pair of sneakers, since you’re most likely to find the 39-year old certified running coach on the track. In fact, the San Antonio, TX, resident recently completed her first 50-mile race! And when she’s not training for a run, this Air Force wife and mother can also be found hiking the trails in her area, working out with her CrossFit instructor or getting zen on the yoga mat. It’s enough to tire anyone out—let alone a 12-year blood cancer survivor!

Lacey’s cancer journey began in 2006 when she started feeling extra tired. But she spent nearly two years thinking her excess weight—at the time she weighed over 250 lbs—was the culprit. It wasn’t until she saw her doctor for a urinary tract infection and had bloodwork done that her elevated white blood cell count was discovered.

“Initially my doctor assumed it was due to the infection, but asked me to have my numbers re-checked when it was cleared,” Lacey remembers. “Unfortunately, even after the UTI was gone, my white cell count stayed high.” A subsequent visit to a hematologist and more tests confirmed that Lacey had chronic lymphocytic leukemia (CLL).

“I didn’t know anything about CLL—I had no clue it even existed—but thankfully I had an amazing diagnosing oncologist who walked me through it,” Lacey says. “I went from desperate to determined.”

“I had to see my daughter grow up”

Lacey immediately began the treatment protocol prescribed by her healthcare team, including chemotherapy and a targeted therapy. While she usually maintained a positive attitude, there were moments when she found it hard to “wrap her head around” the process.

“On those difficult days, I’d be frustrated and mad that I was going through all of this,” she admits. Yet she’d look at her husband, Bryan, and little girl, Jayce, to find the strength she needed to go on. “I had to get through this disease because I had to be there for my family and see my daughter grow up.”

So Lacey made a pact with herself: She would not give up fighting. And when treatment was over, she was going to run a marathon!

“Cancer is not a stop sign”

In December 2014, Lacey finally heard the words she’d been waiting to hear: She was “NED”—No Evidence of Disease, meaning there was no detectable level of CLL in her body. So she laced up her sneakers and hit the pavement. Her progress was slow, but she took it one step at a time. “In late 2015, I ran my first half-marathon!” she rejoices.

Over the following year, Lacey ran more races—and dropped 100 pounds! Then in June 2017, her health took an unexpected turn: The CLL was back. After a watch-and-wait period, Lacey began a different treatment in spring 2019—six infusions of a new targeted therapy combined with a chemotherapy.

To her relief, the side effects were minimal. “The day after treatment, I felt like I was hit by a truck, but I was back to normal the following day. It was nothing like my previous treatment.” With the approval of her doctors, she continued to run long distances and started training for a 50-mile run—even though at times she had to modify her workouts. “When I felt like my body needed less impact, I hiked or did yoga,” she says. Four months after starting this new treatment, Lacey was back to being NED.

These days, Lacey—who completed a coaching certification course with the Road Runner Club of America—is gearing up for her biggest run yet: A 100K race that’s taking place in February 2020. The main message she hopes to relay to others is that life happens one step at a time.

“I have a saying that I came up with throughout my journey and I replay it when I have bad days: *Cancer is only a speedbump, not a stop sign.* Yes, life will not be exactly the same as it was pre-diagnosis, but that doesn’t mean it can’t be good,” she says. “In fact, I don’t know where I would have been if I had not gotten cancer. In a way, having CLL saved my life. It gave me the awakening I needed, and it has made me a fitter person!”

LACEY’S TIPS FOR THRIVING

Here, Lacey shares more of the strategies that have been helping her feel her best. Ask your physician if her tips could work for you, too.

- **Research with care.** “I’m a very knowledge-driven person, so I wanted to learn more about my CLL, but a lot of the information you find online is unreliable or depressing,” Lacey says. “Since my sister-in-law is a critical care surgeon, I asked her which websites are legitimate, so now I stick to those when I do research. It’s much better than relying on Dr. Google!”
- **Clean up your diet.** “As a household, we make more conscious choices about eating heathy alternatives that still taste good,” she states. For example, instead of beef meatballs, her family enjoys chicken meatballs, and many nights they’ll swap zucchini noodles for white pasta.
- **Banish stress.** Not only has running and hiking helped Lacey drop more than 100 lbs and build muscle, but her workouts also serve as a form of self-care. “It’s fantastic therapy for my brain,” she states. “Most of the time I don’t even run with headphones. I take in my surroundings and let whatever problems and stressors I’m having just flow through my head.”
- **Connect with others.** Along with having a strong faith, as well as the support of her husband and daughter (“They are my biggest cheerleaders”), Lacey—who shares her wellness journey on Instagram @laceybuchorn—also relies on the love from close friends for keeping her spirits high.

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Coverage may vary by health plan. You may still incur out-of-pocket costs for other treatments or tests as directed by your healthcare provider.

Ask your doctor if VENCLEXTA + GAZYVA is right for you.

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Use and Important Safety Information

Use

VENCLEXTA is a prescription medicine used to treat adults with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).

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

Important Safety Information

What is the most important information I should know about VENCLEXTA?

VENCLEXTA can cause serious side effects, including:
Tumor lysis syndrome (TLS). TLS is caused by the fast breakdown of cancer cells. TLS can cause kidney failure, the need for dialysis treatment, and may lead to death. Your healthcare provider will do tests to check your risk of getting TLS before you start taking VENCLEXTA. You will receive other medicines before starting and during treatment with VENCLEXTA to help reduce your risk of TLS. You may also need to receive intravenous (IV) fluids into your vein. Your healthcare provider will do blood tests to check for TLS when you first start treatment and during treatment with VENCLEXTA. It is important to keep your appointments for blood tests. Tell your healthcare provider right away if you have any symptoms of TLS during treatment with VENCLEXTA, including fever, chills, nausea, vomiting, confusion, shortness of breath, seizures, irregular heartbeat, dark or cloudy urine, unusual tiredness, or muscle or joint pain.

Drink plenty of water during treatment with VENCLEXTA to help reduce your risk of getting TLS. Drink 6 to 8 glasses (about 56 ounces total) of water each day, starting 2 days before your first dose, on the day of your first dose of VENCLEXTA, and each time your dose is increased.

Your healthcare provider may delay, decrease your dose, or stop treatment with VENCLEXTA if you have side effects.

Who should not take VENCLEXTA?

Certain medicines must not be taken when you first start taking VENCLEXTA and while your dose is being slowly increased because of the risk of increased TLS.

- **Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. VENCLEXTA and other medicines may affect each other causing serious side effects.
- Do not start new medicines during treatment with VENCLEXTA without first talking with your healthcare provider.

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

- have kidney or liver problems.
- have problems with your body salts or electrolytes, such as potassium, phosphorus, or calcium.
- have a history of high uric acid levels in your blood or gout.
- are scheduled to receive a vaccine. You should not receive a "live vaccine" before, during, or after treatment with VENCLEXTA, until your healthcare provider tells you it is okay. If you are not sure about the type of immunization or vaccine, ask your healthcare provider. These vaccines may not be safe or may not work as well during treatment with VENCLEXTA.
- are pregnant or plan to become pregnant. VENCLEXTA may harm your unborn baby. If you are able to become pregnant, your healthcare provider should do a pregnancy test before you start treatment with VENCLEXTA, and you should use effective birth control during treatment and for at least 30 days after the last dose of VENCLEXTA. If you become pregnant or think you are pregnant, tell your healthcare provider right away.
- are breastfeeding or plan to breastfeed. It is not known if VENCLEXTA passes into your breast milk. Do not breastfeed during treatment with VENCLEXTA.

What should I avoid while taking VENCLEXTA?

You should not drink grapefruit juice or eat grapefruit, Seville oranges (often used in marmalades), or starfruit while you are taking VENCLEXTA. These products may increase the amount of VENCLEXTA in your blood.

What are the possible side effects of VENCLEXTA?

VENCLEXTA can cause serious side effects, including:

- **Low white blood cell counts (neutropenia).** Low white blood cell counts are common with VENCLEXTA, but can also be severe. Your healthcare provider will do blood tests to check your blood counts during treatment with VENCLEXTA.
- **Infections.** Death and serious infections such as pneumonia and blood infection (sepsis) have happened during treatment with VENCLEXTA. Your healthcare provider will closely monitor and treat you right away if you have a fever or any signs of infection during treatment with VENCLEXTA.

Tell your healthcare provider right away if you have a fever or any signs of an infection during treatment with VENCLEXTA.

The most common side effects of VENCLEXTA when used in combination with obinutuzumab or rituximab or alone in people with CLL or SLL include low white blood cell counts; low platelet counts; low red blood cell counts; diarrhea; nausea; upper respiratory tract infection; cough; muscle and joint pain; tiredness; and swelling of your arms, legs, hands, and feet.

VENCLEXTA may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider if you have concerns about fertility.

These are not all the possible side effects of VENCLEXTA. For more information, ask your healthcare provider or pharmacist.

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

If you cannot afford your medication, contact www.medicineassistancetool.org for assistance.

Please see Brief Summary of Full Prescribing Information on the last page of this advertisement.

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Patient Information

Read the Medication Guide that comes with VENCLEXTA before you start taking it and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical condition or treatment.

What is the most important information I should know about VENCLEXTA?

VENCLEXTA can cause serious side effects, including:

Tumor lysis syndrome (TLS). TLS is caused by the fast breakdown of cancer cells. TLS can cause kidney failure, the need for dialysis treatment, and may lead to death. Your healthcare provider will do tests to check your risk of getting TLS before you start taking VENCLEXTA. You will receive other medicines before starting and during treatment with VENCLEXTA to help reduce your risk of TLS. You may also need to receive intravenous (IV) fluids into your vein. Your healthcare provider will do blood tests to check for TLS when you first start treatment and during treatment with VENCLEXTA. It is important to keep your appointments for blood tests. Tell your healthcare provider right away if you have any symptoms of TLS during treatment with VENCLEXTA, including:

- fever
- chills
- nausea
- vomiting
- confusion
- shortness of breath
- seizures
- irregular heartbeat
- dark or cloudy urine
- unusual tiredness
- muscle or joint pain

Drink plenty of water during treatment with VENCLEXTA to help reduce your risk of getting TLS.

Drink 6 to 8 glasses (about 56 ounces total) of water each day, starting 2 days before your first dose, on the day of your first dose of VENCLEXTA, and each time your dose is increased.

Your healthcare provider may delay, decrease your dose, or stop treatment with VENCLEXTA if you have side effects.

See "**What are the possible side effects of VENCLEXTA?**" for more information about side effects.

What is VENCLEXTA?

VENCLEXTA is a prescription medicine used:

- to treat adults with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).
- in combination with azacitidine, or decitabine, or low-dose cytarabine to treat adults with newly-diagnosed acute myeloid leukemia (AML) who:
  - are 75 years of age or older, **or**
  - have other medical conditions that prevent the use of standard chemotherapy.

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

Who should not take VENCLEXTA? Certain medicines must not be taken when you first start taking VENCLEXTA and while your dose is being slowly increased because of the risk of increased tumor lysis syndrome (TLS).

- **Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. VENCLEXTA and other medicines may affect each other causing serious side effects.
- Do not start new medicines during treatment with VENCLEXTA without first talking with your healthcare provider.

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

- have kidney problems
- have liver problems
- have problems with your body salts or electrolytes, such as potassium, phosphorus, or calcium
- have a history of high uric acid levels in your blood or gout
- are scheduled to receive a vaccine. You should not receive a "live vaccine" before, during, or after treatment with VENCLEXTA, until your healthcare provider tells you it is okay. If you are not sure about the type of immunization or vaccine, ask your healthcare provider. These vaccines may not be safe or may not work as well during treatment with VENCLEXTA.
- are pregnant or plan to become pregnant. VENCLEXTA may harm your unborn baby.
  - If you are able to become pregnant, your healthcare provider should do a pregnancy test before you start treatment with VENCLEXTA.
  - Females who are able to become pregnant should use effective birth control during treatment and for at least 30 days after the last dose of VENCLEXTA.
  - If you become pregnant or think you are pregnant, tell your healthcare provider right away.
- are breastfeeding or plan to breastfeed. It is not known if VENCLEXTA passes into your breast milk. Do not breastfeed during treatment with VENCLEXTA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. VENCLEXTA and other medicines may affect each other causing serious side effects. See **"Who should not take VENCLEXTA?"**

How should I take VENCLEXTA?

- Take VENCLEXTA exactly as your healthcare provider tells you to take it. Do not change your dose of VENCLEXTA or stop taking VENCLEXTA unless your healthcare provider tells you to.
- When you first take VENCLEXTA:
  - You may need to take VENCLEXTA at a hospital or clinic to be monitored for TLS.
  - If you are taking VENCLEXTA for CLL or SLL, your healthcare provider will start VENCLEXTA at a low-dose. Your dose will be slowly increased weekly over 5 weeks up to the full dose. Read the **Quick Start Guide** that comes with VENCLEXTA before your first dose.
  - If you are taking VENCLEXTA for AML, your healthcare provider will start VENCLEXTA at a low-dose. Your dose will be slowly increased daily up to the full dose. Follow your healthcare provider's instructions carefully while increasing to the full dose.
- Follow the instructions about drinking water described in the section of this Medication Guide about TLS called **"What is the most important information I should know about VENCLEXTA?"** and also in the **Quick Start Guide**.
- Take VENCLEXTA 1 time a day with a meal and water at about the same time each day.
- Swallow VENCLEXTA tablets whole. Do not chew, crush, or break the tablets.
- If you miss a dose of VENCLEXTA and it has been less than 8 hours, take your dose as soon as possible. If you miss a dose of VENCLEXTA and it has been more than 8 hours, skip the missed dose and take the next dose at your usual time.
- If you vomit after taking VENCLEXTA, do not take an extra dose. Take the next dose at your usual time the next day.

What should I avoid while taking VENCLEXTA?

You should not drink grapefruit juice, eat grapefruit, Seville oranges (often used in marmalades), or starfruit while you are taking VENCLEXTA. These products may increase the amount of VENCLEXTA in your blood.

What are the possible side effects of VENCLEXTA?

VENCLEXTA can cause serious side effects, including:

- **See "What is the most important information I should know about VENCLEXTA?"**
- **Low white blood cell count (neutropenia).** Low white blood cell counts are common with VENCLEXTA but can also be severe. Your healthcare provider will do blood tests to check your blood counts during treatment with VENCLEXTA.
- **Infections**. Death and serious infections such as pneumonia and blood infection (sepsis) have happened during treatment with VENCLEXTA. Your healthcare provider will closely monitor and treat you right away if you have fever or any signs of infection during treatment with VENCLEXTA.

Tell your healthcare provider right away if you have a fever or any signs of an infection during treatment with VENCLEXTA.

The most common side effects of VENCLEXTA when used in combination with obinutuzumab or rituximab or alone in people with CLL or SLL include:

- low platelet counts
- low red blood cell counts
- diarrhea
- nausea
- upper respiratory tract infection
- cough
- muscle and joint pain
- tiredness
- swelling of your arms, legs, hands, and feet

The most common side effects of VENCLEXTA in combination with azacitidine or decitabine or low-dose cytarabine in people with AML include:

- nausea
- diarrhea
- low platelet counts
- constipation
- fever with low white blood cell counts
- low red blood cell counts
- infection in blood
- rash
- dizziness
- low blood pressure
- fever
- swelling of your arms, legs, hands, and feet
- vomiting
- tiredness
- shortness of breath
- bleeding
- infection in lung
- stomach (abdominal) pain
- pain in muscles or back
- cough
- sore throat

VENCLEXTA may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider if you have concerns about fertility.

These are not all the possible side effects of VENCLEXTA. For more information, ask your healthcare provider or pharmacist.

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 VENCLEXTA?

- Store VENCLEXTA at or below 86°F (30°C).
- For people with CLL/SLL, keep VENCLEXTA tablets in the original package during the first 4 weeks of treatment. **Do not** transfer the tablets to a different container.

Keep VENCLEXTA and all medicines out of reach of children.

General information about the safe and effective use of VENCLEXTA.

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

What are the ingredients in VENCLEXTA?

Active ingredient: venetoclax

Inactive ingredients: copovidone, colloidal silicon dioxide, polysorbate 80, sodium stearyl fumarate, and calcium phosphate dibasic.

The 10 mg and 100 mg coated tablets also include: iron oxide yellow, polyvinyl alcohol, polyethylene glycol, talc, and titanium dioxide. The 50 mg coated tablets also include: iron oxide yellow, iron oxide red, iron oxide black, polyvinyl alcohol, talc, polyethylene glycol, and titanium dioxide.

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Chart your treatment results

While chronic lymphocytic leukemia (CLL) can't be cured, today's options mean you *can* get the condition under control, helping you live a healthy, active life for many years. And making sure your treatment is working is one of the best ways to do that! Fill out the information below to track your progress during your journey, then review your answers with your healthcare team during your exam.

WHAT DO YOUR TESTS SHOW?

Common tests include the following:

Complete blood count

	DATE:	DATE:	DATE:	DATE:
White blood cells				
Absolute neutrophil count				
Red blood cells				
Hemoglobin				
Platelets				

Bone marrow aspiration and biopsy

- Your doctor may recommend bone marrow testing during or after treatment to see how well it is working.
- Date and result of latest test: ______________________________

Imaging tests

- The results of certain imaging tests, such as a CT/PET scan, can help doctors determine if your treatment is working.
- Date and result of latest test: ______________________________

Questions to ask about your test results

1. Are my results within a normal range? If not, what do the numbers indicate?
____
2. Are there any trends or patterns I should be aware of?
____
3. What do the results mean for my treatment?
____

HOW ARE YOU FEELING?

Whether you are experiencing the symptoms of CLL itself or the side effects of treatment, it's important to let your healthcare team know about it. Fill out this worksheet and review it with them.

Symptom	Doesn't affect me	Rarely	A few times per week	Daily	Multiple times per day
Abdominal pain					
Appetite loss					
Bleeding gums					
Bone pain					
Breathlessness					
Bruising					
Constipation					
Extreme thirst					
Fatigue					
Frequent infections					
Frequent urination					
Mental fogginess or confusion					
Nausea					
Nosebleeds					
Weakness or numbness in the legs					
Weight loss					

INFECTION ALERT!

Infections can be life threatening while undergoing cancer treatment, especially if they force you to delay or stop treatment. Ask your care team what you can do to avoid infection and call your doctor immediately if you experience any of the following:

- Fever of 100.5°F or higher
- Chills or shaking
- Unusual sweating
- Cough or bringing up sputum
- Sore throat
- Rash or redness
- Painful urination; bloody or cloudy urine
- Diarrhea with fever
- Earache
- Sinus pain or pressure
- Redness or swelling around a surgery site or port

A PLAN FOR OVERCOMING "SCANXIETY"

It's natural to feel nervous when waiting for the results of your latest tests. One way to manage the uncomfortable feelings? Create a contract with your physician. Decide: 1) Where and how will you receive the news? By phone? Email? In person? 2) When will you receive the results? Within hours or days? 3) What will you do while you're waiting? Plan a soothing activity, even if it's just catching up with a friend over a cup of tea. Or save up some crossword puzzles or other engaging games to work on while you wait.

“CLL hasn’t stopped us from living happy and productive lives!”

Thanks to the latest advanced treatment options for blood cancer, Stephen and Michele are moving forward with a positive mindset and newfound purpose! —BY AMY CAPETTA

“Knowledge is key!”

Stephen Brown,
Philadelphia
Diagnosed in 2006

Get informed.

“Ask the members of your medical team plenty of questions and take notes during appointments—even bring a friend along, if possible,” suggests Stephen. Also, before doing a Google search, he strongly advises asking your healthcare team which online resources can be trusted. “Do not go off on rogue search missions to scour the internet for every little available nugget on CLL—trust me, I made this mistake,” says the husband, father and grandfather. “For every valid and helpful tip, you’ll come across 10 worthless scraps that will be of no use to you and may even upset you for no reason.”

Move it.

“I’m thoroughly convinced that remaining active through my treatments helped me physically, mentally and emotionally,” says Stephen, who played semi-professional soccer in his 20s, moved to multisport racing and has completed countless marathons and ironman triathlons since 1987. The American Cancer Society lists numerous ways that regular workouts could aid during treatment, including increasing stamina, boosting self-esteem and lessening nausea.

Be present.

“I know living with a chronic disease can make it challenging to focus on the moment, but worrying about your next appointment or treatment session will only wear you down,” says Stephen. “More often than not, the anticipation of an upcoming event creates far more stress and anxiety than the event itself.” What works for him? “Be where your feet are at all times, be patient and breathe.”

PHOTO BY KATE MAZZI

Reframe your thoughts.

“The power of positivity is one of the best healing agents available,” says Stephen, who has authored five books and shares his knowledge about fitness and being a CLL survivor on the site *RemissionMan.com*. “Every person reading this article has made it through every bad day and overcome every adversity they’ve ever faced. Therefore, you’ve proven that you have the inner strength to keep moving through the storm.” While he has encountered a few relapses and has endured more than 50 rounds of treatment, Stephen decided to use his diagnosis as a way to inspire others. Over the years, he has served as an advocate for multiple organizations dedicated to individuals living with cancer. “I feel this disease has opened more doors than it has closed and has created more opportunities than it has taken away. It’s all about perspective.”

“Attack your cancer from all angles”

Michele Nadeem-Baker,
Boston
Diagnosed in 2012

PHOTO BY AIDEN RHAA

Add a specialist to your healthcare team.

After a few rounds of routine blood work showed that Michele’s white blood count was elevated, her doctor sent her to a hematologist who diagnosed her with CLL. “I had no idea what he was talking about, and he had no literature to offer me,” she recalls. Within 24 hours, she scheduled an appointment with Jennifer Brown, MD, PhD, director of the CLL Center at Dana-Farber Cancer Institute. “Even though CLL is one of the most common types of leukemia in adults, it is considered a rare disease,” continues Michele. “Community doctors aren’t likely to understand this type of cancer, so I recommend working with both a hematologist oncologist *and* a CLL specialist.”

Consider taking part in a scientific study.

After a three-year watch-and-wait period, Michele qualified to be one of the first patients in a national phase-two clinical trial that used a combination therapy. “You’re watched very carefully and are given regular CT scans and bone marrow biopsies—I’d venture to say you have even better care when you’re in a trial,” she says. “It’s tomorrow’s treatment today, so for me it was a no-brainer to go on it.” Michele feels it’s important to note that your physician will not leave you in a study if the treatment doesn’t appear to be working—and you have the right to drop out at any time.

Don’t focus on the end game.

“Since CLL is so complicated, there are different schools of thought as to when a patient can be declared officially disease-free,” Michele says, adding that she’s grateful to share that her cancer is in deep remission. “Hopefully this means it will take a long time for my CLL to come back.”

Establish healthy routines.

For example, Michele made a conscious effort to overhaul her sleep schedule. Previously, her corporate job as the head of communications for a cruise line kept her on-the-go nearly 24/7 and she slept an average of two to four hours a night. “One of the things I had to admit? I’m not immortal, so I needed to sleep and take care of myself, especially when I thought I was coming down with something,” she says.

Join a supportive community.

It took Michele about one year to locate someone else who was living with CLL; they connected through Patient Power, a site that offers cancer information for patients and professionals. Since she had prior experience as a journalist, Michele decided to become a reporter for the outlet, and her initial assignment was covering her first treatment—live from the infusion chair. “I wanted to demystify the experience.” She knew she had made the right decision when other CLL patients recognized her at the cancer institute and thanked her for informing them about the disease. “I was hoping to help others, and that made me feel better,” adds Michele. “By helping others, we help ourselves.”

Q&A

Help for living your best life with chronic lymphocytic leukemia

STILL FEEL TIRED

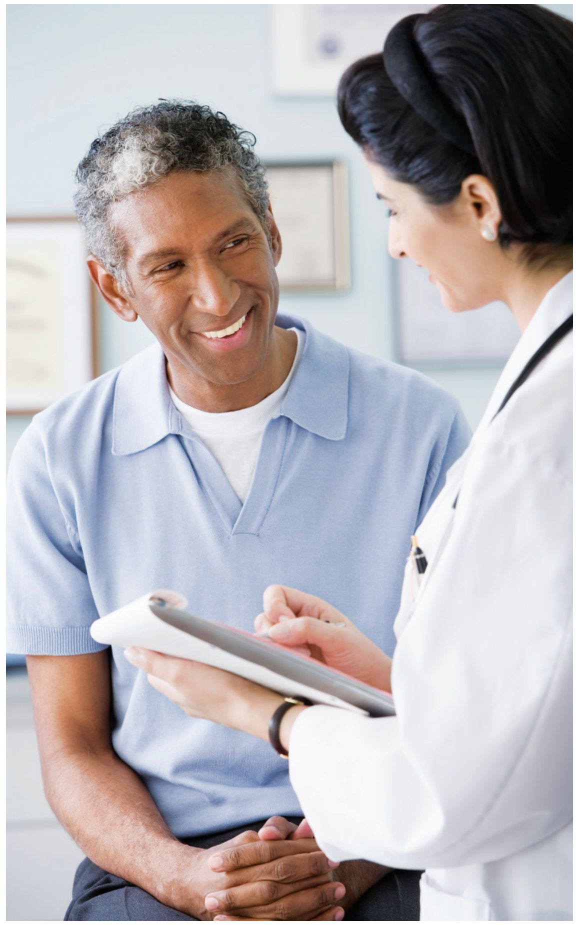
Q *My CLL is being controlled right now with medication, and my doctor says I'm currently in remission. But I still feel so tired all the time. Is this normal? Does it mean my cancer is going to recur?*

A There are many potential explanations for fatigue so the first step should be to tell your physician about your symptoms. Fatigue could be a side effect of your treatment, your cancer, depression, lack of exercise, a change in diet or other health conditions (just to name a few). But keep in mind that it is common for patients to feel fatigued even when their cancer is in remission, and it doesn't mean your cancer is recurring. In the meantime, be sure to get adequate sleep, eat a well-balanced diet rich in fruits and vegetables and, with your doctor's okay, exercise on a regular basis.

NEW TREATMENT FEARS

Q *My CLL has been in remission for a long time but recently has shown signs of recurrence. I'm worried chemo might not do the trick this time. I've heard there are a lot of new treatments out there now—are they really effective?*

A Yes, there are many new effective therapies for the treatment of CLL including immunotherapeutic and targeted therapies such as venetoclax, ibrutinib, idelalisib and duvelisib. And these can be used either alone or in combination with an anti-CD20 therapy such as rituximab. In fact, recent studies have shown these treatments may work even better than the previous standard chemo strategies at controlling CLL. So you have every reason to believe they will work for you!



WILL I NEED A SPLENECTOMY?

Q *I read online that people with CLL almost always need splenectomies. Is this true? Is there any way I can avoid that?*

A No, in fact a splenectomy is rarely needed in CLL and most patients do not need to have this procedure. The reasons someone with CLL might need a splenectomy include having a markedly enlarged spleen that is causing symptoms, or due to chronically low platelet counts. Luckily, there are many medications available (such as chemo and immunotherapy) that are often more effective in treating CLL and, thus, allow patients to avoid splenectomy.

Our expert: *Carol Ann Huff, MD,*
Medical Director, Department of Oncology, Multiple Myeloma Program, Division of Hematologic Malignancies; Associate Professor of Oncology, Johns Hopkins University, Baltimore

Get the nutrition *you* need!

While today's powerful treatments for chronic lymphocytic leukemia are taking aim at the disease like never before, they can sometimes make it challenging to eat right. For times when your energy, appetite and overall well-being take a hit, these strategies can help you get the nutrients you need to feel your best.

Fill your pantry with blood cell-boosting goodies. You can help your body produce more healthy red blood cells with iron-rich foods like red meat; organ meats; dark, leafy greens; eggs; and beans. Immune boosters like citrus, bell peppers and garlic can help your white blood cells. And platelets (the blood cells that help with clotting) like folate-rich foods, such as asparagus, avocado and Brussels sprouts.

Seek balance. Unless otherwise directed by your healthcare provider, try to avoid restrictive diets that eliminate whole food groups, as they can make it extra challenging to get the balance of nutrients you need right now. The Leukemia & Lymphoma Society recommends that blood cancer patients consume a diet that consists of fruits and vegetables, whole grains, fat-free or low-fat dairy, lean proteins and healthy oils like olive oil.

Prep food on high-energy days. "You probably know you'll be tired for three days after chemo," says Tiffany Barrett, RD, of the Winship Cancer Institute at Emory University. And other prescription treatments can also cause fatigue. "So make meals on days you feel well and store them. When you need to eat, all you have to do is pop them in the oven or microwave."

Reach for grab and go. Keep snacks like yogurt and peanut butter-filled crackers on hand. Or make a smoothie in the morning and save half for later in the day. And keep in mind: The most nutritious snacks offer a combination of protein, carbs and a little fat.

Stay upright after you eat. Lying down right after you eat interferes with digestion. Try to spend some time on your feet, whether doing the dishes or taking a light stroll.

Practice good food safety. CLL and its treatment can lower your immune system, which means it's even more important for you to avoid food-borne illnesses. Stay away from raw or undercooked seafood and meats, thoroughly wash any produce you eat and wash your hands frequently to avoid cross-contamination.

Put a *stop* to side effects!

If CLL or its treatment is causing you to feel less than your best, consult your care team, who may be able to prescribe a medication or adjust your current treatment to help ease your symptoms. You can also ask if the following strategies make sense for you.

Fatigued?

Get moving. The number-one energy booster for all cancer patients is exercise, according to the National Cancer Research Institute—but that doesn't mean you need to sign up for an hour-long Zumba class. A simple 15-minute walk led to a marked reduction in fatigue levels for patients, according to a study published in the *JAMA Oncology*.

- ***Ask:*** “Can I safely do [a particular] exercise?” If CLL has affected your bones or sense of balance, you may benefit from a more stationary form of exercise, like chair yoga.

Battling nausea?

Stick to mini meals. Eating small frequent meals can help offset the risk of nausea, advises Tiffany Barrett, RD, of the Winship Cancer Institute at Emory University. The reason? If your stomach gets too empty, your stomach creates more acid that can lead to stomach upset. And if it gets too full, it makes it more difficult for your digestive system to work.

- ***Ask:*** “Can I eat before taking my meds or before a chemo infusion?” Many people have found that nausea is reduced when they are able to receive their treatment on a fuller stomach.

Coping with diarrhea?

Try the BRAT diet! “Some medications that treat CLL can cause diarrhea,” says Natalie Ledesma, RD, at the University of California at San Francisco Helen Diller Family Comprehensive Cancer Center. “But the BRAT diet—bananas, rice, applesauce and toast—can help. Also, drink plenty of liquids to replace the fluid you're losing,” says Ledesma, who also advises steering clear of gas-producing foods such as broccoli, onions and beans. “Now is not the time to eat raw vegetables, particularly raw leafy greens, nor the skins, seeds and stringy fibers of unpeeled fruit.”

- ***Ask:*** “Could my pain meds be causing diarrhea?” While many pain medications can cause constipation, few people realize certain ones can have the opposite effect. Check with your care provider to see if these could be causing your stomach upset and what other options you might try.

Problem with pain?

Report symptoms clearly! Everyone's pain threshold (the point at which you feel discomfort) is unique, and no two people experience pain in the same way—plus pain related to cancer can have many different causes. Because of that, it's important to communicate to your care provider how your pain is affecting you and exactly what it feels like. That way, they will be better equipped to treat the symptom. Rate your pain on a scale of 1-10 (with 10 being the worst) and let them know where you're feeling it. You can also describe your pain as: constant, intermittent, growing, stabbing, burning, dull, achy, hot, tender, sharp, shooting, throbbing or cramping.

- ***Ask:*** “When can I take my pain meds?” Most pain medications work best if taken as soon as symptoms crop up, and some must be taken regularly to prevent pain. It may also help to ask what situations may warrant you to increase your dose, how much is safe and for how long.

Worried about infection?

Keep germs at bay! CLL impacts your white blood cells, which means it can lower your ability to fight germs and infection. Because of that, it's important to avoid getting sick. The Centers for Disease Control devotes an entire website to helping cancer patients avoid infection (visit it at *preventcancerinfections.org*), but here's the main takeaway: Wash your hands frequently and stay away from crowds! Avoid shared party snacks from bowls or plates, and contact your doctor immediately if you notice a fever, sore throat or redness or swelling anywhere on your skin.

- ***Ask:*** “Should I get a flu shot?” Whether it's right for you depends on your treatment, but for most people fighting cancer it's highly recommended by the CDC.

Ask these at *today's* exam

Get the conversation started with your care team about your chronic lymphocytic leukemia (CLL). Having an open, honest dialogue with your doctors can help you get the best treatment possible.

1. Is my CLL fast-growing or slow-growing? How do we know?
2. Am I a candidate for treatment? If so, what do you recommend and why? If not, what are the signs that I may need to begin treatment?
3. How will we know if my current treatment is working?
4. If my current treatment isn't working, what options do I have?
5. What are some signs that my CLL might be relapsed or refractory, and what should I do if I notice them?
6. What effect could my CLL or its treatment have on my day-to-day activities?
7. What can I do to manage any side effects I might experience?
8. Will making specific lifestyle changes help me live better with CLL?
9. Are there any symptoms or side effects I should report to you immediately?
10. When should I come back for my next appointment?