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COMPLIMENTARY COPY
TAKE ONE HOME

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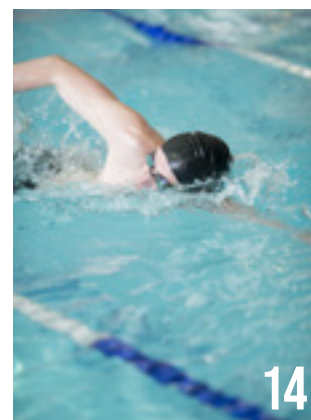
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RECENT HEADLINES

KEEP UP WITH NEW RESEARCH

FAMILY CONNECTION

If you have CLL, your brothers and sisters might want to talk to their doctors about their own risk. It's true with many cancers that if you have a close relative who had that type of cancer, your risk may be higher, too. New research zeroes in on which relatives impact each other's odds the most in blood cancers. In the study of 153,115 patients with various blood cancers, researchers found that people who had a sibling with CLL were more likely to develop the disease themselves than people who had a different relative with the condition.

SOURCE: *Blood*

1 IN 3

Number of adults with leukemia who have CLL.

SOURCE: American Society of Clinical Oncology

Most common age range of people who receive a CLL diagnosis.

65 TO 74

SOURCE: National Cancer Institute

TAKE A BREATH

Stress management may be an important part of treatment for CLL. In a study, researchers found that among about 100 people with CLL, those who had the most cancer-related stress also had more cancer cells in their bloodstream and higher levels of three other signs of cancer in the blood. The researchers measured stress with questions like "How often do you have intrusive thoughts about your cancer?" and "How often do you try to avoid thinking about cancer?" The researchers will follow the 100 people throughout their treatment to learn about the longer-term impact of stress.

SOURCE: *Cancer*



TREATMENT FROM A FLOWER?

The next treatment for chronic lymphocytic leukemia (CLL) may come from your garden. Researchers extracted a compound from feverfew and used them to kill CLL cells in a petri dish. Feverfews look like daisies—tiny white flowers with a yellow center. The cancer-killing compound within them is parthenolide. When scientists treated CLL cells with the plant extract, it caused levels of a molecule called reactive oxygen species (ROS) to rise. Too much ROS kills cancer cells. This isn't the plant's only potential health benefit. Vitamin shops sell feverfew supplements as a remedy for many aches and pains, including migraine and menstrual pain.

SOURCE: *MedChemComm*

For adults with CLL/SLL

CHOOSE A FUTURE FREE FROM CONTINUOUS CLL TREATMENT:



Only VENCLEXTA regimens are **CHEMO-FREE** and designed to be



For previously untreated CLL/SLL with VENCLEXTA + GAZYVA® (obinutuzumab)



For previously treated CLL/SLL with VENCLEXTA + rituximab

Ask your doctor if VENCLEXTA is right for you.

*From Cycle 1, Day 1 of rituximab, after 5-week VENCLEXTA dose ramp-up.

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 following pages.

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Actor portrayal

VENCLEXTA® (ven-KLEKS-tuh)
(venetoclax tablets)

CONSUMER BRIEF SUMMARY
CONSULT PACKAGE INSERT FOR FULL
PRESCRIBING INFORMATION

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.	
<div><div><div>What is the most important information I should know about VENCLEXTA?</div><div><div>VENCLEXTA can cause serious side effects, including:</div><div><div>Tumor lysis syndrome (TLS).</div><div>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:</div><div><div><div><div><div>• fever</div><div>• chills</div><div>• nausea</div><div>• vomiting</div><div>• confusion</div><div>• shortness of breath</div></div><div><div>• seizures</div><div>• irregular heartbeat</div><div>• dark or cloudy urine</div><div>• unusual tiredness</div><div>• muscle or joint pain</div></div></div></div><div><div>Drink plenty of water during treatment with VENCLEXTA to help reduce your risk of getting TLS.</div><div>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.</div><div>Your healthcare provider may delay, decrease your dose, or stop treatment with VENCLEXTA if you have side effects.</div><div>See “What are the possible side effects of VENCLEXTA?” for more information about side effects.</div></div></div></div><div><div>What is VENCLEXTA?</div><div>VENCLEXTA is a prescription medicine used:</div><div><div><div>• to treat adults with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).</div><div>• in combination with azacitidine, or decitabine, or low-dose cytarabine to treat adults with newly-diagnosed acute myeloid leukemia (AML) who:</div><div><div>• are 75 years of age or older, or</div><div>• have other medical conditions that prevent the use of standard chemotherapy.</div></div></div><div>It is not known if VENCLEXTA is safe and effective in children.</div><div><div>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).</div><div>• 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.</div></div></div></div></div></div></div>	<div><div><div>• Do not start new medicines during treatment with VENCLEXTA without first talking with your healthcare provider.</div><div><div>Before taking VENCLEXTA, tell your healthcare provider about all of your medical conditions, including if you:</div><div><div>• have kidney problems</div><div>• have liver problems</div><div>• have problems with your body salts or electrolytes, such as potassium, phosphorus, or calcium</div><div>• have a history of high uric acid levels in your blood or gout</div><div>• 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.</div><div>• are pregnant or plan to become pregnant. VENCLEXTA may harm your unborn baby.</div><div><div>• If you are able to become pregnant, your healthcare provider should do a pregnancy test before you start treatment with VENCLEXTA.</div><div>• 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.</div><div>• If you become pregnant or think you are pregnant, tell your healthcare provider right away.</div><div>• are breastfeeding or plan to breastfeed. It is not known if VENCLEXTA passes into your breast milk. Do not breastfeed during treatment with VENCLEXTA.</div></div></div><div><div>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.</div><div>See “Who should not take VENCLEXTA?”</div></div></div><div><div>How should I take VENCLEXTA?</div><div><div>• 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.</div><div>• When you first take VENCLEXTA:</div><div><div><div>• You may need to take VENCLEXTA at a hospital or clinic to be monitored for TLS.</div><div>• 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.</div><div>• 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.</div></div></div></div></div></div></div>	<div><div><div>• 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.</div><div>• Take VENCLEXTA 1 time a day with a meal and water at about the same time each day.</div><div>• Swallow VENCLEXTA tablets whole. Do not chew, crush, or break the tablets.</div><div>• 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.</div><div>• If you vomit after taking VENCLEXTA, do not take an extra dose. Take the next dose at your usual time the next day.</div></div></div> <div><div>What should I avoid while taking VENCLEXTA?</div><div>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.</div></div> <div><div>What are the possible side effects of VENCLEXTA?</div><div><div>VENCLEXTA can cause serious side effects, including:</div><div><div>• See “What is the most important information I should know about VENCLEXTA?”</div><div>• 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.</div><div>• 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.</div></div><div>Tell your healthcare provider right away if you have a fever or any signs of an infection during treatment with VENCLEXTA.</div><div><div>The most common side effects of VENCLEXTA when used in combination with obinutuzumab or rituximab or alone in people with CLL or SLL include:</div><div><div><div><div>• low platelet counts</div><div>• low red blood cell counts</div><div>• diarrhea</div><div>• nausea</div></div><div><div>• cough</div><div>• muscle and joint pain</div><div>• tiredness</div><div>• swelling of your arms, legs, hands, and feet</div></div></div><div><div>• upper respiratory tract infection</div></div></div></div></div></div>	<div><div><div>How should I store VENCLEXTA?</div><div><div>• Store VENCLEXTA at or below 86°F (30°C).</div><div>• 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.</div></div><div><div>Keep VENCLEXTA and all medicines out of reach of children.</div></div><div><div>General information about the safe and effective use of VENCLEXTA.</div><div>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.</div></div><div><div>What are the ingredients in VENCLEXTA?</div><div><div>Active ingredient: venetoclax</div><div>Inactive ingredients: copovidone, colloidal silicon dioxide, polysorbate 80, sodium stearyl fumarate, and calcium phosphate dibasic.</div><div>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.</div></div></div></div><div><div>Manufactured and Marketed by:</div><div>AbbVie Inc.</div><div>North Chicago, IL 60064</div><div>© 2019 AbbVie Inc.</div><div>Ref: 03-B947 Revised July 2019</div><div>LAB-2672 MASTER</div></div><div><div>Marketed by:</div><div>Genentech USA, Inc.</div><div>A Member of the Roche Group</div><div>South San Francisco, CA 94080-4990</div><div>© 2019 Genentech, Inc.</div><div>US-VENC-200093</div><div><div>abbvie</div><div>Genentech</div></div></div></div>

MANAGING

SIDE EFFECTS

KNOW WHAT TO WATCH FOR DURING TREATMENT

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

Your medical team's goal as they treat your CLL is to slow down cancer cell growth, to relieve you of symptoms caused by the cancer, and to get you to remission. Along the way, you'll likely deal with several side effects of these treatments. Just like your CLL treatment is unique to you, your side effects will depend on the type of treatment you need. Be on the lookout for these common examples so you're prepared to deal with whatever comes your way.

INFUSION REACTIONS

You get immunotherapy drugs through an IV infusion. These infusions can sometimes cause a reaction of mild symptoms such as fever, chills, itching, fatigue, or headache. Or sometimes the side effects can be more serious, and involve shortness of breath, chest pain, racing heart, swelling of your face or tongue, or dizziness.

"Fortunately, these medications have been around for long enough that we've learned how to give them to help prevent these reactions," says Herbert Eradat, MD, director of the CLL program, and associate clinical professor of medicine at the

UCLA Jonsson Comprehensive Cancer Center.

Typically, you'll get your first infusion very slowly, and at a very low dose. There are also medications you can take to help prevent reactions. You shouldn't have to worry about side effects after your first few infusions. "Really once you get through the first or second dose, your likelihood of having these kinds of infusion reactions is really pretty low," Eradat says. "It might happen the first or second time, but then it shouldn't be an issue."

INFECTION

Since CLL itself alters your

immune system, your germ-fighting ability is already low. CLL treatment can drop your blood count, which robs you of even more of your defenses. "When the counts drop, people get anxious, but it's important to know that it will recover on its own without having to do much," Eradat says.

What's key, he says, is safeguarding yourself from viruses and bacteria as well as possible so you don't find yourself knocked out by a sinus infection or pneumonia. "You don't need to put yourself in a bubble, but be logically careful," he says. "Don't go hug a person with a cold, be sure what you're eating is clean and washed,

don't go to salad bars where stuff has been sitting there for hours. Just be cautious."

Watch for signs of infection, too, so you can treat them as soon as possible. Call your doctor if you have a fever of 101 degrees or higher, sore throat, chills, coughing that won't go away, pain when you pee, or diarrhea.

BRUISING AND BLEEDING

Your doctor may prescribe certain drugs that promote red blood cell growth to help ease these symptoms. If your platelets get severely low, you might also have reddish urine, black or bloody bowel movements,



GETTY IMAGES



3 RED FLAGS

HERBERT ERADAT, MD, EXPLAINS HOW TO KNOW WHEN A SIDE EFFECT ISN'T NORMAL.

Heart changes

+ Signs like skipped heartbeats, becoming keenly aware of your heartbeat, or any type of problem that affects your heart function could signify you need immediate medical attention.

Lack of stamina

+ Shortness of breath, lightheadedness, or an issue like not being able to last as long doing activities as before, these are things we would say to call your doctor about.

Anything new and constant

+ Tell your doctor as much as possible about any new symptoms that come on and persist. Good communication between you and your oncologist is important.

headaches, dizziness, weakness, and pain in your joints. You may bleed more than you used to when you cut yourself or see more bruises than usual.

A drop in your blood count also affects your red blood cells and platelets. Fewer red blood cells can cause anemia. Anemia can make you feel cold, lightheaded, fatigued, short of breath, and you may have pale skin and gums.

Use care when you brush your teeth, avoid contact sports, and ask your doctor before using aspirin, acetaminophen, or ibuprofen. In serious cases, you can have a platelet infusion or blood infusion to replenish blood counts, but it's rare for

people to need these. Note that these medications can affect bleeding and blood clotting.

NAUSEA AND DIARRHEA

Even though treatments are getting better at targeting cancer cells and sidestepping normal cells, nausea is still a common side effect, especially when you're taking chemotherapy drugs. But Eradat says you can expect your tummy woes to be fairly mild. "I can tell you that in contrast to 15 years ago, it's extraordinarily unusual now for someone to have vomiting from chemotherapy," he says.

If you do get queasy, he

says, there are plenty of effective medications to quell it. Diarrhea can be common, too, especially in the first few months of treatment. "Depending on how bad the diarrhea is, we might have to temporarily stop your medication," Eradat says. If that happens, your doctor can call in an antidiarrheal for you to take. Once you've recovered, you can start treatment again.

LONG-TERM SIDE EFFECTS

Be sure you talk to your doctor about how certain treatments may affect your health over time so you can weigh the pros and cons of

different CLL therapies. "Some treatments can cause ongoing issues that become permanent," Eradat says.

For example, your blood pressure may go up and stay there, or you might start having an irregular heart rhythm that requires more medication. Immunotherapy can also reduce your body's antibody production over time, which stunts your ability to fight bacteria and viruses, Eradat says.

"If you have repetitive infections your doctor can give something called intravenous immunoglobulin, or IVIG, to reduce the risk of infection. It's not often required, but it's available as a solution if you need it."

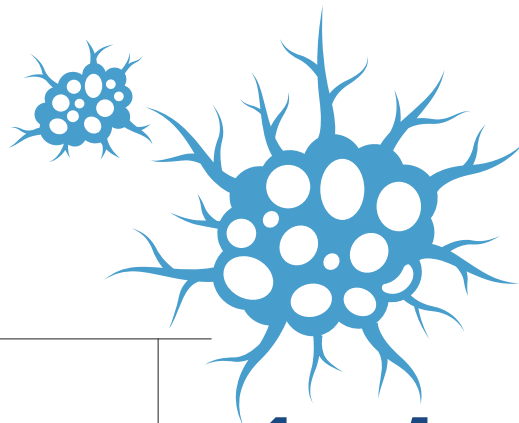
FACTS AND STATS

By Sonya Collins

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

1 IN 175

Number of **people who will develop CLL** in their lifetime.



12,930

Estimated number of **men** who will learn they have **CLL** in 2020.



8,110

Estimated number of **women** who will learn they have **CLL** in 2020.

3%

Increase in CLL **survival rates every year** for the past 10 years.

1 in 4

NUMBER OF NEW CASES of leukemia that are CLL.

70

Average age of people at diagnosis.

1.2%

Percentage of **new cancer cases** that are CLL.

85%

Percentage of people age 20 and older **who survive 5 years** after a CLL diagnosis.

1 IN 2

NUMBER OF PEOPLE with CLL who may not need treatment.

SOURCES: American Cancer Society, Cancer.Net, National Cancer Institute, World Health Organization

WHAT TO EXPECT

LEARN WHAT LIES AHEAD AS YOU TREAT YOUR CHRONIC LYMPHOCYTIC LEUKEMIA

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

Although chronic lymphocytic leukemia (CLL) doesn't yet have a cure, today's treatments can help you reach a partial or complete remission and live a long time. Most often, doctors wait until you're either having symptoms or your cancer is growing before starting any kind of treatment.

OPTIONS FOR CLL TREATMENT INCLUDE:

- Targeted therapies (drugs that work on specific genes, proteins, or tissues)
- Chemotherapy
- Monoclonal antibodies (artificial immune system proteins that target cancer)
- Combinations of these treatments

Doctors may also use radiation, surgery, and stem cell transplants to treat some CLL symptoms, but this is very rare.

FIRST-LINE TREATMENTS

The treatment doctors often turn to first for CLL is targeted drugs or the combination of targeted drugs with monoclonal antibodies. Studies show these therapies bring longer remissions, are less toxic, and may help you live longer than chemotherapy treatment did in the past, says Paul M. Barr, MD, associate professor of medicine and director of the Clinical Trials Office at the Wilmot Cancer Institute at the University of Rochester Medical Center in New York.

When you're treating your CLL with targeted drugs alone, you take them as a pill once a day by mouth. You should not stop taking it unless your doctor tells you to.

You get monoclonal antibodies through an IV.

SIDE EFFECTS

Targeted therapy treatments come with fewer side effects

than chemotherapy. "While chemotherapy can cause hair loss, lots of nausea, mouth stress, and fatigue, targeted therapies are generally well tolerated," says Barr.

Side effects to watch for with targeted therapies include:

- Loose stools
- Achy joints and muscles
- Fatigue
- Leg swelling
- Rash
- Diarrhea

Barr says there are a few risks with targeted therapy, including a slight chance of:

- Heart arrhythmias
- Bleeding
- Blood pressure increase
- Low blood count
- Tumor lysis syndrome,

a rare side effect that harms your kidneys

When you get the antibody IV, you might have reactions to the infusion, such as:

- Chills
- Shaking
- Fever
- Lowered blood pressure

Taking a combination of treatments can give you more side effects than getting one therapy alone.

Your doctor may decide to have you take a break, adjust the dose, or change the administration in some way

PAVE THE WAY TO REMISSION

Paul M. Barr, MD, shares tips for optimizing your overall health as you treat your CLL.

VACCINATE

Immunizations are a solid safeguard against infection.

GET SKIN CHECKS

CLL raises your risk for skin cancer, so see your dermatologist regularly.

STAY BALANCED

Eat for health, stay active, don't smoke, and enjoy alcohol only in moderation.

REPORT INFECTIONS

Cancer weakens your immune system over time, so report respiratory or other problems to your doctor quickly.

so you can reduce the side effects. In some cases, you may need to find a different treatment altogether.

TREATMENT OUTLOOK

Though your results can vary depending on different factors, the bottom line about treatments for CLL is that most often they work. "The response rate—that's the percentage of patients that respond to the treatment—is above 90%," Barr says. "The majority of people can live many years, if not decades, with this disease."



GET SUPPORT

MANAGE YOUR MEDICAL, FINANCIAL, NUTRITIONAL, AND EMOTIONAL NEEDS

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

A chronic lymphocytic leukemia (CLL) diagnosis can be overwhelming and stressful. Find out who to turn to so you can best cope with the mental and physical symptoms of your cancer treatment as well as the day-to-day details of dealing with a chronic condition.

DOCTORS who specialize in diseases of the blood are called hematologists. If possible, it's best to find a hematologist who specializes in CLL so you're getting the most up-to-date treatments and information on your cancer.

"Your hematologist will work with you to make decisions about the timing

and type of treatment, manage potential complications, and monitor your disease progression," says Leslie Andritsos, MD, professor in the division of hematology/oncology at the UNM Health Sciences Center in Albuquerque, NM.

Your hematologist may also recommend you see other doctors, such as oncologists, infectious disease doctors, cardiologists, or pulmonologists, to round out your care.

NURSES are another key player in your medical care. They help with management of medication side effects as well as potential CLL complications. "Nurses who

care for patients with CLL are often the first ones called when a complication develops, and they must be prepared to quickly identify and help manage problems and recognize symptoms that may actually be side effects of CLL treatment, such as worsening hypertension," says Andritsos.

PHARMACISTS have a larger role in CLL care now that many of the newer CLL treatments are targeted therapies in pill form. They can help you understand side effects and show you how to take your medications. "It can be extremely complicated starting a new oral therapy for CLL," says Andritsos. "The pharmacist is trained to help with both the physical and logistical issues that may come with it."

PATIENT EDUCATORS on staff at hospitals and clinics can guide you through decisions like when to call the office versus when to go to the ER. They can help you understand lab results. They can also be a source for exercise, diet, and sleep tips so you develop healthy

lifestyle patterns during your treatment.

COUNSELORS can help you with the stress of being diagnosed with a chronic illness. Many people with CLL say this stress is higher during the "watch and wait" period before treatment starts, says Andritsos. And even after treatment is over, you may have PTSD-like symptoms.

"If you're having trouble coping with your diagnosis, especially if you're experiencing depression or anxiety, a counselor may help you develop a set of coping skills," she says.

SUPPORT GROUPS, either in person or online, give you the chance to connect with other people who know what you're going through and can help you gather helpful information. "Patient advocacy groups and professional organizations such as the Leukemia and Lymphoma Society offer high-quality information on their websites as well as opportunities to interact with other people with CLL," says Andritsos.

THE DETAILS

From understanding insurance to finding rides to your treatments, there's a lot to attend to during your CLL care. Leslie Andritsos, MD, shares some tips for getting through the daily details.

CALL YOUR INSURER

+ Many insurance companies provide "navigators"—people to help with coverage questions for specific therapies.

USE CLINIC RESOURCES

+ Some cancer centers or practices have social workers and financial assistance personnel who can help you troubleshoot transportation issues, nutritional needs, home health/home care, and disability applications.

PICK A PARTNER

+ Ask a trusted family member or friend to serve as your note-taker, cheerleader, and errand-runner as you go to appointments and recover from treatments.

LIVING WITH CLL

A MARATHONER AND TRIATHLETE MANAGES HIS CONDITION

By Stephen Brown

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor



STEPHEN'S TIPS

Research wisely.

Blind Google searches aren't a good idea. Ask your doctor for trustworthy, reliable resources to get the information you need about CLL.

Stay present.

Don't think too much ahead, don't think too much about the what-ifs. Be present, and focus on the here and now.

Keep doing things you love.

Whatever it is that makes you feel good in life, whether that's staying active, birdwatching, needlepoint, whatever—hold on to that. Don't feel like your life has to shut down.

In late 2005, I started having trouble swallowing. It felt like something was stuck in my throat. In the beginning, it happened with solid food, and then it was liquids, and then just swallowing my own saliva felt like choking down a golf ball. Like many busy guys who say they don't have time to have things looked at, it took me a while to really sit down and say, "OK, what's going on?" and make a doctor's appointment.

The ENT [ear, nose, and throat specialist] took one look in my mouth and said, "You still have your tonsils? They're a train wreck. We have to take them out." So there I was at 45 years old scheduling a tonsillectomy. Then, after the routine preadmission testing for the procedure, I got the phone call nobody ever wants. It was the ENT surgeon saying there was a problem with my bloodwork. He referred me to an oncologist/hematologist.

I remember those days like they're my own birthday. That was February 17, and for the next week, it was just a battery of more bloodwork, PET scans, CT scans, bone marrow biopsies, and X-rays. The whole time I was thinking it was some sort of infection. I mean, I'm a healthy guy. I honestly thought it was one of those ultraconservative, precautionary approaches to play it safe. I kept wondering when we were going to move on. Finally, I asked the oncologist what he was fishing for or trying to rule out. And that was the first time I heard the words chronic lymphocytic lymphoma. Soon after, I got my official diagnosis.

The hardest part was breaking the news to my wife and two high school-aged daughters. I've always been really fit and active—I've run 27 marathons and a bunch of Ironman races—and that's the dad and husband they've always known. So to sit down and have to use the words cancer and leukemia and chemotherapy, that was a little daunting. But I immediately tried to set the tone just through positivity. I told them what it was and how I was going to handle it. I was entirely open and tried to be as [much] myself as I could.

When my oncologist learned of my endurance sports background and lifestyle, he suggested I should put all of that on hold. But I told him he might as well take my legs

from me. If I stopped doing these things I love, it wasn't just going to be a blood cancer we were dealing with, but an emotional meltdown. So we reached an agreement. He said I could work out when I felt good. He told me to stay out of the pool and "petri dish" gyms and stick to fresh air exercise. And he told me to listen to my body. If I had a bad day or a labored workout, he made me promise to shut it down and go home and rest.

I started treatment almost right away—a combination of a monoclonal antibody and chemotherapy. I did have side effects, some nausea, flu-like symptoms, and an itchy hives reaction to the chemo infusion. But the team did a great job of pretreating me with cocktails to head off some of that stuff. I'd come home from chemo, crash, and the next day I might feel punk. But slowly I'd work my way back to my normal schedule. I even ran home from some of my chemo treatments. That was psychological for me. It made me feel in control and healthy.

That initial round of treatments kept me in

remission for several years. When I started to become symptomatic again around 2012, my doctors put me on steroids and an occasional infusion of monoclonal antibodies. Eventually, I moved to a targeted therapy pill, which I still take daily. I don't have side effects. I'm in remission. I feel good.

I used to go through life feeling pretty invincible. I thought cancer was something that only happens to other people. It's been enlightening and humbling to go toe-to-toe with it. There's no such thing as an equilibrium in life. It's not about who you are or what you have or what you do, it's about how you adapt and adjust.



PUT YOURSELF FIRST

HOW TO CALM YOUR WORRIES AND LIVE BETTER LONG-TERM WITH CLL

By Stephanie Watson

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

Typically, when people get a cancer diagnosis, they launch straight into aggressive treatment mode. Chronic lymphocytic leukemia (CLL) is different. Doctors often take a watch-and-wait approach until symptoms appear or the white blood cell count surges. Waiting is the norm, but it can be stressful.

“Essentially, we’re telling someone they have cancer, but we’re not going to do anything about it,” says Josie Montegaard, a nurse practitioner in the Center for Chronic Lymphocytic Leukemia at Dana-Farber Cancer Institute in Boston. Though it can be hard to grapple with the idea of putting your treatment on pause, your doctor has good reasons to wait. “We don’t want them to start treatment right away and have side effects, when they may not need treatment for many years,” Montegaard says.

Take comfort in knowing that your doctor won’t just leave you hanging. Your medical team will regularly monitor your cancer’s progress, using tests to predict how it might change over time, Montegaard says.

When you’re in this holding pattern and you don’t have symptoms, you should feel pretty close to normal. As the disease progresses and you start treatment, side effects like nausea, fatigue, diarrhea, and constipation can become issues. Your doctor can give you medicines to control most of these side effects—including anti-nausea drugs, anti-diarrhea drugs, and stool softeners.

Fatigue is another common complaint with CLL. Though it might seem difficult to contemplate

exercise when you’re tired, it’s one of the best ways to boost your energy levels. Do whatever type of exercise you enjoy and can handle. Take a daily morning walk, ride a stationary bike, or swim. Because you could be at increased risk for bleeding, avoid activities like boxing or horseback riding that can cause injuries.

True to its name, CLL is a chronic disease. It’s going to be with you long term, along with the stress of having cancer. Manage that stress with relaxation techniques like meditation, deep breathing, acupuncture, or massage. These techniques will also steer your mind away from the constant worries over your disease.

Get advice from other people who’ve traveled the same path by joining a CLL support group through your cancer hospital or the Leukemia & Lymphoma Society. “We always try to encourage our patients to get into a support group if they feel alone in their disease and they just want someone to talk to about it,” Montegaard says.

Although CLL can seem all-consuming sometimes, remember that it’s only one aspect of your overall health. Stay up to date on your other cancer screenings with regular mammograms, pap smears, colonoscopies, and skin cancer checks. Because your cancer and its treatments put you at greater risk for infections, it’s also important to get all of the vaccinations your doctor recommends. “The best thing for patients to do is keep their whole body healthy by preventing any opportunistic infections or diseases,” Montegaard says.

ALL ABOUT REMISSION

AN EXPERT EXPLAINS THE INS AND OUTS

By Rachel Reiff Ellis
Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

Hematologist and oncologist Michael Choi, MD, associate clinical director at UC San Diego Health Moores Cancer Center, talks about what you can expect once your CLL is in remission.

Q. WHAT DOES IT MEAN TO BE IN REMISSION?

Remission means the cancer isn't getting worse or causing problems. There are varying degrees. Sometimes you can have a partial remission, meaning we can still detect CLL cells in your blood, but the cancer is no longer at a point where it's threatening your health. In other cases, it's complete: bloodwork, imaging, and often even your bone marrow is normal. Remission doesn't necessarily mean "cured." The CLL isn't all the way gone, but we've knocked it back to a point where it's not a problem for the foreseeable future. CLL can often come back, even after it's down to undetectable levels. That's why it's so important for us to monitor you and make sure you know which symptoms to be aware of.

Q. HOW COMMON IS REMISSION FROM CLL?

With our current therapies, we expect the majority of people—around 80 to 90%—to have some sort of remission.

There are exceptions. Treatments may not work for some people. But as CLL treatments improve, this happens less often. Broadly speaking, usually within a month or two after starting treatment, you should be headed toward or already in remission.

Q. HOW OFTEN DO I NEED TO SEE MY DOCTOR?

The first question you should ask is, "Do I need continued treatment to maintain my remission?" With some drugs, ongoing treatment is the way to maintain control over the disease. Other treatments we stop after one to two years. Either way, you need regular exams to make sure you're tolerating continued treatment well or to watch for signs the disease is coming back. I usually see people in remission once a month to every three months, depending on how well they're doing and whether they're on a treatment.

Q. WHAT SYMPTOMS SHOULD I BE ON THE LOOKOUT FOR?

You'll usually have symptoms very similar to the ones you had before your treatment. Examples include fevers, sweats, unexplained weight loss, weakness, dizziness, or easy bruising.

You may also have pain or discomfort or an inability to eat full meals, which could mean you have an enlarged lymph node or spleen.

Q. HOW DO I DEAL WITH THE WORRY THAT CLL WILL RETURN?

For some people that's the hardest part of stopping treatment: knowing that things can come back. But it's very rare for the disease to change its behavior. If you're feeling well, you can trust you're still in remission. There aren't typically surprises at your clinic visits—you'll know before your doctor does that things have ramped up again. You'll be having symptoms, and they'll typically show up in the same way they did in the first place, so you'll know what you're dealing with.

With regular visits and exams, we can stay one step ahead of things, so that if your CLL does come back, we can repeat what we've done before to treat it. We may even have something better.





NUTRITION SMARTS

YOUR TASTES AND NUTRITIONAL NEEDS CHANGE DURING TREATMENT

By Stephanie Watson

Reviewed by Brunilda Nazario, MD, WebMD Senior Medical Editor

Chronic lymphocytic leukemia (CLL) treatments can destroy your appetite and leave such a bad taste in your mouth (literally) that you have no desire to eat. Good nutrition will give you the strength to fight your cancer, but how can you get it when food is so hard to swallow?

“We have workarounds,” says Margaret Martin, a registered dietitian and nutrition educator with the Leukemia & Lymphoma Society. “If you have a bad taste in your mouth, mix a quart of water with a teaspoon of baking soda and three-quarters

teaspoon of salt and swish that in your mouth.” The rinse will cleanse your palate and moisten your taste buds to make food more palatable.

If the smell of cooking foods turns your stomach, eat them cold or at room temperature. Martin suggests foods like cottage cheese, fruit, or a turkey-and-kale wrap. “Those all have very low aroma points,” she says.

How you serve your food also affects its flavor. Chemotherapy can leave a metallic taste in your mouth that metal silverware accentuates. Use plastic knives, spoons, and forks instead.

Your appetite will suffer if abnormal cancer cells enlarge your spleen to the point where it presses on your stomach. You’ll feel full when you’ve barely eaten anything. Martin suggests that you eat smaller meals more often and get the bulk of your nutrition in the first few bites from high-protein, calorie-dense foods.

Your protein needs will increase during treatment by at least 25%, which you can get by eating more poultry, fish, grains like quinoa and farro, beans, and chickpeas. If you’ve lost weight, add what Martin calls “calorie boosters” to your meals—chopped nuts, low-fat cheese, vegetable oils, or meat.

Nausea and vomiting from your treatment can dehydrate you, so be

mindful of your daily fluid intake. “64 ounces of fluid a day is a good place to start,” Martin says. “It can be fluid from all sources, including water, soups, and popsicles.” Just don’t drink much more than 72 ounces. Too much fluid will dilute critical electrolytes like sodium and potassium in your blood.

Be more careful about what you eat. CLL and its treatments increase your risk for infections. Avoid foods in which bacteria tend to breed, like raw meat, sushi, feta and other soft cheeses, and unpasteurized milk and juice. “Don’t buy any food that looks bruised or spoiled,” says Martin. “Buy things that are in date and look healthy.”

CLL is unique among cancers in that it’s a chronic disease. Adopt a healthy eating style you know you can stick with over the long run.

A dietitian can help you design an eating plan that meets your nutritional needs and tastes. “They can help you find a variety of foods you can tolerate during treatment,” Martin says. “And they can suggest easy food prep tips if there’s fatigue involved.” Make sure the doctor who treats your cancer is also on board to ensure that what you eat is compatible with your treatment.

To learn more about eating for CLL, visit the Leukemia & Lymphoma Society’s website at lls.org/nutrition.