CHRONIC LYMPHOCYTIC LEUKEMIA
A TREATMENT GUIDE FOR PATIENTS AND THEIR FAMILIES

WHERE INFORMATION EQUALS HOPE

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD
IMBRUVICA® (ibrutinib) is a prescription medicine used to treat adults with:

- Chronic lymphocytic leukemia (CLL)/Small lymphocytic lymphoma (SLL) with 17p deletion
- Chronic lymphocytic leukemia (CLL)/Small lymphocytic lymphoma (SLL)

It is not known if IMBRUVICA® is safe and effective in children.

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

- have had recent surgery or plan to have surgery. Your healthcare provider may stop IMBRUVICA® for any planned medical, surgical, or dental procedure
- have bleeding problems
- have or had heart rhythm problems, smoke, or have a medical condition that increases your risk of heart disease, such as high blood pressure, high cholesterol, or diabetes
- have an infection
- have liver problems
- are pregnant or plan to become pregnant. IMBRUVICA® can harm your unborn baby. If you are able to become pregnant, your healthcare provider will do a pregnancy test before starting treatment with IMBRUVICA®
  - **Females** should not become pregnant during treatment and for 1 month after the last dose of IMBRUVICA®
  - **Males** should avoid getting female partners pregnant during treatment and for 1 month after the last dose of IMBRUVICA®
- are breastfeeding or plan to breastfeed. You and your healthcare provider should decide if you will take IMBRUVICA® or breastfeed

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking IMBRUVICA® with certain other medicines may affect how IMBRUVICA® works and can cause side effects.

**How should I take IMBRUVICA®?**

- Take IMBRUVICA® 1 time a day
- Swallow IMBRUVICA® capsules and tablets whole with a glass of water
- Do not open, break, or chew IMBRUVICA® capsules
- Do not cut, crush, or chew IMBRUVICA® tablets
- Take IMBRUVICA® at about the same time each day
- If you miss a dose of IMBRUVICA®, take it as soon as you remember on the same day. Take your next dose of IMBRUVICA® at your regular time on the next day. Do not take extra doses of IMBRUVICA® to make up for a missed dose
- If you take too much IMBRUVICA®, call your healthcare provider or go to the nearest hospital emergency room right away

**What should I avoid while taking IMBRUVICA®?**

- You should not drink grapefruit juice, eat grapefruit, or eat Seville oranges (often used in marmalades) during treatment with IMBRUVICA®. These products may increase the amount of IMBRUVICA® in your blood

**What are the possible side effects of IMBRUVICA®?**

**IMBRUVICA® may cause serious side effects, including:**

- **Bleeding problems (hemorrhage)** are common during treatment with IMBRUVICA® and can also be serious and may lead to death. Your risk of bleeding may increase if you are also taking a blood thinner medicine. Tell your healthcare provider if you have any signs of bleeding, including: blood in your stools or black stools (looks like tar), pink or brown urine, unexpected bleeding or bleeding that is severe or that you cannot control, vomit blood or vomit looks like coffee grounds, cough up blood or blood clots, increased bruising, dizziness, weakness, confusion, change in your speech, or a headache that lasts a long time
- **Infections** can happen during treatment with IMBRUVICA®. These infections can be serious and may lead to death. Tell your healthcare provider right away if you have fever, chills, weakness, confusion, or other signs or symptoms of an infection during treatment with IMBRUVICA®
- **Decrease in blood cell counts.** Decreased blood counts (white blood cells, platelets, and red blood cells) are common with IMBRUVICA®, but can also be severe. Your healthcare provider should do monthly blood tests to check your blood counts
of my CLL by asking my doctor if is the right option for me

IMBRUVICA® has helped many people with CLL live longer. IMBRUVICA® will not work for every patient. Individual results may vary.

- During a clinical trial of 269 previously untreated people (≥65 years) with CLL*: Patients treated with IMBRUVICA® had a 56% lower risk of death than an approved chemotherapy for CLL.1
- During another clinical trial in 391 previously treated people with CLL*: Patients treated with IMBRUVICA® had a 57% lower risk of death than another approved therapy for CLL.1

IMBRUVICA® is a once-daily oral therapy.

If you have CLL, ask your doctor about IMBRUVICA®

Heart rhythm problems (ventricular arrhythmias, atrial fibrillation and atrial flutter). Serious heart rhythm problems and death have happened in people treated with IMBRUVICA®, especially in people who have an increased risk for heart disease, have an infection, or who have had heart rhythm problems in the past. Tell your healthcare provider if you get any symptoms of heart rhythm problems, such as feeling as if your heart is beating fast and irregular, lightheadedness, dizziness, shortness of breath, chest discomfort, or you faint.

High blood pressure (hypertension). New or worsening high blood pressure has happened in people treated with IMBRUVICA®. Your healthcare provider may start you on blood pressure medicine or change current medicines to treat your blood pressure.

Second primary cancers. New cancers have happened during treatment with IMBRUVICA®, including cancers of the skin or other organs.

Tumor lysis syndrome (TLS). TLS is caused by the fast breakdown of cancer cells. TLS can cause kidney failure and the need for dialysis treatment, abnormal heart rhythm, seizure, and sometimes death. Your healthcare provider may do blood tests to check you for TLS.

The most common side effects of IMBRUVICA® in adults with B-cell malignancies (MCL, CLL/SLL, WM and MZL) include:

- Diarrhea
- Rash
- Bruising
- Fever
- Muscle and bone pain
- Nausea
- Tiredness

The most common side effects of IMBRUVICA® in adults with cGVHD include:

- Tiredness
- Diarrhea
- Muscle spasms
- Nausea
- Bruising
- Mouth sores (stomatitis)
- Pneumonia

Diarrhea is a common side effect in people who take IMBRUVICA®. Drink plenty of fluids during treatment with IMBRUVICA® to help reduce your risk of losing too much fluid (dehydration) due to diarrhea. Tell your healthcare provider if you have diarrhea that does not go away.

These are not all the possible side effects of IMBRUVICA®. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

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

Please see the full Important Product Information on the next pages.

*Studies also included patients with small lymphocytic lymphoma (SLL).


If you have questions

Call us at 1-877-877-3536 or visit imbruvica.com

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Imbruvica (ibrutinib)
560, 420, 280, 140 mg tablets | 140, 70 mg capsules
What is IMBRUVICA?
IMBRUVICA is a prescription medicine used to treat adults with:

- Mantle cell lymphoma (MCL) who have received at least one prior treatment
- Chronic lymphocytic leukemia (CLL)/Small lymphocytic lymphoma (SLL)
- Chronic lymphocytic leukemia (CLL)/Small lymphocytic lymphoma (SLL) with 17p deletion
- Waldenström’s macroglobulinemia (WM)
- Marginal zone lymphoma (MZL) who require a medicine by mouth or injection (systemic therapy) and have received a certain type of prior treatment
- Chronic graft versus host disease (cGVHD) after failure of 1 or more lines of systemic therapy

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

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

- have had recent surgery or plan to have surgery. Your healthcare provider may stop IMBRUVICA for any planned medical, surgical, or dental procedure.
- have bleeding problems
- have or had heart rhythm problems, smoke, or have a medical condition that increases your risk of heart disease, such as high blood pressure, high cholesterol, or diabetes
- have an infection
- have liver problems
- are pregnant or plan to become pregnant. IMBRUVICA can harm your unborn baby. If you are able to become pregnant, your healthcare provider will do a pregnancy test before starting treatment with IMBRUVICA.
  - **Females** should not become pregnant during treatment and for 1 month after the last dose of IMBRUVICA.
  - **Males** should avoid getting female partners pregnant during treatment and for 1 month after the last dose of IMBRUVICA.
- are breastfeeding or plan to breastfeed. You and your healthcare provider should decide if you will take IMBRUVICA or breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking IMBRUVICA with certain other medicines may affect how IMBRUVICA works and can cause side effects.

How should I take IMBRUVICA?

- Take IMBRUVICA exactly as your healthcare provider tells you to take it.
- Take IMBRUVICA 1 time a day.
- Swallow IMBRUVICA capsules and tablets whole with a glass of water.
- Do not open, break, or chew IMBRUVICA capsules.
- Do not cut, crush, or chew IMBRUVICA tablets.
- Take IMBRUVICA at about the same time each day.
- If you miss a dose of IMBRUVICA take it as soon as you remember on the same day. Take your next dose of IMBRUVICA at your regular time on the next day. Do not take extra doses of IMBRUVICA to make up for a missed dose.
- If you take too much IMBRUVICA call your healthcare provider or go to the nearest hospital emergency room right away.

What should I avoid while taking IMBRUVICA?
- You should not drink grapefruit juice, eat grapefruit, or eat Seville oranges (often used in marmalades) during treatment with IMBRUVICA. These products may increase the amount of IMBRUVICA in your blood.

What are the possible side effects of IMBRUVICA?

IMBRUVICA may cause serious side effects, including:

- **Bleeding problems (hemorrhage) are common** during treatment with IMBRUVICA, and can also be serious and may lead to death. Your risk of bleeding may increase if you are also taking a blood thinner medicine. Tell your healthcare provider if you have any signs of bleeding, including:
  - blood in your stools or black stools (looks like tar)
  - pink or brown urine
  - unexpected bleeding, or bleeding that is severe or that you cannot control
  - vomit blood or vomit looks like coffee grounds
  - cough up blood or blood clots

- increased bruising
- dizziness
- weakness
- confusion
- change in your speech
- headache that lasts a long time
• **Infections** can happen during treatment with IMBRUVICA. These infections can be serious and may lead to death. Tell your healthcare provider right away if you have fever, chills, weakness, confusion, or other signs or symptoms of an infection during treatment with IMBRUVICA.

• **Decrease in blood cell counts.** Decreased blood counts (white blood cells, platelets, and red blood cells) are common with IMBRUVICA, but can also be severe. Your healthcare provider should do monthly blood tests to check your blood counts.

• **Heart rhythm problems (ventricular arrhythmias, atrial fibrillation and atrial flutter).** Serious heart rhythm problems and death have happened in people treated with IMBRUVICA, especially in people who have an increased risk for heart disease, have an infection, or who have had heart rhythm problems in the past. Tell your healthcare provider if you get any symptoms of heart rhythm problems, such as feeling as if your heart is beating fast and irregular, lightheadedness, dizziness, shortness of breath, chest discomfort, or you faint.

• **High blood pressure (hypertension).** New or worsening high blood pressure has happened in people treated with IMBRUVICA. Your healthcare provider may start you on blood pressure medicine or change current medicines to treat your blood pressure.

• **Second primary cancers.** New cancers have happened during treatment with IMBRUVICA, including cancers of the skin or other organs.

• **Tumor lysis syndrome (TLS).** TLS is caused by the fast breakdown of cancer cells. TLS can cause kidney failure and the need for dialysis treatment, abnormal heart rhythm, seizure, and sometimes death. Your healthcare provider may do blood tests to check you for TLS.

The most common side effects of IMBRUVICA in adults with B-cell malignancies (MCL, CLL/SLL, WM and MZL) include:

- diarrhea
- muscle and bone pain
- rash
- nausea
- bruising
- tiredness
- fever

The most common side effects of IMBRUVICA in adults with cGVHD include:

- tiredness
- bruising
- diarrhea
- mouth sores (stomatitis)
- muscle spasms
- nausea
- pneumonia

Diarrhea is a common side effect in people who take IMBRUVICA. Drink plenty of fluids during treatment with IMBRUVICA to help reduce your risk of losing too much fluid (dehydration) due to diarrhea. Tell your healthcare provider if you have diarrhea that does not go away.

These are not all the possible side effects of IMBRUVICA.

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 IMBRUVICA?

- Store IMBRUVICA capsules at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep IMBRUVICA capsules in the original container with the lid tightly closed.
- Store IMBRUVICA tablets at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep IMBRUVICA tablets in the original carton.

Keep IMBRUVICA and all medicines out of the reach of children.

General information about the safe and effective use of IMBRUVICA.

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

What are the ingredients in IMBRUVICA?

**Active ingredient:** ibrutinib

**Inactive ingredients:**

**IMBRUVICA capsules:** croscarmellose sodium, magnesium stearate, microcrystalline cellulose, and sodium lauryl sulfate. The 70 mg capsule shell contains gelatin, titanium dioxide, yellow iron oxide, and black ink. The 140 mg capsule shell contains gelatin, titanium dioxide, and black ink.

**IMBRUVICA tablets:** colloidal silicon dioxide, croscarmellose sodium, lactose monohydrate, magnesium stearate, microcrystalline cellulose, povidone, and sodium lauryl sulfate. The film coating for each tablet contains ferrosulfate oxide (140 mg, 280 mg, and 420 mg tablets), polyvinyl alcohol, polyethylene glycol, red iron oxide (280 mg and 560 mg tablets), talc, titanium dioxide, and yellow iron oxide (140 mg, 420 mg, and 560 mg tablets).

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For more information, go to www.imbruvica.com or call 1-877-877-3536.

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Understanding CLL

Chronic lymphocytic leukemia (CLL) is a type of hematologic cancer. Hematologic cancers, also called blood cancers, include leukemias, lymphomas and multiple myelomas. CLL is a cancer of the lymphatic system, which is part of the immune system. It is the most common type of leukemia in adults.

Because CLL cells grow slowly and often cause few or no symptoms, your diagnosis may be particularly unexpected. You may have learned you have CLL after having blood tests ordered for another problem or because of findings on a routine physical examination. Or, your CLL diagnosis may be the result of symptoms you’ve had for some time. Regardless, advances in research are enabling doctors to better understand the disease and how it responds to treatment. As a result, they often approach CLL treatment as they would other types of chronic conditions, which allows many people to live longer and with a better quality of life than ever before. Additionally, researchers are currently building on these successes by conducting clinical trials to test new and combination therapies (see Finding Clinical Trials, page 12).

To learn more about CLL and your diagnosis, you’re encouraged to find a doctor with experience treating this type of leukemia. Although extremely skilled, a general medical oncologist may see only a handful of CLL patients each year. A hematologist who specializes in CLL, on the other hand, may see hundreds or more. That extensive experience leads to expertise, and it benefits you to work with a doctor who is an expert in the field. Location may be a factor in your choice of doctor and treatment center. If traveling for treatment is not an option, you may find a specialist who will consult with your local doctor. It’s important to learn as much as you can about the disease and the options available so you can confidently partner with your medical team as you move forward.

ABOUT CLL

Leukemia begins in the blood and bone marrow, the soft, spongy center of some bones. It occurs when the bone marrow makes too many white blood cells. These white cells don’t fight infection like healthy white blood cells do, making an individual susceptible to infection.

CLL is a slow-growing form of leukemia that develops from lymphocytes. Lymphocytes are a type of white blood cell that makes up lymphoid tissue, which is found in the lymph nodes, thymus, spleen, tonsils and other parts of the body. They are a part of the immune system and develop from lymphoblasts (immature cells found in bone marrow) into mature, infection-fighting cells (see Figure 1).

Lymphatic vessels carry a fluid called lymph, which brings oxygen and other nutrients to the cells and takes away waste products. Lymphatic fluid also contains white blood cells, which help fight infections.

CLL develops when mature lymphocytes change and multiply uncontrollably. They grow at a faster rate than normal lymphocytes, and they do not die when they should, causing them to build up in the blood or bone marrow. This leads to an accumulation of them in the blood, bone marrow, lymph nodes and spleen, which interferes with the normal production of healthy cells, including red blood cells, which carry oxygen; white blood cells, which fight infection; and platelets, which are needed for blood to clot. These disruptions cause common CLL symptoms, such as anemia, infections and easy bruising, bleeding, and lymph node and spleen enlargement.

The buildup of abnormal lymphocytes doesn’t form a tumor, which is what people commonly think of when they hear the word “cancer.” Blood cancers are different. Except for lymphomas, they typically do not grow into tumors. Instead, CLL cancer cells circulate in the bloodstream and can spread through the lymphatic system to other parts of the body.

Along with exploring different options available for treating CLL, including clinical trials, this guide offers insights on how to manage this chronic disease. Use the resources in the back of this guide to learn more about CLL. The members of your health care team are also valuable resources. They are working for and supporting you to ensure you never feel alone at any point during treatment. Talk with them about all your questions and concerns. The more you know, the more prepared you will be to make decisions about your overall treatment plan.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
  Chronic Lymphocytic Leukemia
- American Society of Clinical Oncology: www.cancer.net
  Leukemia - Chronic Lymphocytic
- CLL Advocates Network (CLLAN): www.clladvocates.net
- CLL Society: cllsociety.org
  The Basics
- Leukemia & Lymphoma Society: www.lls.org
  Choosing a Blood Cancer Specialist or Treatment Center
- National Cancer Institute: www.cancer.gov
  Chronic Lymphocytic Leukemia Treatment - Patient Version
Living with a Chronic Disease

**Advances from clinical trials enable doctors** to focus on treating chronic lymphocytic leukemia (CLL) as a chronic disease that can be managed, allowing you to enjoy a good quality of life for many years. Although CLL can present certain day-to-day challenges, the goal is to work closely with your health care team to manage the side effects and live the healthiest and happiest life possible.

Once initial treatment is complete, your doctor will put together a follow-up care plan using specific details about your diagnosis, stage of the cancer, type of treatment received and your overall health, including the side effects and issues related to treatment. Similar to treatment plans, follow-up care plans will include a schedule of visits, treatments and/or screenings and may change over time. Some people may live for a long time without disease-related problems, due in part to their commitment to stick to the plan.

**Recurrent Cancer**
Your doctor will monitor you for a potential recurrence. A recurrence, also called a relapse, is when cancer that's the same type as the original cancer comes back. For example, if you are cancer-free after treatment for CLL and, a few years later, you are again diagnosed with CLL, that is recurrent cancer. It can happen weeks, months or years after treatment stops or even while you are on treatment. CLL sometimes comes back because tiny cancer cells occasionally survive treatment and remain in the body undetected. These lingering cells grow and multiply until, eventually, tests can detect them. Be sure to ask for more information about your recurrence risk profile, as it is critically important to contact your doctor at the first signs of the return of cancer.

**Second Cancers**
Your cancer diagnosis increases your risk of developing a second cancer. A second cancer isn't a recurrence of your CLL; instead, it is a completely different or new type of cancer diagnosis. Monitoring may include physical examinations, blood tests and imaging tests. You are encouraged to make and keep regular screening appointments for breast, cervical, colon and prostate cancers. Your doctor will likely ask you to do a monthly self-examination of your breasts and skin and report if you feel any lumps or have any symptoms, such as skin problems or new moles.

If you have chemotherapy to treat your CLL, you are at risk for developing therapy-related myeloid leukemia several years later. Although it is a type of leukemia, it is a different type, so it is not considered a recurrence.

The possibility for developing a second cancer is small, but it’s important to ask your doctor what to be aware of and how you can help minimize your risk.

**Long-Term and Late Effects**
When treatment ends, some people are able to adjust to a new way of life and, for the most part, don’t experience any major health issues related to their experience with the disease. Others, however, experience side effects of treatment that last beyond the end of their therapy regimen. These are known as long-term effects. The side effects of treatment that may appear weeks, months or even years after treatment ends are called late effects. They are notoriously hard to predict and, just as with side effects, every person reacts differently. Some late effects may simply go away over time, and others may be permanent. They often depend on the type of treatment and the length of time it was given, as well as your age, gender and overall health.

Ask your doctor about possible long-term or late effects to expect based on the types of treatment you had. Like almost all side effects, most long-term and late effects can be treated more easily the earlier they’re detected. That’s why it’s so important to stay in contact with your doctor to communicate any new health concerns.

**Healthy Lifestyle Choices**
Although you can’t necessarily prevent a cancer recurrence or diagnosis, research shows a number of health benefits from exercising and eating right, including being better prepared to handle any future health issues.

Taking part in physical activities or regular exercise, such as walking, yoga or bike riding, can help you feel better overall. Weight-bearing activities can help strengthen bones, which is important if you have bone metastasis. It may be challenging to exercise if you are fatigued, but physical exercise is actually the best treatment for fatigue. Studies have shown that people with cancer who exercise regularly feel less tired and have more energy.

Making healthy food choices during and after treatment may increase your strength, help your body heal itself and give you more energy. If you are unsure about the types of foods to eat, consult a dietician. Whether your goal is weight loss, weight gain or just learning how to maintain a healthy diet and lifestyle after treatment, a dietician can help you create a nutritious, balanced eating plan tailored specifically to you.

Getting enough sleep at the right time is important. Set a routine for sleeping and waking, and try to get about eight hours each night. Limit naps to 45 minutes each, and avoid taking them in the late afternoon or early evening as that might prevent you from sleeping at night. Tell your doctor if you aren’t able to sleep, and be sure to mention symptoms, such as pain, nausea or depression, as they may contribute to your sleep problems.

**Supportive Care**
Whether you choose to receive more cancer treatment or not, consider getting supportive care, which treats the symptoms of CLL. These options are not expected to cure cancer or prolong life. Instead, they focus on quality of life and pain management.

**Additional Resources**
- **American Cancer Society:**
  - www.cancer.org
  - Managing Cancer as a Chronic Illness Supportive Care
- **American Society of Clinical Oncology:**
  - www.cancer.net
  - CLL Follow-up Care
- **Leukemia & Lymphoma Society:**
  - www.lls.org
  - Life after Diagnosis and Treatment
- **National Comprehensive Cancer Network:**
  - www.nccn.org
  - Managing Cancer as a Chronic Condition Taking Charge of Follow-up Care
My chronic lymphocytic leukemia (CLL) journey began when I visited the emergency room for sinusitis. The ER physician told me my white blood cell count was elevated. He thought it was likely due to the sinus infection but recommended I follow up with my primary care physician (PCP). He prescribed antibiotics, and it took two refills before I felt better.

I followed up with my PCP about six weeks later. She ran bloodwork and found my white count was still elevated, so she asked me to come back in three months. When I did, the count was even higher. I had an appointment with a neurologist about the same time because of continual headaches. He did bloodwork, too. He also told me the count was high and that I should follow up in six months. I decided not to return for that checkup, however, because I told myself it was unnecessary. I lived a healthy lifestyle and I never even called in sick to work. Aside from hay fever, the occasional migraine, and chills and night sweats, (which I blamed on perimenopause after my OB/GYN told me I had officially entered it), I felt fine.

About a year later, I went back to the ER with chest pains. I had multiple tests, including bloodwork, which showed an even higher white count. I also had a urinary tract infection. It took two rounds of antibiotics to resolve that. Six months later, I came down with sinusitis again and strep throat, something I’d never had. Six months later, I was back in the ER with trouble swallowing and a terrible headache. The ER physician said my white count had been elevated for too long and referred me to a hematologist. That made me uneasy, and I asked why. He told me I could have cancer. I thought there was no way I could have cancer. I said to myself, “That diagnosis would be for someone else. Not me.”

When I met with the hematologist, he examined me and asked several questions, including if any of my close relatives had leukemia. I told him my father, who had passed away in 2006, did. He told me he’d call me when my bloodwork results came in. I was getting ready for work when he called. He asked how I was, and I said I was fine. Then he told me the news that no one wants to hear. I had chronic lymphocytic leukemia — the same diagnosis as my father. I was 51 years old.

When I heard the diagnosis, I was shocked and then just numb. For a little while, I seemed to feel nothing at all. That gave way to moments of anxiety, guilt, fear, shame, anger and sadness. My emotions were all over the place until I could digest the news. I wondered if I’d done something to cause the cancer even though I’d eaten right and exercised. I worried about my two children and how much hair I would lose, and I couldn’t stop thinking about what the future might hold.

But, I didn’t stay in this state of mind long because I knew that the same God that took care of me yesterday would take care of me today and every day thereafter. I had to shake myself out of it. I began to think about how God knows the plans that He has for me. In that same hour, I began to recall a verse to a song my grandmother used to sing called “What a Friend We Have in Jesus.”

Because I was diagnosed at Stage 0, my treatment plan is to watch and wait. I get lab work done every three months and see the doctor every six months. If I continue to be symptom-free, I will see the doctor yearly.

My family and friends have always played an important role in my life. They encourage me to continue to eat healthy and to keep a sense of humor. They show their love and support through their laughter and caring attitudes. When family works together, they can certainly keep hope alive.

I am involved in the Friend for Life Cancer Support Network. It’s a team of cancer survivors who provide one-on-one emotional support to anyone experiencing a diagnosis of cancer. We communicate by text, email, phone and even in person. As a peer navigator, I help others navigate their cancer journey.

I take life one day, and one moment, at a time. My advice to others with CLL is to maintain as much normalcy as you can. I see my cancer as I see any other chronic illness. If not treated, it could become life-threatening.

Right now, I’m enjoying my life. I have up days and a few down ones, but God never said there would be sunshine all the time. I find something to be thankful for every day because I’ve made a decision to live and have no regrets.
Staging and Genetic Testing

Staging is how your doctor learns more about your cancer, specifically whether it has spread from where it began. Your doctor will perform a physical examination to check for any signs of pain and any irregularity in the size of your organs. Then, your doctor will review the results of your diagnostic tests, including a variety of blood tests, along with the results of some or all of the following tests, to stage the cancer and develop the appropriate treatment plan for you.

Hematologic cancers are typically staged according to the type and subtype of the leukemia, abnormalities noticed on physical examination, the microscopic appearance of the leukemia cells, lab and imaging test results, chromosome abnormalities and the results of molecular testing.

A pathologist will analyze these test results and provide your doctor with a pathology report of the findings.

- **Bone marrow aspiration and biopsy** are often done at the same time. During these procedures, bone marrow tissue samples are removed for examination. For bone marrow aspiration, liquid bone marrow is removed. A bone marrow biopsy involves removing a sample of marrow from within the bone.

- **Imaging tests**, such as magnetic resonance imaging (MRI), positron emission tomography (PET) and X-rays, can help identify where CLL is present in the body. They may also be used to determine if certain symptoms are related to CLL and to monitor your body’s response to treatment.

The staging system most commonly used in the U.S. for CLL is the Modified Rai staging system (see Table 1). This system divides CLL into one of five stages according to the number of lymphocytes and other cells in the blood and the presence of certain abnormalities noticed on physical examination. The higher the stage, the more advanced the disease.

The “risk” characteristic assigned in staging is associated with the predicted rate of growth for the disease. If tests show evidence of a fast-growing disease, it is given a higher stage and is, therefore, considered high-risk CLL. Regardless of the identified risk, certain genetic tests may then be performed, and your doctor will consider all of the results when determining the best course of treatment.

In addition to helping diagnose and stage CLL blood tests are used to help determine your prognosis (outlook) and if you have any additional diseases that are related to CLL.

### The Role of Genetic Testing

Genetic tests are an integral part of planning CLL treatment. They may be done to look for certain gene abnormalities or mutations, proteins and changes in chromosomes that may indicate how the disease may progress. Also referred to as molecular profiling, genetic testing is typically performed on a small sample of fluid or tissue — usually blood. Your doctor will use the results to help determine the type of treatment that will be most effective at managing the disease.

For CLL, doctors use these tests to determine whether there are chromosomal or other genetic changes in lymphocytes. Healthy cells in the body contain 23 pairs of chromosomes, but CLL cells often have abnormal chromosome changes, such as deletions or missing parts. In CLL, it is common for parts of chromosomes 11, 13 or 17 to be missing. This is known as a deletion and is often an indication of how slowly or quickly the disease will progress. For example, a deletion in chromosome 13 means that the CLL cells grow slowly, and a deletion in chromosome 17 means the disease will progress quickly and be difficult to treat.

These and other tests are used to study the characteristics of chromosomes (genetic strands) under a microscope and to find mutations in the leukemia cells.

#### Fluorescence in situ hybridization (FISH)

Uses fluorescent dyes that attach to certain chromosomes and can be observed under a microscope. It is often used to detect chromosomal abnormalities in leukemia cells.

#### Karyotype

A test that involves analyzing the shape and number of chromosomes. It can help identify changes in chromosomes that may be associated with rapid disease progression.

#### DNA sequencing

Conducts a test that looks at the order of the chemicals that make up a molecule of DNA. The test is used to identify mutations, or changes, that occur in genes, such as mutations in the immunoglobulin heavy-chain variable (IGHV) region and TP53 genes. Mutations in IGHV indicate a good prognosis, whereas mutations in the TP53 gene do not.

### Table 1: Modified Rai Staging System

<table>
<thead>
<tr>
<th>Stage</th>
<th>Risk</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Low</td>
<td>Lymphocytosis only (the blood contains a significant number of lymphocytes).</td>
</tr>
<tr>
<td>Stage I</td>
<td>Intermediate</td>
<td>+ Adenopathy (the blood contains a significant number of lymphocytes, and lymph nodes are enlarged).</td>
</tr>
<tr>
<td>Stage II</td>
<td>Intermediate</td>
<td>+ Enlarged spleen and/or liver (the blood contains a significant number of lymphocytes, the spleen and/or liver is enlarged, and the lymph nodes may or may not be enlarged).</td>
</tr>
<tr>
<td>Stage III</td>
<td>High</td>
<td>Lymphocytosis + Hgb &lt; 11g/dL (the blood contains a significant number of lymphocytes, and the hemoglobin is less than 11 grams per deciliter).</td>
</tr>
<tr>
<td>Stage IV</td>
<td>High</td>
<td>Lymphocytosis + Plt &lt; 100,000/µL (the blood contains a significant number of lymphocytes, and the platelet count is less than 100,000 microliters).</td>
</tr>
</tbody>
</table>

In addition to this staging system, some oncologists may also use the Chronic Lymphocytic Leukemia International Prognostic Index (CLL-IPI) to predict the risk of disease recurrence and overall survival. Your doctor, after evaluating your physical examination and diagnostic test results, takes into account your status, IGHV mutation status, TP53 mutation = 4 points, IGHV unmutated = 2 points, Serum B2-microglobulin more than 3.5mg/L = 2 points, Rai Stages I-IV = 1 point, Age older than 65 years = 1 point to determine the type and subtype of the leukemia, abnormalities noticed on physical examination, the microscopic appearance of the leukemia cells, lab and imaging test results, chromosome abnormalities and the results of molecular testing.

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

- TP53 mutation = 4 points
- IGHV unmutated = 2 points
- Serum B2-microglobulin more than 3.5mg/L = 2 points
- Rai Stages I-IV
- Age older than 65 years = 1 point

After being examined at a laboratory, the test results are sent back to the doctor or directly to you. A combination of these different factors is used to calculate the CLL International Prognostic Index (CLL-IPI) score, which provides a very accurate estimate of disease risk (see Table 1).

Consulting with a genetic counselor before testing will help you understand your risks for other cancers. After testing, your counselor can help you interpret the results and use them to plan future health care, such as a schedule for screenings for you and family members, if appropriate. If a mutation is identified, your genetic counselor may discuss options to reduce your risk, including earlier or more frequent screenings, lifestyle changes or preventive treatments. If you aren’t working with a genetic counselor, ask your doctor to discuss the results of your tests with you. Don’t feel embarrassed about asking for explanations.

This is a complicated topic, and the more you understand, the more comfortable you will be with the suggested treatment plan.

Genetic testing can be expensive. Medicare and private health insurance cover testing in some cases, but always investigate your insurance coverage before having it done. Testing laboratories may be able to help verify insurance coverage.

Not everyone with CLL needs to begin treatment soon after diagnosis. Low-stage and low-risk CLL may not require immediate treatment if there are no signs or symptoms of the disease, such as drenching night sweats, extreme fatigue, fever or unexplained weight loss (see Exploring Available Treatments, page 10).

Researchers are continuously working to find other changes that occur in CLL chromosomes. As new tumor markers and ways to treat CLL are identified, your doctor may do additional genetic tests to ensure you continue to receive the most effective treatment. These advances offer opportunities for additional options in case your treatment stops working or isn’t working as well as expected.

"Seeking second opinions is always good advice. Along with that, I encourage patients to find a center that has experience treating CLL. They can continue to see their local oncologist, but I recommend adding in visits with someone who specializes in the disease. So many advancements are happening all the time with every type of cancer. It’s impossible for an oncologist to be on the forefront of every cancer type, especially a less common one like CLL. I also encourage patients to learn about CLL. Do research, read and ask questions. The more they understand, the better they will feel about what is ahead." – John Byrd, MD, is a board-certified hematologist whose areas of focus are chronic lymphocytic leukemia (CLL) and acute myeloid leukemia (AML). He serves as the D. Warren Brown Chair of Leukemia Research. He is also a Distinguished University Professor of Medicine, Medicinal Chemistry and Pharmacy for The Ohio State University.

The Importance of a Second Opinion

You are encouraged to seek a second opinion from a doctor skilled in treating CLL. Every specialist offers different experience and may favor a different approach. Another doctor may consider different tests, clinical trials or how a treatment may affect your quality of life. The results will confirm your initial diagnosis and treatment plan or introduce new information.

Many people feel uneasy about getting a second opinion. Some people even feel they are being disloyal to their doctor. However, most doctors support their patients seeking another professional opinion, and many will offer a referral to another specialist.

In some cases, health care insurance plans require a second opinion and may pay for one if you request it. Be sure to check with your insurance provider to ensure you understand your coverage.

Before reaching out for a second opinion, have copies of your medical records, including test results, available. This may help you avoid the time and expense of repeating certain tests, as well as the cost of travel if the doctor you reach out to is not nearby.

The overall goal is for you to get the best care available, and being comfortable with your doctor and your recommended treatment plan is an essential part of that. Many resources are available for finding a specialist, including your doctor’s office, your insurance provider, and local and national advocacy groups.
Y our doctor will consider the stage of your chronic lymphocytic leukemia (CLL), along with any symptoms you may be experiencing, in order to best treat your CLL with one or a combination of the options outlined here. Other factors your doctor will use to determine your treatment plan include your overall health, your age, the type of CLL and your expectations for your quality of life.

CLINICAL TRIALS
A great deal of progress is being made in the ways doctors are able to treat CLL, and much of that occurs through research studies known as clinical trials. Talk with your doctor to learn more about clinical trials and ask if you may be a candidate. See Finding Clinical Trials, page 12, to learn how you can research available trials on your own.

WATCH AND WAIT
CLL often progresses slowly. If you are diagnosed at an early stage, your levels of red blood cells and platelets are normal and you are not having symptoms of active CLL, your doctor will likely suggest watchful waiting. With your help, your doctor will monitor your condition. It is important for you to alert your medical team immediately if you begin to experience any of the symptoms that indicate the disease is progressing, such as drenching night sweats, extreme fatigue, fever or weight loss.

Although it may make sense to “get ahead” of the disease and begin treatment while you feel strong and otherwise healthy, there is no evidence that starting treatment early will offer a better quality of life because you can avoid treatment-related side effects until absolutely necessary. In addition, when you are ready for treatment, more options may be available than when you were diagnosed.

TARGETED THERAPY
Your doctor may use personalized medicine, also known as precision medicine, to treat your CLL. This approach enables the doctor to use the results from your genetic (molecular) testing to target specific genes and proteins that are causing cancer cells to grow and multiply.

Commonly used targeted therapies include monoclonal antibodies, such as those targeting CD-20. Other targeted strategies focus on blocking proteins (BTK, PI3K and BCL-2). This type of therapy allows your medical team to control the disease while limiting damage to healthy cells, which may result in fewer side effects.

CHEMOTHERAPY
This type of drug treatment is used to kill cancer cells or prevent them from growing and dividing. Given in IV form or as a pill, chemotherapy is known as systemic therapy, meaning the drugs travel through the bloodstream and attack cells that grow and multiply quickly. Because both cancer cells and healthy cells grow and multiply rapidly, healthy cells are also affected, which is what causes side effects.

Chemotherapy may consist of one or more drugs given in combination, and is usually given in cycles that consist of a treatment period followed by a break to allow healthy cells to recover. It may be given in high doses before stem cell transplantation in a process known as conditioning.

CORTICOSTEROIDS
A corticosteroid, an anti-inflammatory drug that appears to help cause the death of cancerous white blood cells, is sometimes given along with targeted therapy or chemotherapy.

STEM CELL TRANSPLANTATION
An allogeneic transplantation is a type of stem cell transplantation that may be used to treat CLL. Sometimes referred to as an “allo transplant,” this procedure uses stem cells collected (harvested) from a volunteer donor whose tissue type closely matches yours. If available, a sibling is likely to match most closely because your sibling’s genes come from your same parents. If a sibling or another family member is not a good match, an unrelated volunteer donor may be found through a national registry. A donor who’s not related to you but who has a similar tissue type is called a matched unrelated donor (MUD). To reduce the risk of Graft-versus-Host Disease (GvHD), a serious condition in which healthy cells from the transplant attack your cells, it is important to find a donor whose bone marrow matches yours as closely as possible. The best donor has human leukocyte proteins on his or her white blood cells that are as much like yours as possible.

Doctors treat CLL with the goal of remission, which is when they can no longer find leukemia cells after multiple tests. When patients’ leukemia levels are significantly reduced but there is still evidence of some leukemia cells, it is considered a partial remission. When leukemia cells are still present after treatment, it is called refractory CLL. Several options are available to treat refractory CLL. Your doctor will take into account the options you have already tried and your overall health before recommending another plan. This may be a good time to consider getting a second opinion if your doctor doesn’t specialize in CLL. Doctors have different areas of expertise and you may learn about additional options your current doctor is not aware of. You may also consider possible clinical trials (see Finding Clinical Trials, page 12).

When the leukemia initially responds to treatment but then stops responding after six months or more, it is called relapsed CLL. CLL typically has multiple relapses, which are also referred to as recurrences. If your cancer relapses, your doctor will begin a new cycle of diagnostic tests. These tests may include another tissue biopsy and laboratory tests. The doctor will confirm if the cancer is recurrent and will determine if it has transformed into a more aggressive subtype, which will affect your new treatment plan.
During this procedure, you receive chemotherapy with or without radiation therapy in the conditioning phase to help destroy existing bone marrow and create a clean environment in which new cells can grow. Next, the donor’s stem cells are given to you through a tube placed in a vein (IV). The transplanted stem cells travel to the bone marrow and begin to grow. While you are waiting for new, healthy blood cells to form (this is known as engraftment), you will have very little or no immune defense system. You’ll likely be very tired. Your doctor may give you an antibiotic to prevent or treat infection or a blood transfusion to prevent bleeding and treat anemia.

The goal of transplantation is for your blood counts to return to safe levels and/or remission, which is having no signs or symptoms of cancer.

- **Understanding Medication Adherence**

  Depending on your treatment plan, you may be able to manage your CLL by taking medications at home. The advantages include convenience, fewer medical appointments and the feeling of being in control over this part of your treatment. However, with those benefits comes the responsibility of medication adherence, which is taking your medication exactly as prescribed by your doctor.

  Sticking to that schedule is extremely important in the treatment of cancer because you’re enabling the medication to work as it is intended and be fully effective. Most drug regimens to treat cancer are designed to maintain a specific level of drugs in your system for a specific duration of time, based on your diagnosis, stage, previous treatments and several other factors.

  Taking your medication may seem like a simple concept, but it takes effort and coordination to take it correctly. Even the most motivated and organized patient can have difficulties at some point, which can be dangerous. Because of how the drugs work, even small changes to a treatment plan can have a negative effect. The most serious consequence is running the risk that your treatment will be ineffective. Studies show that not following a treatment regimen as prescribed can lead to cancer progression or recurrence.

  Being able to stick to the schedule may depend on your understanding of the treatment regimen, your financial situation and your ability to manage the potential side effects. Always learn as much as you can about your specific medication, and ask your doctor, nurse or pharmacist for assistance whenever necessary.

  Whether you take your medications in the comfort of your own home or receive them at your doctor’s office, treatment center or hospital, here are some things you can do to help stay on schedule.

  - **Make a list of your medications**, along with the names and contact information for the doctors who prescribed them. Let a caregiver, family member or friend know where you keep the list.
  - **Learn about your medications**, and ask questions about anything you don’t understand before starting them.
  - **Involve your caregiver** or another person who can remind you of your schedule. Adherence is easier when someone can help you.
  - **Set reminders for when to take medications** or when to leave appointments. You have many options for reminder tools, such as setting a timer on your telephone, using an alarm clock or wearing a watch that vibrates to alert you. If you have a smartphone, explore the medication reminder apps that are available. Many are free.
  - **Track when you take medication**. Using tools, such as the downloadable “My Medical Journal” (see page 4), will help you stay on schedule with your medications.
  - **Keep your appointments for testing and monitoring**. These visits allow your doctor to track your progress and analyze the cancer’s response to the medication you’re taking. Use your appointments as an opportunity to ask your health care team about your medications and any side effects you’re experiencing.

- **Allogeneic Donations Offer Lifesaving Treatment**

  - About 30 percent of people who need a bone marrow transplant have a family member who can donate to them. The other 70 percent do not, which means they need an unrelated donor. To help people find donors, organizations such as the National Marrow Donor Program have created registries of millions of potential donors. Be the Match is a donor registry operated by the National Marrow Donor Program.
  - For more information, visit [www.bethematch.org](http://www.bethematch.org)
Significant progress is being made in the ways chronic lymphocytic leukemia (CLL) is treated, and much of that progress is happening in clinical trials. Depending on your unique characteristics, such as your age and if certain genetic mutations are present in your body, your doctor may recommend a clinical trial initially or at some other point in your treatment.

Research conducted in clinical trials provides information about the disease and offers promising new options for people with CLL. Scientists and doctors are working to learn more about how the disease begins, its side effects and symptoms, how it can be treated and the best ways to treat it.

Clinical trials focusing on new and modified targeted therapies are offering promising results. Kinase inhibitors are being evaluated for effectiveness against cancer cells, and new trials that combine novel therapies, such as chimeric antigen receptor T-cells (CAR T-cells), are also underway. Immunotherapy, which uses the body’s own immune system to slow the growth of and kill cancer cells, is being used to treat many types of cancer. Although no immunotherapy treatments are currently approved for CLL, a great deal of research is underway in clinical trials.

Allogeneic stem cell transplantation is being studied to reduce complications associated with treatment.

In addition, many clinical trials aim to improve the complete remission rates, and more research is being conducted for refractory CLL.

**SEARCHING FOR A CLINICAL TRIAL**

Along with asking your doctor about available clinical trials, you’re encouraged to research them on your own (see Assistance & Support Resources, page 17). Navigating the online search tools can be overwhelming. To help prepare you, screenshots from a mock clinical trial search site are shown below.

Before you begin, have your exact diagnosis, pathology report and details of previous treatments handy. If you find a clinical trial that appears to be a good fit but is no longer accepting patients, your doctor may appeal to the U.S. Food and Drug Administration (FDA) for expanded access, also referred to as compassionate use. If you don’t find a clinical trial, know that new clinical trials are being added all the time. You may choose to continue searching while you move forward with your current treatment plan.

**[STEP 1] FILL IN YOUR INFORMATION**

Enter Your Diagnosis
You may conduct multiple searches to create more options. For example, first enter the diagnosis, such as “Chronic Lymphocytic Leukemia” and do the search. Next, try “CLL” to compare the different results.

Location
If you prefer to find a clinical trial that is close to home, enter your home address. If you are willing and able to travel for treatment, enter other locations.

**[STEP 2] READ YOUR SEARCH RESULTS**

The name of the clinical trial will appear at the top of the results page.

Recruitment Status
This indicates whether the trial is actively recruiting, not yet recruiting or otherwise inactive. This will change, so continue to check for status updates.

Summary of Study
This contains detailed information about the clinical trial’s purpose and the treatment being tested. This section is usually written for health care providers and may be difficult to understand. That’s OK. If you find a clinical trial that interests you, print out the information so your doctor can explain it to you.
In 1992, when I was 46 years old, I had a heart attack. The doctors drew my blood and, a week later, I found out that my blood was abnormal — in more ways than one. After having a liver biopsy and bone marrow biopsy, I was diagnosed with chronic lymphocytic leukemia (CLL) and hemochromatosis, a condition in which there is too much iron in the blood. The treatment for hemochromatosis involved getting my blood drawn once a week to lower the iron levels. I am now in remission for that condition.

At the time the CLL was diagnosed, it was not active. My doctor told me that just because I had CLL, it didn’t mean it would ever flare up. He took a watchful waiting approach and continued to monitor me. My CLL was considered benign until 2005 when the lymph nodes under my arm and in my groin area swelled up. At that time, my doctor confirmed it had become active and that I would need treatment.

I began six months of chemotherapy. After about four treatments, I began to have the urge to take off all my clothes. My doctor took me off the chemotherapy right away and said I was having this unusual side effect because my CLL had gone into remission. Another side effect of the chemotherapy was the loss of my appetite. I didn’t want to eat anything. I went from 178 pounds to 158 pounds. One day, as my sister-in-law drove me home from a treatment, she suggested making potato soup and grilled cheese sandwiches. It just sounded so good, and that’s when I started eating again.

In 2017, my oncologist began treating me with a targeted therapy drug. I get little dots on my arms, chest and leg where the blood vessels are close to the surface, but it isn’t painful and I’m tolerating this drug well. Switching to this drug was one of the best decisions of my life. Other than the dots, I haven’t had any side effects from it, and I don’t have any problems with my appetite like I did on chemotherapy. I consider myself very lucky to have my appetite back.

Because the CLL lowers my immune system, I have to be careful about being around sick people and large crowds. At one point, I got pneumonia and was hospitalized for four weeks, two of which I was unconscious. My doctor said a healthy child’s immune system could have taken care of the infection but my immune system couldn’t. I was lucky to survive.

While going through treatment, I experimented with a few things. My niece recommended that I start drinking an instant breakfast drink that contained eight vitamins. I noticed that as long as I drank it every morning, my blood counts improved. When I stopped drinking it, my blood counts were not as good. I went back to drinking it, and my numbers have improved. I can’t say this is the right thing for everyone, but it seemed to help me.

I tried another experiment with exercise. I had been walking during treatment. When I had my blood checked, my numbers were good. For the next three months, I stopped exercising to see if it would have any impact on my blood counts. At the next visit, my numbers were not as good. I am convinced that walking works for me and helps my blood, so I make sure to walk as often as possible.

I decided to have a good attitude about the diagnosis. When people ask me how I am dealing with CLL, I tell them I put it all in the back of my mind and I don’t worry about it. Worrying about it doesn’t fix the problem because I can’t control what happens. I deal with the disease when I need to.

I also tell others with CLL not to worry. The stress can affect your whole body. You do what you can with what you can.
Managing Side Effects

As you discuss treatment options with your doctor, ask about the common side effects of each type and when they are likely to occur. Knowing what to expect will make you better prepared if they do occur. Preventing and managing them is extremely important for the success of your treatment because the better you feel, the more likely you’ll be able to complete your treatment as planned.

Tell your medical team as soon as symptoms or side effects begin, even if you consider them trivial. Write down when they start and include where they occur in your body, how long they last and how severe they are.

Neutropenia (low white blood cell count) commonly occurs in people who are treated with conventional chemotherapy. Neutropenia is a low number of neutrophils, a type of white blood cell. Neutrophils play an important role in preventing infection throughout the body. Having an abnormally low number of them increases the risk of getting an infection, such as pneumonia, bronchitis, sinusitis or shingles. Neutropenia also makes it more difficult for an infection to resolve. The lower the neutrophil count, the greater the risk for infection. Wash your hands often, and use hand sanitizer regularly. Avoid sick people and crowded places. Wear gloves when doing dishes or gardening.

If you experience any of these serious symptoms, contact your doctor immediately: fever (oral temperature over 100.5°F), OR chills OR sweating; flu-like symptoms (body aches, chills, general fatigue) with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat or mouth sores; redness, pain or swelling on skin; pus or drainage from any open cut or sore; pain or burning with urination; pain or sores around the anus; or vaginal discharge or itching.

Skin reactions may include redness and irritation (similar to sunburn), skin rash or dry, flaky skin. These reactions often cause itchiness and discomfort. Although most are mild to moderate, some can become severe if not treated early. Your doctor may prescribe a mild corticosteroid cream or an antibiotic gel. Severe rashes are usually treated with an oral antibiotic and perhaps an oral corticosteroid. When a rash is severe, the dose of the cancer drug(s) is often reduced or temporarily stopped until it improves.

Thrombocytopenia (low platelet count causing bleeding/bruising/clotting issues) may occur because some treatments for CLL can interfere with the body’s ability to make platelets, which are a type of blood cell. This can lead to bleeding and clotting problems as well as easy bruising. Avoid taking Omega 3 supplements, aspirin and other blood thinners during treatment. Tell your doctor about other supplements you’re taking.

Bleeding problems (hemorrhages) and bruising may occur. Tell your doctor if you have a history of bleeding problems. If you experience any of these symptoms, contact your doctor immediately: blood in your stools or black stools (looks like tar), pink or brown urine, unexpected bleeding or severe bleeding that you cannot control, vomit that looks like coffee grounds, coughing up blood or blood clots, increased bruising, dizziness, weakness, confusion, changes in speech or a headache that lasts a long time.

Heart arrhythmia (atrial fibrillation) may occur. Tell your doctor immediately if you experience heart palpitations, rapid or irregular heartbeat, lightheadedness, dizziness, shortness of breath, chest discomfort or fainting.

Fatigue occurs primarily because the body needs extra energy to repair the healthy tissue damaged by cancer treatment. Other side effects of treatment, such as pain, nausea and vomiting, also can cause or worsen fatigue. Increasing activity and performing regular exercise, such as walking or bike riding, are the best ways to combat it.

Anemia (low red blood cell count) can cause many symptoms because red blood cells carry oxygen to the body’s tissues. The most common symptoms are fatigue and weakness. Anemia can be temporary or long lasting.

Diarrhea is common during cancer treatment. When mild, diarrhea is an inconvenience. If left untreated, it can lead to serious problems, such as dehydration, loss of important nutrients, weight loss and fatigue. You may be able to anticipate episodes of diarrhea based on prior experiences during treatments. If so, mark your calendar so that you don’t plan an activity when it is most likely to happen.

Over-the-counter medicines and supplements are available to control diarrhea, but ask your doctor before taking anything. Your doctor may check you for a Clostridium difficile (C. diff) colon infection. If diarrhea is severe, your doctor may prescribe other medications or choose to stop your cancer treatment temporarily until your diarrhea is controlled.

Oral mucositis, commonly known as mouth sores, is small cuts or ulcers that can affect the gums, tongue, roof of the mouth or lips. Pain may range from mild to severe, making it difficult to talk, eat or swallow. Take good care of your teeth and gums, and brush and floss several times a day. Your doctor may suggest rinsing your mouth with special solutions and may prescribe a medication that coats the lining of your mouth or topical pain medications. Keep your mouth and lips moist by using lip balm, sipping water, sucking on ice chips and drinking through a straw. Choose soft, moist foods that are easy to swallow. Avoid alcoholic beverages and tobacco products, as well as hot, spicy, citric, greasy or rough-textured foods.

Fever, an abnormally high body temperature, is the body’s response to infection. Fever can develop in a person who is receiving drug therapy. It can be particularly concerning if it occurs when your white blood count is low. If you recently received chemotherapy and develop a fever, call your doctor immediately. If you know a medication you are taking has fever as a side effect or if you know your white blood count is low, check your temperature if you feel warm or unwell.
Your doctor may recommend over-the-counter medications, such as acetaminophen, to treat the fever related to flu-like syndrome. Avoid non-steroidal anti-inflammatory (NSAID) drugs, as well as aspirin, if you have a bleeding disorder. Discuss all of your options with your doctor before treatment begins to know the best way to manage a fever.

**Muscle and bone pain** may be caused by diagnostic procedures, treatments and the disease itself. Untreated pain, even if it’s minor, can get out of hand quickly and affect your body’s ability to heal. That is why it’s so important to let your health care team know right away if you are in pain.

**Nausea and vomiting** can cause severe dehydration and interrupt your treatment plan. If you experience nausea and vomiting, try eating five to six small meals instead of three large meals, and eat a light meal a few hours before receiving certain treatments. Drink plenty of fluids throughout the day. Sip ginger ale or chamomile tea, or suck on peppermint candies to settle your stomach. Your doctor may reduce your medication doses or add antiemetics (anti-nausea drugs) to keep you comfortable.

Contact your doctor if you experience any of the following serious symptoms: more than three episodes of vomiting per hour for at least three hours; blood in vomit; vomit resembling coffee grounds; inability to drink more than eight cups of fluid or ice chips in 24 hours or eat solid food for more than two days; weakness or dizziness; or if you cannot keep your medications down.

**Graft-versus-Host Disease** (GvHD) is a common side effect of allogeneic stem cell transplantation that can occur when white blood cells from your donor (the graft) recognize healthy cells in your body (the host) as foreign and attack them. Symptoms may range from very mild to life-threatening and include skin rashes, yellowing skin or eyes (jaundice) and diarrhea. If you experience any of the following symptoms of GvHD, contact your doctor immediately: dryness of the eyes and mouth; tightening, blistering or burning of the skin; jaundice; fever; sudden weight loss; abdominal pain or bloating.

**Coughing** can be a treatment-related side effect of CLL. Your doctor may prescribe medications or recommend over-the-counter medications to treat a cough. You may also have difficulty breathing.

**ADDITIONAL RESOURCES**
- **American Society of Clinical Oncology:** www.cancer.net
- **CLL Coping with Treatment**
- **Leukemia & Lymphoma Society:** www.lls.org

**EMOTIONAL CARE**

**Fear** is a common reaction to finding out you have cancer and going through treatment. Fears may include not knowing what to expect, pain, a change in appearance (hair loss or scars), fertility issues or sexuality challenges. To calm your fears, learn as much as you can about your cancer and your treatment. Talk with your doctor and others going through similar treatment.

**Grief** is the feeling of distress or sorrow due to the loss of something. It is normal to grieve the loss of your health, your appearance or your ideas of what your future would be without cancer. Allow yourself to feel a full range of emotions, and ask your friends and family for support.

**Guilt** is the sense that you’ve done something wrong. You may feel responsible or blame yourself for developing cancer due to actions you did or didn’t take regarding your health or lifestyle. You may also feel you are a burden to your loved ones. Talk to a trusted friend, family member or a counselor about your feelings. Be kind to yourself when you don’t have a positive attitude during treatment.

**Loneliness** is a feeling of being alone and isolated from others. Cancer patients often feel alone or alienated from others for several reasons. Talk to others who have the same type of cancer as you. Consider joining a support group, or contact a member of your faith or spiritual community.

**PREVENT THE SPREAD OF GERMS.** Frequent hand washing reduces your risk of infection.

**PROTECT YOUR SKIN.** Wear gloves when gardening to safeguard your hands.

**CARE FOR TEETH AND GUMS.** Preserve oral health by brushing and flossing every day.

**SHARE YOUR FEELINGS.** Find someone to talk to about your emotions.
Having a chronic disease often means you have a weakened immune system, which puts your body at increased risk of infection. Your doctor will talk with you about the infections that may arise from chronic lymphocytic leukemia (CLL), its treatments and its side effects to ensure you know how you can help prevent them, the symptoms to watch for and what to do if they occur. Doing what you can to avoid additional illnesses will help you enjoy a better quality of life.

People with CLL typically have an increased risk of infections of the nose, throat, sinuses, ears and lungs (pneumonia). Be aware of the risk of cytomegalovirus (CMV), a common virus that may be dangerous to someone with a weakened immune system. An anti-viral treatment may be prescribed to lower the risk of getting CMV, and antibiotics may be given to treat infections and prevent them from occurring.

If you get severe infections, your doctor may perform a blood test to confirm the amount of antibodies in your blood. If the number is low, a short infusion of intravenous immunoglobulin (IVIG) may be performed periodically. Immunoglobulins are antibodies that fight infection, and IVIG is a treatment that enhances the immune system by raising the amount of protective antibodies in the blood. During IVIG, immunoglobulins from normal, healthy donors are given intravenously (through a vein via a needle or catheter, which is a thin, flexible tube) to raise the amount of immunoglobulins and prevent infections.

CLL and some of its treatments (commonly chemotherapy) also may cause a shortage of normal white blood cells, a condition called neutropenia, which also increases your risk for infections. If the levels of normal white blood cells become very low, your doctor may recommend growth factors. These are laboratory-made proteins that stimulate your bone marrow to make more white blood cells. Although neutropenia is common, not everyone needs these growth factors. Your doctor may recommend them if you are at risk for developing fever-related neutropenia.

Preventive vaccinations can help guard against certain illnesses, but consult with your health care team first to confirm which vaccines are safe. It is recommended that people with CLL receive the influenza vaccine yearly and the vaccine for pneumonia every five years. However, vaccines that contain live viruses or bacteria, such as the shingles vaccine, should be avoided.

Infections while you’re already managing CLL can become serious. It’s important to monitor your health so you can catch and treat infections as soon as they start.

RECOMMENDED PRECAUTIONS

► Avoid contact with sick people.
► Practice good hygiene.
► Brush your teeth regularly.
► Wash hands frequently, and use lotion to prevent dry, cracked skin.
► Get plenty of rest.
► Eat a well-balanced diet.
► Do not share food, cups, utensils, toothbrushes or makeup.
► Do not change cat litter or handle animal waste.
► Use gloves in the garden and while cleaning.

HANDLING FOOD SAFELY

Your weakened immune system is more vulnerable to infection, including food poisoning. Although you can’t control all situations, you and your caregiver can reduce your risk of infection at home by following four common steps for food safety.

1. Clean. Keep hands and surfaces clean at every step of preparation. Wash hands frequently with hot, soapy water before and after handling food. Wash countertops, cutting boards, dishes and utensils with hot, soapy water before and after preparing food and in between food items. Rinse sponges of bacteria by putting them in the dishwasher. Keep all other items off of tables or countertops where food is prepared. Rinse fruits and veggies with clean water thoroughly before cutting them. Cut off and throw away bruised areas and outer leaves.

2. Separate. To avoid cross contamination, take extra care when handling raw eggs, meats, poultry and seafood. Keep these foods and their juices away from all other foods. Use a specific cutting board and utensils when preparing these foods. Keep these items separate from all others in the grocery cart, grocery bags and in the fridge.

3. Cook. Food must be cooked thoroughly. Use a food thermometer to ensure food is cooked to at least these temperatures:
   - Beef (steaks and roasts): 145°F
   - Fish: 145°F (or until opaque and separates easily)
   - Pork: 145°F
   - Ground meat: 160°F
   - Egg and egg dishes: 160°F
   - Poultry (chicken, turkey, duck, goose): 165°F
   - Casseroles and leftovers: 165°F (no cold spots)

4. Refrigerate. Store food promptly and properly. Keep your refrigerator at 40°F or lower and your freezer at 0°F or lower (cold temperatures slow the growth of harmful bacteria). Refrigerate perishables as soon as you bring them home, and defrost food in the refrigerator, under cold running water or use the defrost function in your microwave. Store leftovers in small, shallow containers for quicker, more efficient cooling, and keep track of stored food so you can discard when it’s no longer safe to eat. Putting a date on the container prevents guessing about freshness. If in doubt, throw it out.

ADDITIONAL RESOURCES

► Centers for Disease Control and Prevention: www.cdc.gov
► People at Risk – People with Weakened Immune Systems
► FoodSafety.gov: www.foodsafety.gov
► Leukemia & Lymphoma Society: www.lls.org
► Infections
► PearlPoint Nutrition Services: www.pearlpoint.org
► Food Safety During Cancer Treatment
FINANCIAL ASSISTANCE

BenefitsCheckUp ................................................................. www.benefitscheckup.org
Bringing Hope Home ...................................................... www.bringinghopenhome.org
CancerCare .......................................................... www.cancer.org/cancer-care
Cancer Financial Assistance Coalition .............................. www.cancerfacs.org
The CHAIN Fund Inc. ...................................................... www.thechainfund.com
HealthWell Foundation ..................................................... www.healthwellfoundation.org
Medicare.gov ............................................................. www.medicare.gov
Partnership for Prescription Assistance ............................... www.ppxrx.org
Patient Access Network Foundation .................................. www.panfoundation.org
Patient Advocate Foundation ........................................... www.patientadvocate.org
Patient Services, Inc. ...................................................... www.patientcso.org
Social Security Administration ......................................... www.ssa.gov
Social Security Disability Resource Center ........................ www.ssdrc.com
State Health Insurance Assistance Programs ...................... www.shiapacenter.org

PRESCRIPTION EXPENSES

The Bone Marrow Foundation ............................................. www.bonemarrow.org, 800-365-1336
CancerCare Co-Payment Assistance Foundation ...................... www.cancerccpay.org, 888-652-6729
Cancer Financial Assistance Coalition .................................... www.cancerfacs.org
Foundation for Health Coverage Education ......................... www.coverageforall.org
Good Days ................................................................. www.mygooddays.org, 972-630-7141
HealthWell Foundation ..................................................... www.healthwellfoundation.org, 888-673-8416
Leukemia & Lymphoma Society ............................................. www.lls.org, 899-955-4572
National Organization for Rare Disorders .............................. raredisorders.org, 203-744-0100
NeedyMed ................................................................. www.needymeds.org, 800-503-6897
Partnership for Prescription Assistance ............................... www.ppxrx.org
Patient Access Network Foundation .................................. www.panfoundation.org, 888-316-7263
Patient Advocate Foundation Co-Pay Relief ......................... www.copayas, 888-512-3861
Patient Services, Inc. ...................................................... www.patientcso.org, 888-366-7741
RxAssist ................................................................. www.rxassist.org
RxHope ................................................................. www.rxhope.com, 877-267-9517
RxOutreach ............................................................... www.rxoutreach.com, 888-796-1234
Together Rx Access ..................................................... www.togetheraccess.com, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Amgen Assist 360 ............................................................ www.amgenassist360.com, 888-427-7478
Arzerra Patient Assistance ................................................ www.us.arzerra.com, 800-282-7630
Bendeka CORE ........................................................... www.bendekacore.com/support/access, 888-587-3263
Gazyva Patient Assistance ............................................... www.gazyva.com/patient/tri/financial-resources.html, 886-22-2377
Genentech Access Solutions ............................................. www.genentech.com/patient-access, 888-422-2377
Genentech BioOncology Co-pay Card ................................. www.copayas.com, 888-652-6227
Gilead Patient Access .................................................... www.gilead.com/responsibility/us-patient-access
Helsinn Care .............................................................................................................. helsinnreimbursement.com, 844-357-4686, select prompt 2
Janssen CarePath ......................................................... www.janssencarespath.com, 877-227-3728
Janssen Prescription Assistance ........................................... www.janssenprescriptionassistance.com
Johnson & Johnson Patient Assistance Foundation, Inc. ........ www.jjpmf.org, 888-652-6227
Merck Access Program .................................................. www.merckaccessprogram.com, 855-257-3932
Merck Helps ............................................................... www.merckhelps.com, 877-727-5400
Neulasta First Step ......................................................... www.neulasta.com/support, 888-657-8371
Neupogen First Step ........................................................ www.amgenassist360.com/patient/neupogen-cost-access,
Novartis Oncology Patient Support .................................. www.patient.novartisoncology.com, 888-282-7630
PAN Foundation ......................................................... www.panfoundation.org/index.php/en/patients/access-programs/
Reimbursement/Financial Assistance/leukemia-lymphoma, 888-316-7263
Patient Rx Solutions ....................................................... www.patientrxsolutions.com, 888-676-5884
Rituxan Patient Assistance Programs ................................. www.rituxan.com/hem/patients/rituxan-patient-assistance,
Rituxan Direct Reimbursement Support ..................................... www.rituxan.com/hem/patient/rituxan-patient-assistance,
Sancuso Patient Assistance .............................................. www.sancus.com/patient/patient-assistance, 888-676-5884
Sandoz One Source ....................................................... www.sandozoresource.com, 844-726-3691
Sandoz Cancer Foundation Patient Assistance Programs .... www.sandozoresource.com, 844-726-3691
Teva CareCare .............................................................. www.tevacares.org, 877-237-4881
Teva Oncology Core Reimbursement Assistance & Support .................................................. www.tevacares.org, 888-587-3623
Together with Teraso ....................................................... www.togetherwithteraso.com, 844-263-7276
Venetix Biologics Co-pay Card ......................................... www.copayas.com, 888-587-3623
Zarzu Sandoz One Source .............................................. www.zarzu.com/patient/support, 844-726-3691
Zydalig AccessConnect .................................................. www.zydeligacessconnect.com, 844-622-2377

CHRONIC LYMPHOCYTIC LEUKAEMIA

American Society of Hematology ...................................... www.hematology.org
Be the Match ............................................................... www.bethematch.org
Blood & Marrow Transplant Information Network .............. www.bmtinfonet.org
Cll Advocates Network ................................................... www.clladvocates.net
Cll Society .............................................................................................. www.cllsociety.org
Delete Blood Cancer DKMS ............................................. www.dkms.org
Leukemia & Lymphoma Society ............................................ www.lls.org
National Bone Marrow Transplant Link ................................. www.nbtmlink.org

CLINICAL TRIALS

ACCESS ................................................................. www.accessclinicaltrials.gov
AccuraNet ................................................................. www.accuranet.org
ACT (About Clinical Trials) .................................................. www.actaboutclinicaltrials.org
Center for Information and Study on Clinical Research Participation ........................................ www.searchclinicaltrials.org
CenterWatch .............................................................. www.centerwatch.com
ClinicalTrials.gov ........................................................ www.clinicaltrials.gov
Jason Carter Clinical Trials Program (blood cancers) .............. www.jasoncarterclinicaltrialsprogram.org
Lazarin Cancer Foundation ................................................ www.lazarin.org
LIVESTRONG Foundation ................................................. www.livestrong.org
MolecularMatch ........................................................ www.molecularmatch.com
My Clinical Trial Locator .................................................. myclinicaltriallocator.com
National Cancer Institute ................................................. www.cancer.gov/cancernet
NCI Contact Center (Cancer Information Service) ............. 800-422-6273
Stand Up To Cancer ........................................................ www.standup2cancer.org
TrialCheck ................................................................. www.trialcheck.org

CAREGIVERS & SUPPORT

4th Angel Mentoring Program ........................................... www.4thangel.org
Advocacy Connector ....................................................... www.advocacyconnector.com
CancerCare .......................................................... www.cancer.org
Cancer101 ................................................................. www.cancer101.org
Cancer Action ............................................................. www.canceraction.org
Cancer and Careers ...................................................... www.cancerandcareers.org
CancerCare .......................................................... www.cancer.org
Cancer Connection ....................................................... www.cancerconnection.org
Cancer Hope Network .................................................... www.cancerhopenetwork.org
Cancer Information and Counseling Line ......................... 800-525-3777
Cancer Support Community ............................................. www.cancersupportcommunity.org
Cancer Support Helpline ................................................ 888-793-9355
Cancer Survivors Network ................................................ www.cancersurvivors.org
Cancer Wellness Center .................................................... www.cancerwellness.org
Caregiver Action Network ................................................ www.caregiveraction.org
CaringBridge ................................................................. www.caringbridge.org
Center to Advance Palliative Care ..................................... www.capc.org
Cleaning For A Reason ..................................................... www.cleaningforareason.org
Cooking with Cancer ....................................................... www.cookingwithcancer.org
Cuddle My Kids ............................................................. www.cuddlemykids.org
Family Caregiver Alliance ................................................ www.familycaregiver.org
Fighting Chance ............................................................. www.fightingchance.org
Friend for Life Cancer Support Network .............................. www.friendforlife.org, 866-374-3634
The Gathering Place ....................................................... www.touchingcancer.org
Guide Posts of Strength, Inc. .............................................. www.cancergps.org
The Hope Light Foundation .............................................. www.hopenightproject.com
Imerman Angels ............................................................. www.imerranangels.org
LIVESTRONG Foundation ................................................ www.livestrong.org
LivingWell Cancer Resource Center ................................. www.livingwellrc.org
Lotsa Helping Hands ....................................................... www.lotsahelpinghands.com
MyLifeLine ................................................................. www.mylline.org
The Lydia Project ............................................................. www.thelydiaproject.org
Patient Empowerment Network ......................................... www.powerfulpatients.org
Patient Power ............................................................... www.patientpower.info
SHARE Caregiver Circle .................................................. www.sharecancersupport.org/caregivers-support
Strike Out Cancer ........................................................ www.strikeoutcancer.org
Stronghold Ministry ........................................................ www.mystronghold.org
Triage Cancer ............................................................... www.triagecancer.org
Turning Point ............................................................... www.turningpointtc.org
Well Spouse Association ................................................ www.wellsposse.org
wesPARK Cancer Support Center ...................................... www.wespark.org
Wonders & Worries ........................................................ www.wondersandworries.org

PatientResource.com