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CHRONIC MYELOID LEUKEMIA

A guide for patients and their families

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BEATING CANCER IS IN OUR BLOOD.

CHRONIC MYELOID LEUKEMIA

IN THIS GUIDE

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Understanding your diagnosis is an important first step

Learning you have chronic myeloid leukemia (CML) is life changing; however, it may be comforting to know that progress in treating and managing CML continues to be made. Educate yourself about your diagnosis and surround yourself with an experienced medical team and a solid support network. The more you know, the better prepared you will be to move forward.

CML is a slow-growing cancer of the bone marrow and blood that begins in the myeloid cells. In CML, too many granulocytes are produced, particularly neutrophils. Most people who have CML have a genetic mutation known as the Philadelphia chromosome (see *The Philadelphia Chromosome*, page 3). To understand your diagnosis, it may help to know some biology basics.

LEUKEMIA 101

Cancer can develop in almost any part of the body, including the blood. Cells typically divide in an orderly fashion. When they are worn out or damaged, they die, and new cells replace them. Cancer develops when genes begin to change, or mutate, within the structure of normal cells. These cells – now called cancer cells – grow against normal cells. Sometimes they form tumors; other times, they don't. Tumors can be benign (noncancerous) or malignant (cancerous).

Cancer can metastasize (spread) to other organs, tissues, bones or blood, but it is diagnosed according to where it begins in the body. If cancer starts in the blood, it is known as a hematologic (blood) cancer. If it spreads to the brain, however, it is still considered blood cancer and is treated as such. It does not become brain cancer.

Leukemia is a type of blood cancer. Blood cells are made in the bone marrow, the soft, spongy center of some bones. They begin as immature blood stem cells that become either a myeloid stem cell or a lymphoid stem cell (see Figure 1).

Myeloid stem cells can mature into red blood cells, platelets and myeloblasts, which mature into granulocytes, a type of immune cell that has granules (small particles) with enzymes that are released during infections, allergic reactions and asthma. Granulocytes are a type of white blood cell involved in the immune system, and include basophils, eosinophils and neutrophils.

Lymphoid stem cells mature into lymphoblasts, which become B-lymphocytes, T-lymphocytes and natural killer cells. These white blood cells are also a part of the immune system.

Normal white blood cells help the body fight infections, and when they become old or damaged, they die and are replaced by new, healthy cells. However, in leukemia, the leukemic cells cannot fight infections properly and do not die when they should.

Large numbers of the leukemic cells accumulate in the bone marrow and/or the blood, which may slow down or prevent normal body functions, including the bone marrow's normal production of healthy blood cells.

Leukemia is categorized by how fast the disease progresses and by the type of white blood cell it affects. "Acute" means it grows quickly; "chronic" means it grows slowly.

There are four major types of leukemia: acute lymphocytic leukemia (ALL), acute myeloid leukemia (AML), chronic lymphocytic leukemia (CLL) and chronic myeloid leukemia (CML).

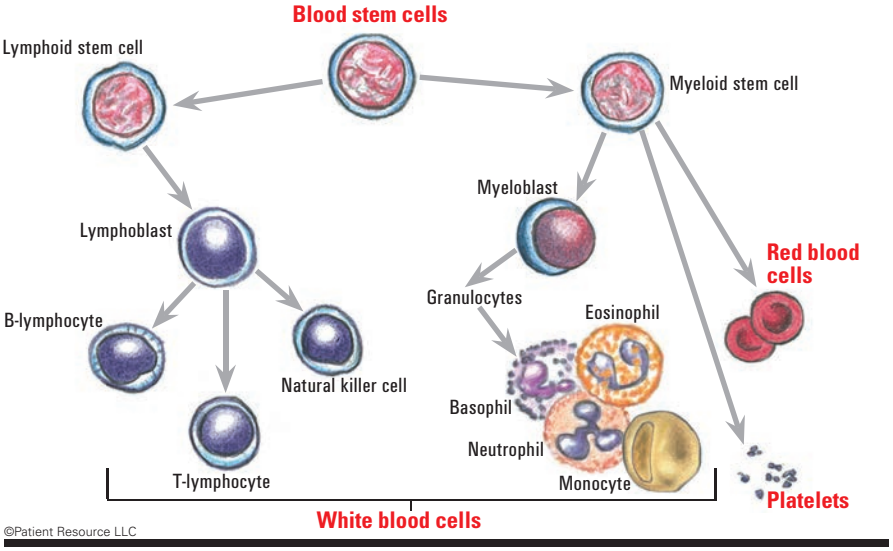
In acute leukemia, the leukemia cells look similar to immature white blood cells. The number of immature cells increases rapidly, preventing the bone marrow from making normal blood cells. Treatment should begin as soon as possible once a leukemia expert physician has been consulted because these fast-growing cells can quickly become life-threatening.

In chronic leukemia, the leukemia cells look similar to healthy, mature white blood cells, but the cells are unable to mature fully. The leukemia cells grow slowly and at different rates. Like acute leukemias, chronic leukemias are also classified as lymphocytic or myelogenous (myeloid) based on the type of cells in the bone marrow that become abnormal.

Lymphocytic leukemia begins in cells that become lymphocytes. Lymphocytic leukemias are also sometimes called lymphoid or lymphoblastic leukemias.

Myeloid leukemia begins in early myeloid cells, which become white blood cells (except for lymphocytes), red blood cells or cells that make platelets. Myeloid leukemias are sometimes called myelogenous, myelocytic or myeloblastic leukemias.

FIGURE 1
BLOOD CELL DEVELOPMENT



DIAGNOSING CML

Your doctor will use a variety of tests to look for leukemic cells, chromosome abnormalities (which may indicate the Philadelphia chromosome), molecular markers and an enlarged spleen.

Complete blood count (CBC) with differential measures the number of red blood cells, white blood cells and platelets in the blood, including the different types of white blood cells (neutrophils, lymphocytes, monocytes, basophils and eosinophils). Hemoglobin (the substance in the blood that carries oxygen) and hematocrit (the amount of whole blood that is made up of red blood cells) are also measured.

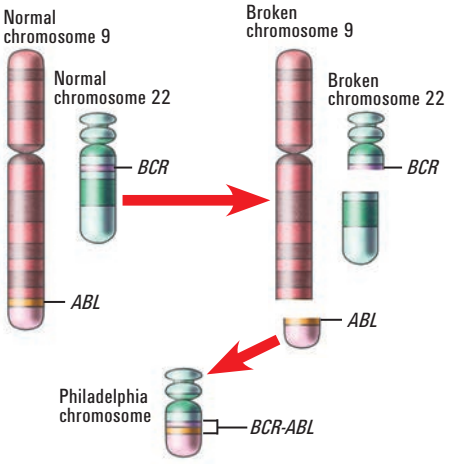
Blood chemistry study tests a sample of blood

The Philadelphia Chromosome

People with CML often have a mutation in their bone marrow called the Philadelphia chromosome, so it's helpful to understand what this means. Every cell has a nucleus, which is a structure inside a cell that contains 46 chromosomes — 23 from your mother and 23 from your father. Each chromosome is made of DNA. Sections of DNA are known as genes, which contain the information to create a specific protein. The body needs proteins to function properly. If mutations (changes) occur in a gene, the protein it creates may not be able to perform its intended function. Or, it may create a new protein that normally doesn't exist in the body.

Chromosomes contain specific genes. For example, chromosome 9 contains the *ABL* gene and chromosome 22 contains the *BCR* gene. In people with CML, the *ABL* gene on chromosome 9 breaks off and switches with a piece of chromosome 22 to form an abnormal chromosome 22 that contains the *BCR-ABL1* gene. The abnormal chromosome created from the switching of the *BCR* and *ABL1* genes is named the Philadelphia chromosome.

This type of mutation is known as a translocation because parts of the chromosomes break off and fuse together to form a new abnormal gene, which is also known as a fusion gene. This mutation is not inherited (passed from parent to child), and this fusion gene is not present in normal blood cells. It occurs during cell division when all the DNA is duplicated into a new cell.



The Philadelphia chromosome is created when the *ABL* gene from chromosome 9 and the *BCR* gene from chromosome 22 break off and combine.

to measure the amount of certain substances in the body, including electrolytes (such as sodium, potassium and chloride), fats, proteins, glucose (sugar) and enzymes. Blood chemistry studies give important information about how well the kidneys, liver and other organs are working.

Flow cytometry measures the number of cells, the percentage of live cells and certain characteristics of cells, such as size and shape, in a sample of blood, bone marrow or other tissue.

A hepatitis panel looks for Hepatitis B, which can occur with CML.

Bone marrow aspiration and biopsy are two procedures that often are done at the same time. A bone marrow aspiration uses a needle to remove a sample of fluid containing bone marrow. A bone marrow biopsy removes a sample of bone and bone marrow. Both the bone marrow and bone samples are sent to a laboratory to be examined under a microscope.

Molecular tests may be used to diagnose CML. Molecular testing is the process of identifying a disease by studying molecules, such as proteins, DNA and RNA, in tissues or fluids. With suspected CML, very sensitive tests may be used:

- Polymerase chain reaction may be used to detect the *BCR-ABL* fusion gene.
- Reverse transcription polymerase chain reaction (RT–PCR) test may be used to look for activation of certain genes, which can help diagnose a disease, such as CML.
- Quantitative reverse transcriptase polymerase chain reaction (qPCR) may be done at initial diagnosis to look for the presence of the *BCR-ABL1* gene on the Philadelphia chromosome. This test may be repeated at specific intervals using a blood sample after treatment begins to monitor treatment effectiveness.

Cytogenetic analysis is used to look for changes in chromosomes, including broken, missing, rearranged or extra chromosomes in a sample of blood or bone marrow. It involves testing samples of tissue, blood or bone marrow, and it may be used to help diagnose a disease or condition, plan treatment or find out how well treatment is working. With CML, this test may be used to look for the Philadelphia chromosome.

Types of cytogenetic tests include the following:

- Karyotyping looks at a limited sample of

Understanding Blood and Bone Marrow

Following are some of the components and functions of blood and bone marrow.

Blood is composed of red blood cells (erythrocytes), white blood cells (granulocytes, monocytes and lymphocytes), platelets and other substances suspended in fluid called plasma.

Blood stem cells are immature cells that can develop into all types of blood cells, including white blood cells, red blood cells and platelets. They may also be called hematopoietic (pronounced hee-MA-toh-poy-EH-tik) stem cells.

Bone marrow is the soft, spongy center of some bones, where blood is created.

Granulocyte is a type of immune cell that has granules (small particles) with enzymes that are released during infections, allergic reactions and asthma. Neutrophils, eosinophils and basophils are granulocytes, which are a type of white blood cell.

Hematopoietic stem cell is an immature cell that can develop into all types of blood cells, including white blood cells, red blood cells and platelets. Hematopoietic stem cells are found in the peripheral blood and the bone marrow.

Lymphoid refers to lymphocytes, a type of white blood cell.

Myeloblast is a type of immature white blood cell that forms in the bone marrow. Myeloblasts become mature white blood cells called granulocytes, which include neutrophils, basophils and eosinophils.

Myeloid refers to bone marrow and may also describe certain types of hematopoietic (blood-forming) cells found in the bone marrow. Myeloid is sometimes used as a synonym for myelogenous.

Plasma is the liquid component of blood that carries water, nutrients, hormones, proteins and enzymes to many parts of the body.

Plasma cells produce antibodies to help fight germs and viruses and to stop infection and disease. They are primarily found in the bone marrow.

Platelets are blood cells that gather around wounds to form clots and stop bleeding. They also play a part in repairing wounds and creating new blood vessels.

Red blood cells carry oxygen from the lungs to other parts of the body.

White blood cells help the body fight infection.

bone marrow cells that are stimulated to divide in a culture dish.
- Fluorescence in situ hybridization (FISH) looks at genes or chromosomes in cells and tissues. It is used to identify where a specific gene is located on a chromosome, how many copies of the gene are present and any chromosome abnormalities.

Computed tomography (CT) uses a computer linked to an X-ray machine to make a series of detailed pictures of areas inside the body. The pictures are taken from different angles and are used to create three-dimensional (3-D) views of tissues and organs. A dye may be injected into a vein or swallowed to help the tissues and organs show up more clearly.

Magnetic resonance imaging (MRI) uses radio waves and a powerful magnet linked to a computer to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue. MRI is especially useful for looking at the brain and the spine.

Ultrasound uses high-energy sound waves to look at tissues and organs inside the body. The sound waves make echoes that form pictures of the tissues and organs on a computer screen (sonogram).

QUESTIONS TO ASK YOUR DOCTOR

- ***What phase of CML do I have?***
- ***What does my CML phase mean for my outlook?***
- ***Do I have the Philadelphia chromosome?***

CLASSIFYING CML

Diagnostic test results are typically used to determine the type or subtype of cancer. Solid tumors are usually staged based on the size of the tumor, whether lymph nodes contain cancer and whether the cancer has spread from the original site to other parts of the body. Because leukemias often do not form solid tumors, doctors use alternative methods to classify them.

The World Health Organization (WHO) classification system is used to classify CML into chronic phase, accelerated phase and blast crisis phase (see Table 1). This helps doctors determine the best disease management plan and prognosis (predicted outcome after treatment). The phases primarily describe the differences in the number of immature white blood cells, which are also known as myeloblasts or blasts. Other blood cell count levels and chromosome changes are also considered.

The progression of CML in the chronic phase is generally slow, and it may be several months or years before the next phase is reached (see Table 2). Response to treatment is typically better when treatment begins in this phase. The most advanced and aggressive phase is the blast crisis phase.

It is normal for bone marrow to contain 5 percent blasts. In a person who is diagnosed with CML, the blasts are usually higher than 5 percent. The higher the percentage of blasts, the more advanced the CML.

Most people with CML will have the Philadelphia chromosome but other chromosomes may begin to mutate in the accelerated and blast phases. Almost all people with CML will have the *BCR-ABL* gene detected in their blood or bone marrow.

GETTING A SECOND OPINION

You may feel overwhelmed with the new information surrounding your CML diagnosis. To help ensure you understand the diagnosis and the suggested disease management plan, consider seeking a second opinion.

This involves asking another cancer specialist or group of specialists to review your medical records and confirm your doctor's diagnosis and recommended plan. Other specialists can confirm your diagnosis and might suggest changes or alternatives to the proposed treatment. They can also answer any additional questions you may have.

Getting a second opinion does not mean you question your doctor. It simply gives you more information. Doctors in each oncology specialty bring different training and perspectives to cancer treatment planning. Another doctor's opinion may change the diagnosis or reveal a treatment your first doctor was not aware of. You need to hear recommendations and reasoning for all your treatment options. A second opinion is also a way to ensure your pathology diagnosis and classification are accurate and to make you aware of potential clinical trials. ■

TABLE 1
WHO CLASSIFICATION SYSTEM

Phase	Description
Chronic phase	• Immature (blast) cells make up less than 10% of the cells in bone marrow or blood.
Accelerated phase	This phase is determined by any of the following features: • Blast cells make up 10% to 19% of cells in the bone marrow or blood OR • Basophils make up at least 20% of the blood OR • Very low platelet count not related to treatment OR • Very high platelet count that does not decrease with treatment OR • Increased size of the spleen OR • Increased white blood cell count that does not decrease with treatment
Blast crisis phase	• Blast cells make up at least 20% of cells in the bone marrow or blood. • Blast cells rapidly increase outside of the bone marrow. • Large groups of blast cells found in bone marrow biopsy.

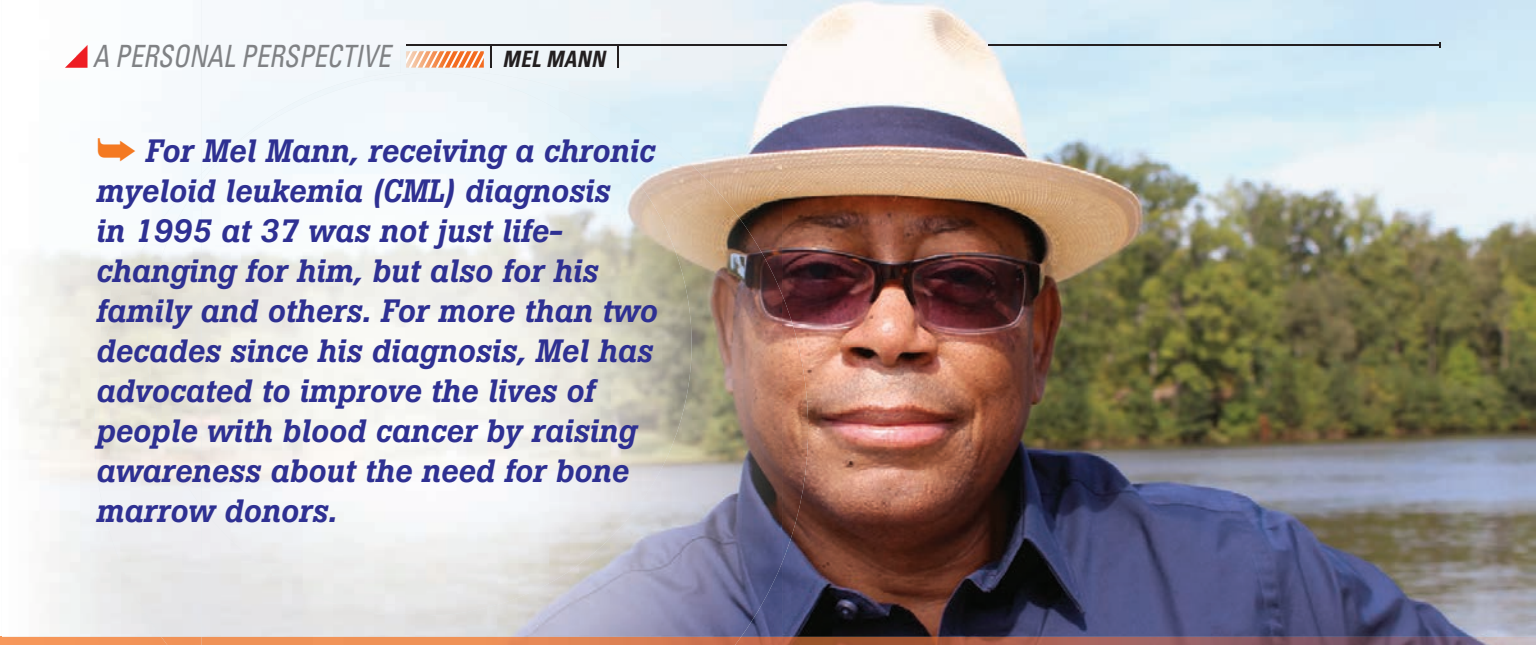
Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

TABLE 2
THREE PHASES OF CML

Phase	Key Indicators	Symptoms	Progression
Chronic (CP-CML)	Increased number of white blood cells	None to a few	Very slow (months to years)
Accelerated (AP-CML)	Low platelet count Increasing anemia Increase in chromosome abnormalities	Fever, poor appetite and weight loss Increasing spleen size	Four to six months
Blast or Blast Crisis (BP-CML)	Very high white blood count Extra copy of chromosome 8 An abnormality in chromosome 17 An extra copy of the Philadelphia chromosome	Fatigue, fever, poor appetite, weight loss, enlarged spleen	Without treatment, this phase will develop in about 3 to 4 years after diagnosis.

KEY TAKEAWAYS

- **Chronic myeloid leukemia is a cancer of the white blood cells.**
- **The majority of people diagnosed with CML have the Philadelphia chromosome.**
- **Classification helps your doctor recommend treatment based on the details of your CML.**



For Mel Mann, receiving a chronic myeloid leukemia (CML) diagnosis in 1995 at 37 was not just life-changing for him, but also for his family and others. For more than two decades since his diagnosis, Mel has advocated to improve the lives of people with blood cancer by raising awareness about the need for bone marrow donors.

Persistence and dedication empower survivor to help others

A lasting backache, general fatigue and no endurance prompted me to visit the clinic at the Michigan military base where I was stationed with my wife and five-year-old daughter. Results from blood tests and a bone marrow aspiration and biopsy confirmed I had chronic myeloid leukemia (CML) in the chronic phase.

The prognosis was grim: three years. Even worse, the doctor couldn't tell me where I was within that three-year outlook. I was in denial. I visited a larger military clinic for a second opinion. Doctors there confirmed the diagnosis, so I accepted it.

The doctor felt my best chance for long-term survival was a bone marrow transplant. Though it came with significant risks, I was willing to try so the search began to find a match through the national bone marrow registry. I soon learned that was easier said than done. There were very few African Americans in the national bone marrow registry, and I was told I had less than a one percent chance of finding a match. That wasn't good enough for me, so I got involved.

I held bone marrow drives on my base, at the mall and in churches. Local television stations promoted them. My military colleagues helped, flying me to bases in other parts of the country to organize drives while others managed drives in different parts of the world for me. Getting people registered wasn't as easy as today's cheek swab. Back when I was diagnosed, donors had to give blood.

Meanwhile, other things were happening. I began treatment to bring down my white blood cell count, then moved to a form of immunotherapy. My medical status prevented me from being on active duty and deployment, and the military began the long process of putting me on medical retirement. We moved to Georgia to have the support of my wife's family. I can't say enough about having support. Just talking about my situation with family and friends was so valuable for my mental wellness.

During one of the bone marrow drives in Georgia, a man told me about his leukemia treatment at a major cancer center in another state. He encouraged me to go there and learn about the medications they had access to. I hadn't yet found a donor match, so I flew out for a consultation and discovered clinical trials. The doctor I saw enrolled me in one that then turned into others when my CML didn't respond to the medications being used.

I reached the "three-year-mark" with no real solution. I was losing weight and becoming more fatigued. Sleep and coffee made no difference. My doctor felt the only hope was a clinical trial drug that wasn't yet available. Eight months later – and in my opinion, just in time – I became part of a Phase I clinical trial. I relocated to the cancer center with the trial in August 1998 for three months.

The trial drug was an oral targeted therapy, and it worked for me. It put me into major remission. Just 10 months after starting it, I ran a full 26.2-mile marathon in Alaska. In fact, it still works for me all these years later. It's no longer part of a clinical trial. It was approved as a treatment a few years after I began taking it.

If you can believe it, my donor match was never found so I'm especially blessed this medication works for me. It has given me more years than I could have imagined — enough to see our little girl grow up to be a doctor. I still take my daily pill like clockwork, which is really important. I've seen firsthand how CML is able to evolve and take someone out of remission when they don't take it as prescribed. I'm not willing to jeopardize that.

The need for more donors is still great. My wife and I continue to work with many organizations, such as The Leukemia & Lymphoma Society and Be the Match, to raise awareness.

I'm glad there are researchers who are working on these therapies and that people who are diagnosed with CML today have more treatment options than I did. I wish I'd have known about clinical trials when I was first diagnosed. Just knowing they might be an option would have given me hope.

I lead a healthy lifestyle of a balanced diet, exercise and fresh air. I also keep my follow-up appointments to monitor how the CML is reacting to the treatment. Depending on the protein levels in my blood work, I may be able to stop the treatment someday but, at this point, why rock the boat? ■

Agree with your doctor on the goals of treatment

Scientific research has led to several treatment options for CML over the past two decades. And, through clinical trials, researchers are looking for ways to improve current treatments as well as learn more about this blood cancer. To develop the most appropriate disease management plan for you, your doctor will take into consideration the phase of the CML, the presence of chromosome abnormalities and your general health.

Once your diagnosis is confirmed, consider working closely with a hematologist or oncologist who specializes in treating people with CML. Together you can discuss the goals of treatment, which will vary depending on the phase of CML (see Table 1), potential side effects of treatment, supportive care and your expectations.

Along with your doctor, you may also work with a team of health care professionals who are experts in different specialties. This multidisciplinary team may include oncology nurses, social workers, pharmacists, counselors, dietitians, financial counselors and others.

SURVIVOR VOICE / Jeanie S.

"Hitting a year (post transplant) was a big milestone. As they gradually weaned me off the medications, I felt I had beaten the odds. We had a big party for our family and friends because I couldn't have done it by myself."

CML THERAPIES DEFINED

Standard of care refers to a diagnostic and treatment process that a clinician is recommended to follow for a certain type of patient and illness. In general, treatment may be considered first line or second line. First-line therapy is the first treatment given. Second-line therapy is given when the first-line therapy doesn't work, is no longer effective or is not well-tolerated.

Treatments may be local or systemic. Local treatments are directed to a specific organ or limited area of the body. For CML, this may include surgery to remove the spleen (splenectomy) if it becomes too enlarged. Systemic treatments travel throughout your body and are typically drug therapies such as targeted therapy, immunotherapy or chemotherapy.

Your initial treatment strategy will be based on several factors, including the phase of your CML (chronic, accelerated or blast), risk group, personal preferences, age and overall health.

Some doctors further categorize CML into risk groups. Risk groups (low, intermediate and high) may be used to plan treatment and predict prognosis (outcome).

Three scoring systems may be used to determine your risk group (see Table 2):

- **Sokal score** is based on age, spleen size, platelet counts and percent of blasts.
- **Hasford score** is based on age, spleen size, platelet counts and percent of blasts, eosinophils and basophils.
- **EUTOS score** is based on spleen size and percent of basophils.

Your doctor may recommend one or more of the following types of treatment.

Targeted therapy uses drugs or other substances to identify and attack specific cancer cells, and may also target genes, proteins or tissue around the cancer that support it. Some targeted therapy drugs are oral medications given in pill form, and others are given intravenously (IV).

Targeted therapy, given orally in pill form, is often the first line of treatment for chronic phase CML. More advanced stages of CML will usually respond temporarily but quickly require additional treatment; however, some patients in the chronic phase can receive targeted therapy and remain in remission for many years.

Targeted therapies treat many cancer types. For CML, they target the *BCR-ABL* tyrosine kinase enzyme. The Philadelphia chromosome creates the *BCR-ABL1* protein (also known as a tyrosine kinase). Kinases are a type of enzyme that speeds up chemical reactions in the body. The Philadelphia chromosome causes an overgrowth of this abnormal kinase. Tyrosine kinase inhibitors (TKIs) are used to block the action of the abnormal kinase created by the Philadelphia chromosome. This approach is designed to prevent CML cells from growing.

Several TKIs are approved for treating CML and each works slightly differently. Some are specifically approved for newly diagnosed patients, while others are approved for use after other therapies have failed due to resistance, changes in mutations or intolerance.

Sometimes TKIs stop working, which is known as resistance (see *Relapsed and*

TABLE 1
GOALS OF TREATMENT

Phase	Goal
Chronic phase	Reduce symptoms of CML Eliminate cells containing *BCR-ABL1* gene Achieve complete cytogenetic response Remission Prevent disease progression
Accelerated phase	Eliminate cells containing *BCR-ABL1* gene Prevent disease progression Return CML to Chronic phase Remission
Blast phase	Control CML until a bone marrow transplant can occur Remission

TABLE 2
RISK GROUPS

Risk Group	Scoring System
Low	Sokal score: less than 0.8 Hasford score: 780 or less EUTOS long-term survival score: 1.5680 or less
Intermediate	Sokal score: between 0.8 and 1.2 Hasford score: between 781 and 1480 EUTOS long-term survival score: between 1.5680 and 2.2185
High	Sokal score: more than 1.2 Hasford score: more than 1480 EUTOS long-term survival score: more than 2.2185

Resistant CML, page 8). If resistance to a targeted therapy develops, other TKIs may work. The response to the TKI therapy (complete response, partial response or no response) can be monitored by a blood test.

If you and your doctor choose a TKI as part of your disease management plan, it is important to share with your doctor any supplements, vitamins, over-the-counter drugs, herbs or other medications you take because of the risk of a drug interaction. Ask your doctor about the supplements known to interfere with TKIs. Also, tell your doctor if you take antacids, heart medicine or anti-depressants.

To help you keep track of your medications, download a free medication tracking sheet at *PatientResource.com/CMLMedicationJournal.aspx*. Or, make a copy of or tear out page 15 to take it to your medical appointments.

Stem cell transplantation can restore your body's ability to produce blood cells. Another name for a stem cell transplant is a hematopoietic transplant. There are two types of stem cell transplants: autologous (one that uses your own stem cells) and allogeneic (one that uses donor stem cells). Only an allogeneic ("allo") stem cell transplant is used for patients with CML. It may be recommended when the disease is in the accelerated or blast phase.

A stem cell donor for an allo transplant may be found through a national or international registry. To ensure the donor tissue matches yours as closely as possible, human leukocyte antigen (HLA) matching is performed before a donor stem cell transplant. HLAs are molecules found on the surface of most cells in the body. HLA antigens make up a person's tissue type, which varies from person to person. They play an important part in the body's immune response to foreign substances. Blood and tissue samples are used to test for HLAs. Your HLA type will be compared to the donor's HLA type to see how closely you match. Doctors look for the highest match so that your body does not reject the donor's cells, nor do the donor's cells attack you.

WHO'S WHO ON THE HEALTH CARE TEAM

Your multidisciplinary team may include many of the following specialists, as well as other health care professionals.

Hematologist: A doctor who has special training in diagnosing and treating blood disorders

Medical oncologist: Trained to treat cancer using medicines

Nurse navigator: Guides a patient and their caregiver through the healthcare system. Your nurse navigator will be your go-to resource who knows your case – and you – the best.

Pathologist: Has special training in identifying diseases by studying cells and tissues under a microscope

Radiation oncologist: Uses radiation therapy to treat cancer

Social worker: The patient's personal advocate who acts on their behalf by collaborating with health care professionals and non-medical personnel to help overcome various financial, logistical and other common barriers to care.

This potentially serious condition is called Graft-versus-Host Disease (GvHD). The donated cells see your tissues as foreign and attack them. It is more common in older patients or when using a donor who is not related to you, especially if the donor is not a complete match. Symptoms of GvHD include a skin rash, and stomach, liver, lung or muscle problems.

Stem cell transplants generally occur as follows:

1. **Stem cell collection.** A medical professional collects, filters and processes stem cells from a donor. In some cases, the cells are frozen and stored for use later.
2. **Conditioning.** You receive high-dose chemotherapy and/or full-body radiation therapy to destroy the cancer cells and to suppress your immune system so that you will not reject the donor's cells.
3. **Stem cell transfusion.** A doctor injects the harvested stem cells into your body intravenously (IV).
4. **Recovery and engraftment.** Generally, within about 30 days, healthy cells begin to grow (engraft). Until your weakened immune system recovers, you will be at risk for infection. You may receive antibiotics and other drug therapy in the hospital and at home. Your doctor will monitor your numbers of different blood cells until they are back to safe levels.

QUESTIONS TO ASK YOUR DOCTOR

- ***How will you monitor my progress?***
- ***How often will I need tests to check the effectiveness of my treatment?***
- ***What other options will I have if the CML becomes resistant?***
- ***What should I watch for, and when should I call you?***

Donor stem cells can save lives

At any given moment, thousands of people need lifesaving blood stem cell transplants but have no available donor. Organizations such as Be The Match (operated by the National Marrow Donor Program) have created registries of millions of potential donors. Minority donors are especially needed.

➡ **Learn more at www.bethematch.org**

Donor lymphocyte infusion (DLI) is a type of therapy in which lymphocytes (a type of white blood cell) from the blood of a donor are given to a patient who has already received a stem cell transplant from the same donor. This helps boost the attack on leukemia cells. DLI is used to kill the remaining CML cells that have not gone away completely or have come back following the transplant.

Immunotherapy uses substances that stimulate or suppress the immune system to help the body fight cancer, infection and other diseases. Some types of immunotherapy only target certain cells of the immune system. Others affect the immune system in a general way. It may be a treatment option for CML, but it is not typically used as the first treatment.

The type of treatment used for CML is cytokine immunotherapy. It is known as nonspecific immune stimulation and aids in immune cell communication. For CML, alpha interferon is the most commonly used type that boosts the ability of certain immune cells to attack cancer cells.

Chemotherapy uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. It may be given alone or with other treatments, such as surgery or radiation therapy. It is an

option for treatment and is used especially for CML that does not respond to targeted therapy and then progresses to an advanced phase (accelerated or blast phase). It may also be used to treat CML that has not improved after treatment with TKIs.

Corticosteroids are drugs used to treat some blood cancers and can be used alone or in combination with other drug therapies. Corticosteroids also help reduce inflammation and may offer other benefits.

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

Clinical trials may be an option to consider (see *Clinical Trials*, page 9). Ask your doctor or research trials on your own to see if any may be available for you. Examples include trials for new treatments for relapsed or resistant CML, ways to prevent a recurrence or methods to reduce the side effects of treatment.

MONITORING AND TREATMENT MILESTONES

Throughout treatment and after, you will be monitored closely so that your doctor can ensure your response is as effective as possible. This may include having multiple blood tests, imaging studies and, possibly, bone marrow biopsies (see *Overview*, page 3). Your doctor will watch to see how the cancer responds to treatment, including if it develops a new mutation, returns or becomes resistant to the current therapy.

Before treatment begins, your doctor may perform a special polymerase chain reaction (PCR) test called a quantitative reverse transcriptase polymerase chain reaction (qPCR). It uses a blood sample to measure the number of cells carrying the *BCR-ABL1* gene. The results will be compared to a baseline known as the International Scale (IS). This test will be repeated frequently after you begin treatment (approximately every three months for two years and every three to six months thereafter) to monitor your treatment's effectiveness at controlling the leukemia.

When CML reaches the accelerated phase or blast phase, it is known as advanced phase CML. When this occurs, additional testing may be required to determine if the blast cells are myeloid or lymphoid, if new chromosomal abnormalities besides the Philadelphia chromosome have developed and if a stem cell transplant is an option.

If your CML progresses to an advanced phase, your doctor will also test for new mutations in the *BCR-ABL1* gene, which may lead to resistance to some targeted therapies. As a result, your doctor may adjust your disease management plan.

Doctors measure treatment response with milestones. They compare your test results to expected milestones to determine if your treatment is working effectively. If not, your treatment may be adjusted or new options may be considered. Therefore, keeping follow-up appointments and communicating new symptoms to your doctor between appointments is crucial for catching changes early so that your treatment can be modified as necessary (see *Living with a Chronic Condition*, page 14).

Response milestones include hematologic (blood), cytogenetic and molecular responses (see Table 3). The two most important milestones are early molecular response, which indicates how well the treatment will work in the long term, and complete cytogenetic response, which occurs when the Philadelphia chromosome cannot be found through testing.

TRAVELING FOR TREATMENT

You are encouraged to consider a doctor with expertise in CML, and if a stem cell transplant is part of your plan, a center with extensive experience in stem cell transplantation. This may require you to travel. Some treatment centers and organizations offer assistance with travel and temporary lodging during treatment. Talk with your health care team at the transplant center and advocacy organizations to learn about the resources available to assist. ■

Relapsed and Resistant CML

The goal of treating CML is to reach remission, which occurs when cancer cells can no longer be found after multiple tests. Even with complete remission, small numbers of cancer cells may still be in the body. A partial remission occurs when some but not all signs and symptoms have decreased or disappeared.

CML may return (relapse) after treatment. If that happens, your doctor will begin a new cycle of testing to determine any changes in your blood counts and physical symptoms. A new treatment plan may be developed for relapsed CML. You may also want to consider finding a clinical trial.

Sometimes CML stops responding to treatment, which is called resistance. It is possible for CML to become resistant to targeted therapies. A treatment plan for resistant CML may use a combination of therapies, which may include switching targeted therapies. Another option may be a clinical trial (see *Clinical Trials*, page 9.)

TABLE 3
MEASURING FOR EFFECTIVENESS

Response	Indications
Hematologic	
Complete hematologic (blood) response	Normal levels of white blood cells and platelets No immature cells (myelocytes or blasts) Spleen is normal size No CML symptoms
Partial hematologic response	Blood counts are not normal Some blasts remain in the blood Spleen may be enlarged Symptoms and blood counts have improved since initial treatment started
Cytogenetic	
Complete cytogenetic response	No cells with Philadelphia (Ph) chromosome
Major cytogenetic response	Philadelphia chromosome positive (Ph+) cells found in 0% to 35% of cells
Partial cytogenetic response	(Ph+) cells found in 1% to 35% of cells
Minor cytogenetic response	(Ph+) cells found in 36% to 65% of cells
Molecular	
Complete molecular response	No cells with *BCR-ABL1* fusion found
Major molecular response	Level of *BCR-ABL1* gene is very small (more than 1,000 times fewer than when diagnosed)
Early molecular response	Level of *BCR-ABL1* gene is 10% or less at 3 and 6 months

Educate yourself about clinical trials

Depending on your CML diagnosis, phase of the disease and other factors, you and your doctor may consider a clinical trial. When you discuss this potential option with your health care team, it may boost your confidence to have a basic understanding of clinical trials and how they work.

WHAT ARE CLINICAL TRIALS?

Clinical trials are research studies that help doctors and researchers find new ways to prevent, diagnose and treat cancer. They are designed to improve many aspects of cancer care, such as the following:

1. The safety and efficacy of new treatments
2. Whether new treatments work better than current treatments
3. Prevention
4. Diagnosis
5. Side effect management
6. Quality of life

There are many reasons to consider a clinical trial:

- You or a loved one needs treatment for any stage of cancer.
- By simply participating, you would contribute to the future of cancer care.
- You could gain access to a treatment that works better than the one you currently take.
- Your specific cancer has limited treatment options, and a trial could increase your options.
- You would like to improve the side effects of treatment or the cancer itself.

Keep in mind that, as with any cancer treatment, the treatments used in clinical trials may present risks:

- The treatment used may cause side effects.
- There is no guarantee that a clinical trial will be successful for you, even if it has worked for other people with your type and stage of cancer.
- The trial may require more office visits, tests or procedures, which could present challenges in terms of work, school, travel or transportation.

NEXT STEPS

If you are interested in learning more about CML clinical trials, you have several options:

1. Ask your medical team if you may be a candidate for a clinical trial. If your medical team is not aware of a clinical trial for you, you may consider getting a second opinion.
2. Search reputable sources online. Clinical studies can be sponsored by pharmaceutical companies, academic medical centers, federal agencies such as the National Institutes of Health, the U.S. Department of Defense and the U.S. Department of Veterans Affairs, as well as other organizations. Use the list below to check the availability of trials that may apply to you.
3. Be aware that you must meet certain eligibility criteria to be admitted to a trial. This is important because patients in each clinical trial must be similar in many ways to ensure the data collected and conclusions drawn are valid. The criteria may include, but are not limited to, exact diagnosis, previous treatments, general health and personal characteristics, such as age and existing health conditions. You may be required to have certain tests or procedures.
4. It is possible that though you may potentially benefit from a clinical trial, you do not qualify. Some of the reasons include the following:
   - You may not meet the required eligibility criteria.
   - You may be too sick or have other problems that keep you from participating.
   - The trial may already be full. In some cases, your doctor may ask the study sponsor or clinical investigator for an eligibility waiver or special exception to allow you to take part in the study. If you are granted a waiver, you would be treated according to the study protocol (the same tests, doctor's visits, follow-up, etc.), but your results are not included in the final study results. Sometimes, it is possible for patients who desperately need treatments to gain access to late-phase clinical trials. This is known as expanded access or compassionate use. ■

MYTHS vs. FACTS

Now that you know what clinical trials are in general, it is also important to know what they are not. Many misconceptions surround clinical trials and, unfortunately, incorrect information could prevent you from getting the best available care.

Following are common myths about clinical trials. Discuss these and other concerns with your medical team. Being informed is key to moving forward with confidence.

[MYTH] ***Once I start a clinical trial, I can't leave.***
[FACT] You can stop participating at any time, for any reason.

[MYTH] ***I could get a placebo instead of effective cancer treatment.***
[FACT] Placebos are rarely used alone in cancer clinical trials unless there is no known treatment. You can always expect to receive at least the standard-of-care treatment for your diagnosis.

[MYTH] ***Clinical trials aren't safe.***
[FACT] Many safeguards are in place during clinical trials. Monitoring by special groups throughout the clinical trial process ensures participants are protected.

[MYTH] ***Clinical trials are too expensive.***
[FACT] Before turning down a clinical trial because of potential costs, talk with your insurance provider about your coverage. Health insurance and Medicare (if applicable) may cover the routine costs of care, including care within a clinical trial. In some cases, the study sponsor may absorb the cost of the treatment and may pay for special tests and additional medical visits.

CLINICAL TRIAL RESOURCES → **ClinicalTrials.gov:** www.clinicaltrials.gov / **The Leukemia & Lymphoma Society:** www.lls.org/ctsc
National Cancer Institute: www.cancer.gov/clinical trials / **NCI Cancer Information Service:** 800-422-6237

Plan with your doctor for possible side effects

Many areas of your life may be affected by CML, and it is important to realize that you are not expected to shoulder everything alone. While your medical team focuses on treating the disease, other specialists can help you navigate some of the physical, psychological, social and spiritual aspects of your CML. These services are known as supportive care, and they can begin as early as the day you receive your diagnosis or at any time throughout your cancer care.

Also referred to as palliative care, comfort care and symptom management, supportive care is designed to better position you for the cancer-related challenges ahead. Studies have shown that integrating palliative care into a patient's usual cancer care soon after a diagnosis of advanced cancer can improve their quality of life and mood, and may prolong survival.

Palliative care is often confused with hospice care. Palliative care services may be used at any time during the cancer care continuum, while hospice care focuses on end-of-life care.

You may receive these services from an advanced practice nurse, physical therapist, dietitian or palliative medicine specialist who has extra training in symptom management. These services may be offered at a hospital, cancer center or medical clinic.

To ensure that your supportive care meets your unique needs, you'll work closely with palliative care specialists or other members of your health care team.

PHYSICAL SIDE EFFECT MANAGEMENT

Though cancer treatments typically have side effects, keep in mind that you likely won't have all of them and that every person responds differently, even to the same type of treatment.

Talk with your doctor ahead of time about side effects to watch for and what to do if they occur.

Tell your palliative care team about any pain, discomfort or other side effects you have. Track your symptoms and side effects, including what you feel, how often, the time of day it happens and how bad it is. Share your notes with your palliative care team to make it easier for them to pinpoint the cause of the problem and treat it.

Today, there are many ways to relieve symptoms and side effects. To provide relief for physical side effects, your palliative care team may draw on resources from the following areas: pain management; nutrition counseling; physical, occupational and speech therapies; complementary medicine and others.

Be alert for side effects that may develop long after treatment has started or even after it ends. These are known as "late effects." Late side effects or medical conditions can develop months or years after treatment has started or ended.

Potentially severe side effects may occur with certain types of treatment. Talk with your doctor before beginning treatment to ensure you know what to do if one occurs and if any require immediate medical help.

Some severe side effects may include the following:

Fluid retention, or edema, is swelling caused by an abnormal amount of fluid in the body. It can occur in the feet, legs, hands, arms, face, chest and abdomen. When this happens in the abdomen, it is called ascites; around the lungs, it is called pleural effusion; around the heart, it is called pericardial effusion.

Gastrointestinal problems, including diarrhea, constipation, stomach indigestion and pain, may occur.

Heart complications may occur. Ask your doctor about symptoms to be aware of.

Infection can occur as a result of a low white blood cell count (neutropenia) or other factors.

Contact your doctor immediately if you have an oral temperature over 100.4 °F; chills or sweating; body aches, fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching.

Liver toxicity may occur. Ask your doctor about symptoms to be aware of.

Myelosuppression is a condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells and platelets.

Tumor lysis syndrome can occur after treatment of a fast-growing cancer, especially certain leukemias and lymphomas (cancers of the blood). As tumor cells die, they break apart and release their contents into the blood. This causes a change in certain chemicals in the blood, which may cause damage to vital organs, including the kidneys.

Pancreatitis is inflammation of the pancreas. Abdominal pain is the primary symptom.

Some additional physical side effects that you may experience are listed below. Monitor for these and any other new symptoms or health concerns and discuss them with your doctor.

Abdominal pain related to nausea, diarrhea, constipation and other gastrointestinal issues, may occur.

Anemia is an abnormally low red blood cell count. Fatigue, shortness of breath, headaches, insomnia and bleeding problems are some of the symptoms of anemia.

Constipation is difficulty passing stools or having less frequent bowel movements compared to your usual bowel habits. Other symptoms may include painful bowel movements and feeling bloated, uncomfortable and sluggish.

Diarrhea is frequent loose or watery bowel movements and is measured against your regular bowel habits. Diarrhea can become serious if left untreated. Tell your doctor if diarrhea is keeping you homebound or otherwise interfering with your daily activities. Severe diarrhea can cause dehydration and other health problems.

Fatigue is marked by extreme tiredness and inability to function due to lack of energy. Though you may feel as if you get enough sleep, cancer-related fatigue may be strong enough to affect your daily life. If this happens, tell a member of your care team.

Graft-versus-Host Disease (GvHD) occurs after a stem cell transplant when white blood cells from a donor recognize healthy cells in your body as foreign and attack them. Graft-versus-Host Disease can be severe and even life-threatening, causing damage to your tissues and organs, especially the skin, liver, intestines, eyes, mouth, hair, nails, joints, muscles, lungs, kidneys and genitals.

Nausea and vomiting. Nausea is feeling queasy and sick to your stomach, like you might throw up. Vomiting is throwing up the food and liquid in your stomach.

Neuropathy is a nerve problem that causes pain, numbness, tingling, swelling or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time.

Neutropenia is an abnormally low white blood cell count. Being neutropenic means you have a higher risk of getting serious infections because you do not have enough neutrophils, a type of white blood cell, to kill organisms that cause infection.

Rash can occur in one area of the body or all over. It can affect the skin's texture or color and may look inflamed or irritated. The skin may be red, warm, scaly, bumpy, dry, itchy, swollen or painful. It may also crack or blister. Tell a member of your palliative care team at the first symptom so it can be managed before it worsens.

Thrombocytopenia is a condition of fewer-than-normal platelets in the blood, which can lead to easy bruising and excessive bleeding.

CARING FOR YOUR EMOTIONAL HEALTH

A cancer diagnosis can cause feelings of distress that affect your mental, physical, social and spiritual being. You may experience a range of emotions, from sadness and anger to anxiety and depression. These feelings, and all others you experience, are valid. It is normal to be concerned about how cancer treatments will affect your health, family and daily life.

Various situations, such as the following, can trigger distress:

- Receiving a cancer diagnosis
- Undergoing tests to diagnose or monitor your condition (see *Getting a Handle on Testing Anxiety,* page 14).
- Being hospitalized
- Experiencing severe side effects or life-altering common side effects
- Hearing that the cancer has advanced or returned
- Learning that treatment is ineffective

Taking care of your emotional well-being will help you handle the challenges of cancer treatment. Consider addressing these feelings with the following resources:

- A counselor, psychologist, psychiatrist, nurse or another specialist.
- Support groups. Some offer one-on-one buddy programs that pair you with another person who has the same type of cancer as you. Talking with someone who has gone through a similar experience can be invaluable. In addition, telephone and email cancer helplines and advocacy groups are available.
- Exercise. It may reduce the risk of anxiety and depression. Research shows that regular exercise can greatly improve mental health at any time during treatment. Even if you were not active before being diagnosed with CML, a customized exercise program can be a benefit.
- Stress management and relaxation techniques, such as yoga or meditation.

Contact your doctor about excessive crying or continued feelings of hopelessness or despair. Get immediate medical attention for thoughts of suicide or death.

ADDRESS PRACTICAL CANCER-RELATED ISSUES

Coordinating cancer care can be complicated and may require resources you do not typically have:

- Transportation to and from medical appointments and treatments
- Child care
- Help with personal care
- Housekeeping
- Food preparation

The social worker on your palliative care team or at the hospital can help you make a plan to manage these and other types of everyday challenges.

Spiritual support may be a welcome resource. People sometimes question their beliefs or the meaning of life when faced with a serious illness. You can share your concerns with a chaplain or spiritual care advisor. Many hospitals offer a chaplain who is trained to talk about spiritual concerns such as life and death, regardless of your faith.

If you don't know where to find spiritual support, ask your palliative care team for a referral.

Financial support to help with the unexpected costs related to cancer treatment may be available. A social worker or financial counselor may be available to connect you with resources.

Dietary support may be necessary if eating becomes a challenge due to treatment. Some side effects may make it difficult to eat, preventing you from getting the nutrition your body needs, which is crucial during cancer treatment. A dietitian can work with you and your caregiver to develop a nutrition plan specifically for you. ■

Financial options for palliative care

The costs related to cancer care can add up quickly. It's important to use all the resources available to you. Check to see if your private health insurance covers palliative care as part of your cancer treatment.

Medicare and Medicaid usually pay for some palliative care. Medicare is the U.S. government's health insurance for older people. Medicaid is government health insurance for people who earn less than a certain amount. Medicare Part B pays for some medical services that address symptom management, and Medicaid covers some palliative care services but they vary by state.

If you do not have health insurance or Medicare or Medicaid, a hospital social worker or financial counselor may be able to help you find ways to pay for the care you need.

Be proactive and bring a positive attitude

When Bill Tafel needed an allogeneic bone marrow transplant for his chronic myeloid leukemia, he discovered how difficult it can be to find a match. Determined to increase the list of potential donors, he found a way to add more donors to the National Marrow Donor Registry. He encourages people to be their own advocate and to be proactive in their care.

Edema and fatigue began in early 1993 when I was 36. By March, the doctor said I had leukemia, but more tests were needed to find out which type. This news was stressful because it came on the day of my daughter's birthday party while my wife, Rebecca, was eight months pregnant with our third child. I delayed telling my wife a day so she could enjoy the family birthday party before I shared my diagnosis.

Despite not knowing which type I had, I immediately went to the library and began researching everything I could find in books and magazines about leukemia. The information was discouraging because it seemed to me that the prognosis would not be good.

Additional tests later confirmed I had chronic myeloid leukemia (CML) in the blast crisis phase. My doctor immediately started me on high-dose chemotherapy and radiation therapy for about three weeks to knock the leukemia down, which put me into remission. He also encouraged me to have an allogeneic bone marrow transplant (one that uses a donor) in the future. As BMT was still a relatively new procedure, I did research to find a hospital with extensive experience and expertise in doing them. My research indicated that place was across the country.

By July, tests showed I was coming out of remission, indicating it was time to do the BMT. I was concerned about leaving my wife, infant daughter and two other children in Louisville, Ky., and I worried what would happen to them if I didn't return home. My wife helped me make the decision. She asked me, "If the situation were reversed, would you want me to go to the best place possible?" I said, "Absolutely." She responded, "Then let's do it!" That made me feel more confident.

To begin the process, I had HLA typing to get matched with a donor. It was discouraging to learn that from a list of 900,000 potential donors in the National Marrow Donor Program including Canada, England or Germany, there wasn't a match. I faced the choice of giving up or getting involved. I decided to do something about it.

I discovered that the Red Cross routinely collects the bone marrow types of people who donate platelets, which help blood to clot. But for privacy reasons, this information wasn't shared with the registry. Seeing the untapped potential of that information, I was determined to change this so that volunteers could sign a form to share their information with the bone marrow registry. Management at Red Cross suggested I contact Senator Elizabeth Dole in Washington, D.C. I called her office frequently, and one day I even went to her office. Her appointment secretary arranged for me to ride with Mrs. Dole on her way to the airport.

While sharing the ride, I explained my idea and she liked it. She sent letters to Red Cross centers to ask donors to consider being registered with the National Marrow Donor Registry when they donate platelets. Several Red Cross centers began sending letters to platelet donors asking if they'd also sign up for the marrow registry. Although there's been progress, more needs to be done.

Luckily, a few months later, a woman from France was a match for me. I flew to the hospital I'd chosen and received the transplant in November. The next three months were very difficult. I had high fevers from a rare infection the doctors struggled to identify. Once they identified it, they were able to treat it, and I was released from the hospital in February.

Taking steroids for seven months post-transplant weakened my bones, and I had to have both hips replaced in 1996 as a result. That same year, I had cataract surgery because of damage from the radiation therapy.

Support from my wife, family and friends was so important. Coworkers donated their frequent flyer miles so that family members could visit me while I was at the hospital across the country. That really kept me going.

Remember, a good attitude can make all the difference in the world. Be proactive about learning all you can. It's your body. Be your own best advocate. Don't hesitate to ask questions, even the ones you think are dumb.

I don't worry about a recurrence, but if it comes back, we'll treat it. In the meantime, I continue working to get more Red Cross centers to ask platelet donors to consider being in the bone marrow registry, and I'm working toward a goal of coordinating all of the national donor programs, including bone marrow, blood and organs so more people can find matches and save lives. ■

Moving forward, take each day step by step

How you manage your CML will depend on your unique diagnosis, your overall health and other factors. Focus on making positive choices in many areas of your life. Read on for suggestions, and ask your health care team about other ways to manage your condition.

Start by taking charge. Having a long-term illness can make you feel out of control, so it may help to find things you can control. Commit to being an active partner with your health care team. Learn how to manage your medication. Choose to have a positive attitude. Get organized.

Follow a healthy diet. Make smart nutrition choices, such as eating fresh fruits and vegetables, lean protein and low-fat dairy products, and drinking water.

Maintaining a healthy body weight is important. That may be challenging if side effects of treatment make it difficult to eat. An oncology dietitian or a registered dietitian can help you develop a nutrition plan that meets your specific nutritional needs. If you do not have that resource on your health care team, ask your doctor for a referral.

Stay active. Studies show that being physically active is beneficial for people who are recently diagnosed with cancer or who are in treatment.

Ask your doctor about taking part in physical activities, such as walking or bike riding. Moderate exercise even for a short time can enhance physical well-being and spur recovery as well as increase muscle strength, joint flexibility and general conditioning, improve cardiovascular function and protect bone health. It can also help reduce fatigue, a common treatment-related side effect.

Lower your risk of infection. Having CML may make you neutropenic at times. Neutropenia is a condition caused by a decreased number of white blood cells that fight off infection. If you are neutropenic, your immune system is weak and you are at an increased risk of infection.

Ask your doctor about the infections that may arise from CML and its treatments and side effects to ensure you know how you can help prevent them, what symptoms to watch for and what to do if they occur. This may include how to avoid developing infections from pets, while gardening or during travel. Also ask which vaccinations are safe for you.

Practicing food safety can reduce your risk of food poisoning caused by eating food contaminated with harmful bacteria, viruses or parasites. Ask your health care team for ways you can help protect yourself against foodborne illnesses.

Care for your emotional well-being. Living with CML may bring up a range of emotions, and addressing them is important for your mental health. Recognize that it is OK to be angry, anxious or depressed. Talk with a counselor or practice stress management and relaxation techniques. Exercise is also a natural mood lifter. If you become depressed, talk with your doctor. Counseling or medication may help. If you have suicidal thoughts, seek medical attention immediately.

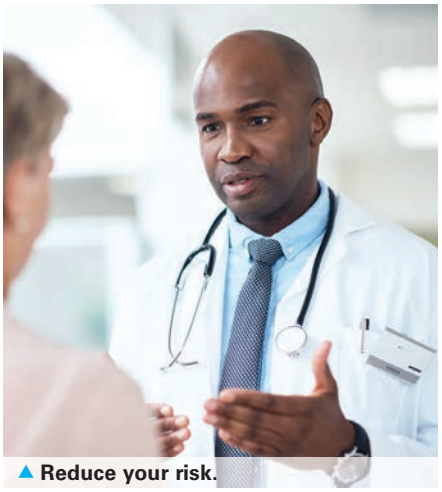
Surround yourself with support. Support comes in many forms. Along with drawing on relationships with family members, friends and coworkers, you may also choose to explore support groups. They are available in many formats, from in-person groups and online forums to one-on-one telephone calls. Talking with others who are in or who have been through a situation similar to yours may be extremely helpful.

Many types of support groups exist. Some focus on learning about cancer or working through feelings. Others are informal and social. Look online to find a group or ask your health care team for a referral. You may try a few before you find one that is a fit for you.

Religion may be a source of strength. Some members of the clergy are specially trained to help people with cancer and their families. Spirituality may be important to you. Performing small acts of kindness helps some people. Others meditate or spend time in nature. Find whatever helps you heal. ■

KEY TAKEAWAYS

- **CML is often treated like a type of chronic or long-lasting condition.**
- **Be an active partner in your care with your medical team.**
- **Keep a healthy body weight.**
- **Try to be active every day even if it's just for a short time.**
- **Practice food safety to reduce your risk of infection.**



▲ Reduce your risk.

▲ Eat a balanced diet.

▲ Be active.

Follow-up care is an essential part of living with CML

Some people who are diagnosed with CML manage their condition much like they would a chronic disease. This typically includes consistently being on some form of treatment, making and keeping follow-up doctor's visits and communicating openly and honestly with their health care team.

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

You will also be monitored for treatment-related side effects. These follow-up visits are a good time to talk with your health care team about any changes or problems you notice and any questions or concerns you have. However, if you notice new symptoms or side effects in between follow-up appointments, be sure to contact your doctor.

Living with CML may affect your emotional well-being, causing you to feel anxious, worried or even depressed. Support is available to help you manage these emotions. Look within your community to family, friends and religious organizations, or ask your health care team for referrals to support organizations or professional counselors. Many organizations offer online and telephone options.

STAY ON SCHEDULE WITH YOUR MEDICATIONS

For some patients, CML treatments are pills that can be taken orally from the convenience of home. Other treatments are given by injection or infusion at a cancer center or medical office. Regardless of how you receive your CML treatment, it is crucial to take it exactly as prescribed. This is known as medication adherence, and it is key to getting the intended benefit.

Not taking medication as intended is called nonadherence. Even people with the best intentions can forget a dose, take the wrong dose or miss a medical appointment, but it is very important to know that doing so may lead to worse overall outcomes, such as the medications being less effective, more side effects and a poorer quality of life.

Your prescription is designed specifically for you. Take it as your doctor intends to give your treatment plan the best chance for success. These suggestions may help:

- Read the entire medication label on the container to make sure you take the right dose.
- Take your pills at the same time every day, such as first thing in the morning or at the same meal time.
- Use a chart, calendar or reminders to set a schedule and to help you track when you take your medication. Download a free medication tracking sheet at *PatientResource.com/CMLMedicationJournal.aspx*
- Use a weekly pill case so you know whether you've taken each day's medication.
- Ask family members or friends to remind you.

Talk with your pharmacist or another member of your health care team about anything that affects your ability to take your medications, such as medication cost concerns, side effects that impact your daily life or confusion about how to take them. Be sure to review with your doctor or pharmacist any other medications, herbs or supplements you might be taking because they may interfere with the effectiveness of your CML treatment or increase the risk of serious side effects. ■

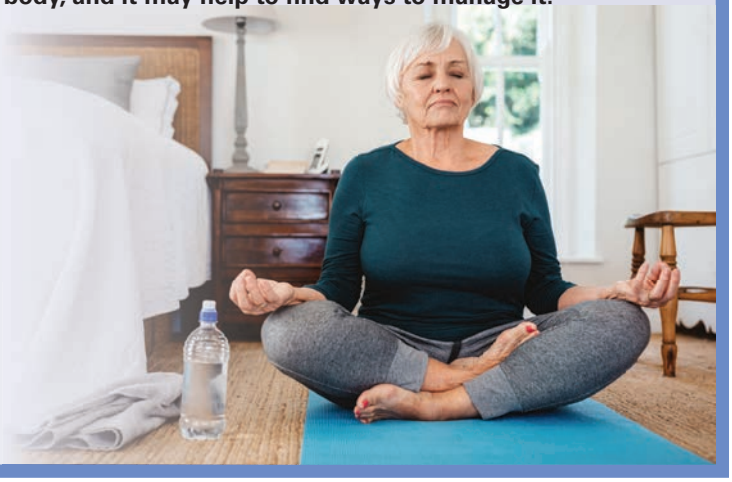
KEY TAKEAWAYS

- **Follow-up appointments are necessary for monitoring your condition.**
- **Taking the right drug exactly as prescribed is known as medication adherence.**
- **Your health care team can offer solutions for challenges that may make taking your medication difficult.**

Getting a Handle on Testing Anxiety

Having follow-up exams and laboratory testing may bring up feelings of anxiety. The feeling is understandable because the results will indicate whether your treatment is working the way it is intended. You may begin to feel anxious as the appointment nears and stay that way until you get your results. That is a lot of stress to put on your mind and your body, and it may help to find ways to manage it.

- **Set expectations with your doctor or nurse about when and how you will receive the results so you are not left waiting and wondering.**
- **Recognize and accept that it is normal to feel this way. Consider discussing your fears with your friends, a support group or a therapist.**
- **Keep your mind occupied with things you enjoy, such as reading, playing games or gardening. Staying busy gives you less time to worry.**
- **Try to calm your nerves with meditation or deep breathing.**



KEEPING TRACK

MY CML MEDICATION JOURNAL

Cancer-related therapies must be taken exactly as prescribed to be fully effective. Use this document to track each dose, including any missed doses. Make additional copies as needed. Share with your doctor during follow-up appointments.

MY DIAGNOSIS

Cancer Type/Subtype	*Leukemia / chronic myeloid leukemia*
Phase	
Diagnosis Date (year)	
Biomarkers (if any)	

MY HEALTH CARE TEAM CONTACTS

TYPE OF CONTACT	NAME	PHONE/E-MAIL
Oncologist/Specialist		
Nurse Navigator		
Primary Care Physician		
Case Manager		
Pharmacy		

MY MEDICATION TRACKER

DATE	MEDICATION	DOSAGE/ FREQUENCY	NOTE THE TIME YOU TOOK YOUR LAST DOSE			TREATMENT APPOINTMENT	DETAILS OF ANY SIDE EFFECT
5/01/21	*Drug name*	*1 pill daily*	*9 a.m.*	*5 p.m.*	*10 p.m.*	*10 a.m.*	*Fatigue*

MISSED DOSES

Date	*Drug name*	*Dosage / frequency*	*Note the time you missed your dose*	*Notes*

Contact your doctor if you experience any new symptoms.

Download and print at → **PatientResource.com/CMLMedicationJournal.aspx**

UPCOMING APPOINTMENTS	DATE	TIME	HEALTH CARE TEAM MEMBER & ADDRESS
	5/2/21	*10 a.m.*	*Dr. Smith at the Medical Plaza*

NOTES

Access the support that may be available for you

CANCER EDUCATION

Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov
National Cancer Institute ..... www.cancer.gov
U.S. National Library of Medicine ..... www.nlm.nih.gov

CLINICAL TRIALS

ClinicalTrials.gov ..... www.clinicaltrials.gov
National Cancer Institute ..... www.cancer.gov/clinicaltrials, 800-422-6237
NCI Cancer Information Service 800-422-6237

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Bristol-Myers Squibb Access Support ..... www.bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation ..... www.bmspaf.org, 800-736-0003
Novartis Financial Assistance ..... www.patient.novartisoncology.com/financial-assistance, 800-282-7630
Novartis Patient Assistance NOW ..... www.patientassistancenow.com, 800-245-5356
Pfizer Oncology Together ..... www.pfizeroncologytogether.com/patient, 877-744-5675
Pfizer RxPathways ..... www.pfizerrxpathways.com, 866-706-2400
Takeda Oncology Here2Assist ..... www.here2assist.com, 844-817-6468, option 2
Teva Cares Foundation Patient Assistance Program ..... www.tevacares.org, 877-237-4881
Teva CORE ..... www.tevacore.com, 888-587-3263

Funding and Support by: