

YOUR GUIDE TO CHRONIC MYELOID LEUKEMIA

A RESOURCE CO-CREATED WITH INPUT FROM ACTUAL CML PATIENTS



DON'T BEAR THE WEIGHT ALONE

**SPEAKUP
CML**

LIVING WITH CML?

USE THIS GUIDE AS AN

EDUCATIONAL RESOURCE



HAVE YOU BEEN RECENTLY DIAGNOSED WITH CML?

ARE YOU ALREADY ON A CML TREATMENT?

Wherever you are with your treatment, this guide can help you have productive conversations with your doctor. To learn more, visit **[SpeakUpCML.com](https://www.speakupcml.com)**

SPEAKUP
CML



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CML CAN STRIKE LIKE A BOLT OUT OF THE BLUE

Sometimes a routine checkup can lead to an urgent call from your doctor. Before you know it, you're meeting with an oncologist to talk about blood cancer.

WHAT IS CML?

CML is a cancer of the blood and bone marrow. Bone marrow is a sponge-like tissue in the center of most bones responsible for creating different types of blood cells.

MEDICATIONS CAN HELP MAKE CML MANAGEABLE

For more than 20 years, medications have helped make chronic myeloid leukemia (CML) more manageable for many people. With the help of targeted therapies called tyrosine kinase inhibitors (TKIs), most people who are diagnosed with CML can now anticipate having a life expectancy that's close to the general population.

DISCUSS ANY CONCERNS WITH YOUR DOCTOR

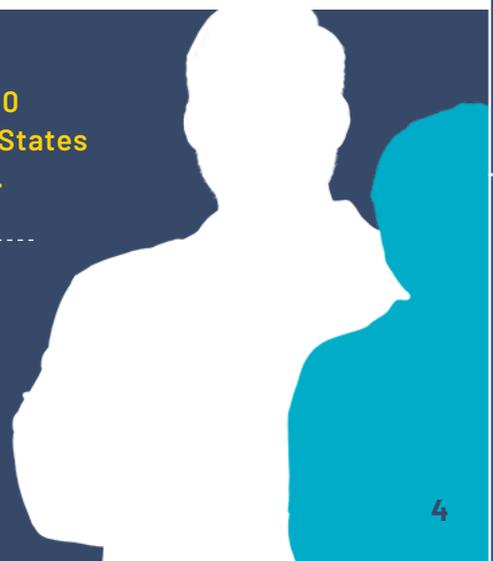
While CML medications can be effective, some people may experience resistance or unmanageable side effects that can keep them from doing the things they enjoy. Before starting on a treatment, be sure to ask your doctor what to be aware of, including possible side effects. If you are already taking a CML medication, don't try to "tough out" side effects. Speak up and tell your doctor how you're feeling.

70,000

In 2021, almost 70,000 people in the United States were living with CML.

8,900

In 2023, more than 8,900 people in the United States were diagnosed with CML.



SIGNS AND SYMPTOMS OF CML

While CML may come as a shock to many people, some patients may report symptoms, including:

- Feeling unusually tired
- Shortness of breath while doing everyday activities
- Fever
- Bone pain
- Unexplained weight loss
- Pain or a feeling of fullness on the upper-left side of the belly area (abdomen), under the ribs
- Unusual sweating at night

CML HAS 3 PHASES

Many types of cancer are categorized into stages. With CML, doctors assign 1 of 3 phases to the disease:

1.

CHRONIC PHASE

The first phase of CML. The number of white blood cells is higher than normal. Most adults are diagnosed in the chronic phase, and most people respond to treatment.

2.

ACCELERATED PHASE

In the second phase of CML, the number of immature white blood cells (also called “blast” cells) in the blood and bone marrow may increase quickly.

3.

BLAST PHASE

The third phase of CML has the highest amount of immature white blood cells in the blood and bone marrow.

Your doctor may discuss the importance of keeping CML from progressing from the chronic phase to the more advanced accelerated or blast phases. If CML is left untreated, it is more likely to progress.

MOST PEOPLE HAVE Ph+ CML

More than 95% of people with CML have Philadelphia chromosome–positive chronic myeloid leukemia (Ph+ CML).

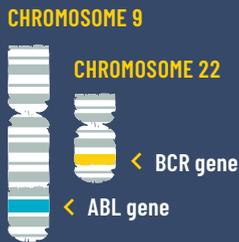
While there are still questions about why some people get Ph+ CML, there is an understanding of the biology behind the disease.



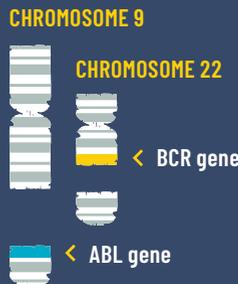
- Ph+ CML is caused by an abnormal fusion gene, called *BCR::ABL1*, which results from a change in chromosomes in the body
- Each cell in the human body has 23 pairs of chromosomes
- In CML, pieces of chromosomes 9 and 22 break off and trade places
- This can create a new abnormal chromosome—the Philadelphia (Ph+) chromosome
- It creates the defective *BCR::ABL1* gene, which produces an abnormal protein called BCR-ABL

You are not born with Ph+ CML. It’s also not handed down from parent to child.

NORMAL CHROMOSOMES



CHROMOSOMES BREAK



CHROMOSOMES CHANGE



Q.

WHAT HAPPENS IN YOUR BODY WHEN YOU HAVE CML?

- **Blood-forming cells** of the bone marrow create too many white blood cells
- **Damaged white blood cells** crowd out healthy red blood cells, white blood cells, and platelets
- **This is caused by an abnormal fusion gene**, which results from pieces of 2 chromosomes in the body that break off and trade places
- **This creates a new abnormal chromosome**—the Philadelphia (Ph+) chromosome

THE ROLE OF MEDICATIONS IN TREATING CML

One size doesn't fit all in CML medications. That's why you need to work with your doctor to find an effective treatment for you.

Most people with CML are treated with medications known as tyrosine kinase inhibitors (TKIs). TKIs are a targeted treatment that are thought to work by inhibiting the BCR-ABL protein that leads to uncontrolled growth of leukemic cells.

YOUR DOCTOR CAN EDUCATE YOU ABOUT YOUR OPTIONS

It takes a team to take on CML, and your doctor plays a key role in explaining both your CML and treatment options. Because a CML diagnosis doesn't have to hold you back. By working together, you and your doctor may be able to find a treatment to treat your CML and make side effects more manageable for you. A balanced diet and exercise can also help you manage side effects.

START ON A CML MEDICATION YOU MAY BE ABLE TO STAY WITH

Having a CML medication that combines effectiveness with side effects that may be manageable for you can make it easier to stay on treatment. That may mean better results for you.

The Questions to Ask Your Doctor on page 25 can help you talk about your treatment options.



SETTING TREATMENT GOALS

While every patient is different, it's important to work closely with your doctor to discuss treatment goals. Some common goals include:

- **Reducing the number of leukemic cells** in the body
- **Reducing the amount of BCR-ABL protein** in the body to an undetectable level
- **Keeping CML from progressing**

WHAT ARE CML MILESTONES?

Your doctor may talk about CML treatment milestones. These are goals that may be within your reach once you start on treatment.

The illustrations on the next page can help you see how the number of leukemic cells may decrease over time with treatment. The blue dots represent the amount of *BCR::ABL1* in the body.

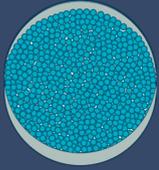
It's important to realize that not every patient will reach every milestone. That's okay—as long as you and your doctor continue to discuss your results and your individual treatment goals.

YOU AND YOUR DOCTOR ARE IN IT TOGETHER

It takes a team effort to fight CML. You need to take your medication as prescribed, and your doctor should be open to discussing any issues you may be having.

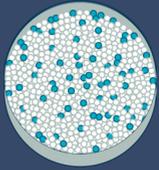
The Questions to Ask Your Doctor on pages 25-26 can help you make the most of your doctor's appointments.

GOALS OR MILESTONES IN CML



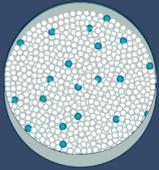
AT DIAGNOSIS: BASELINE

- At the time of a CML diagnosis, the amount of the abnormal *BCR::ABL1* gene in the body is different for everyone. Your doctor will use the results of blood tests to determine your baseline. This is typically 100%



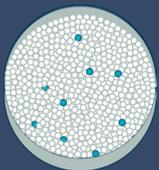
EARLY MOLECULAR RESPONSE (EMR)

- Blood counts for red blood cells, white blood cells, and platelets return to normal
- With EMR, *BCR::ABL1* (International Scale or IS) is between 10% and 1% at 3 months and 6 months



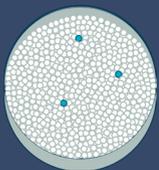
COMPLETE CYTOGENETIC RESPONSE (CCyR)

- If there are no Ph+ cells detected in the bone marrow, your doctor may say you have a CCyR
- With CCyR, *BCR::ABL1* in the blood is $\leq 1\%$



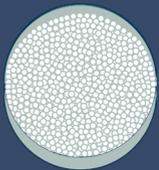
MAJOR MOLECULAR RESPONSE (MMR)

- With MMR, *BCR::ABL1* in the blood is $\leq 0.1\%$



DEEP MOLECULAR RESPONSE (DMR): MR4.0 OR MR4.5

- With DMR, *BCR::ABL1* in the blood is $\leq 0.01\%$ (MR4.0) or $\leq 0.0032\%$ (MR4.5)



COMPLETE MOLECULAR RESPONSE (CMR)

- With CMR, *BCR::ABL1* in the blood is undetectable

WHAT TO EXPECT DURING THE COMMON **FIRST STEPS** OF YOUR CML JOURNEY



- 1 YOUR DOCTOR CALLS AND YOU NEED TO SEE A HEMATOLOGIST/ONCOLOGIST
- 2 IT'S CML, WHICH IS GENERALLY MANAGEABLE
- 3 STARTING ON YOUR FIRST CML MEDICATION
- 4 MONITORING YOUR RESPONSE TO MEDICATION
- 5 ONGOING SYMPTOM AND TREATMENT MANAGEMENT, INCLUDING SWITCHING TREATMENTS IF NEEDED

SPEAKUP
CML

STEP 1

YOUR DOCTOR CALLS AND YOU NEED TO SEE A HEMATOLOGIST/ONCOLOGIST



Patient portrayal

- **Test results from a routine physical** may show that you have a high white blood cell count
- **Your doctor sends you to a hematologist** for further testing
- **You may feel shocked and confused** as many people with CML have no signs or symptoms
- **The hematologist/oncologist orders more tests**, such as a bone marrow biopsy to determine your diagnosis
- **You wait for your test results** and use that time to research CML and your potential treatment options online. (See **page 32** for information on CML advocacy groups and organizations)



QUESTIONS TO ASK YOUR DOCTOR

- **Why are you referring me** to a hematologist?
- **Why do I need a bone marrow biopsy?**
- **How long will it take to get the results?**

STEP 2

IT'S CML, WHICH
IS GENERALLY
MANAGEABLE

Patient portrayal

- **Based on the bone marrow biopsy**, the hematologist says you have CML
- **You may be shocked by a cancer diagnosis** while also trying to understand unfamiliar terms
- **The doctor explains that CML is manageable** for many people
- **You work with your doctor to choose a CML treatment**

QUESTIONS TO ASK YOUR DOCTOR

- **What medications are available**, and what's the difference between them?
- **What type of side effects might I experience** on these medications?
- **What are the possible long-term side effects** of taking these medications?
- **What is medication resistance**, and how will I know if it's impacting me?



STEP 3

STARTING ON
YOUR FIRST CML
MEDICATION

Patient portrayal

- **You don't know what to expect** as a new cancer patient and whether your treatment will work
- **You wonder about potential side effects** from the medication and whether they will affect your daily life
- **Your doctor's office works through any insurance hurdles** so you can start on your medication, but it can take time
- **You're concerned about insurance and whether you can afford your treatment** so you search the medication's website for co-pay and financial assistance options

QUESTIONS TO ASK YOUR DOCTOR

- **What kind of results** can I expect with this medication?
- **How will we know if the medication is working?**
- **What kind of side effects** should I anticipate on this medication?
- **Why do I need to take my medication every day?**



STEP 4

MONITORING YOUR RESPONSE TO MEDICATION



Patient portrayal

- **You visit your doctor soon after starting treatment** to see if you are responding
- **As a new patient, you might need help explaining to your doctor how you are feeling physically and emotionally**
- **You bring a family member or friend with you to your doctor's appointments** to help you take notes and remember information
- **If your numbers haven't improved,** you ask your doctor about the time it will take for the treatment to start working

QUESTIONS TO ASK YOUR DOCTOR

- **Is my treatment working? How do my results align with my treatment goals?**
- **If you struggle with side effects:**
I'm glad to see that my numbers are going down, but side effects are taking their toll on me. How can you help me manage the side effects?
- **If side effects become unmanageable:**
Side effects are impacting me in the following ways. What are my options? Can you help me get through the side effects or should we consider reducing my dose or trying a different medication?



STEP 5

ONGOING SYMPTOM AND TREATMENT MANAGEMENT, INCLUDING SWITCHING TREATMENTS IF NEEDED



Patient portrayal

- **Although your numbers may start to improve**, you may sometimes experience unmanageable side effects
- **You may feel the urge to keep side effects to yourself** because you don't want to bother your doctor, but you tell your doctor how side effects are affecting your daily life
- **If your treatment is not working for you**, your doctor may switch your treatment
- **You may want to consider whether you should get a second opinion** based on what you've read or heard from other CML patients, including on social media

QUESTIONS TO ASK YOUR DOCTOR



- **If side effects are becoming unmanageable or if your treatment is not working:** Is there another CML medication we should consider?
- **Other CML patients that I've connected with have suggested that I see a CML specialist.** Is there a specialist you could recommend that you could collaborate with to guide my treatment?

HELPFUL TOOLS FOR YOUR CML JOURNEY



HELPFUL TOOLS

- **SpeakUpCML.com** and its doctor discussion guide
- **CML advocacy** group websites
- **Websites** of different CML medications
- **Materials related to your medication** like the financial resources or patient support services section of your medication's website
- **Social media** CML forums



ARE YOU FEELING THE WEIGHT OF YOUR CML TREATMENT?



UNDERSTANDING CML

CML TREATMENT JOURNEY

MANAGING YOUR
CML TREATMENT

COMMUNICATING WITH
YOUR DOCTOR

SUPPORT AND RESOURCES

SPEAKUP
CML

Patient portrayal

IF SIDE EFFECTS BECOME A BURDEN

If you are already taking a CML medication, there are times you may feel the weight of your CML treatment.

For example, side effects from a medication may lead you to accept a “new normal” that is interfering with your job, your social life, or your emotional health. Or a CML medication that worked for awhile may stop working. Discuss any concerns about your medication’s effectiveness or side effects with your doctor.

You may find it helpful to **give your doctor specific examples of how side effects are interfering with your daily activities or affecting your relationships.** That can help your doctor understand the impact side effects are having on you.

COMMON SIDE EFFECTS OF CML MEDICATIONS

Below is a list of some common side effects of different CML medications that you should discuss with your doctor.

- Fever
- Diarrhea
- Nausea/vomiting
- Bone, muscle, and joint pain
- Difficulty breathing/shortness of breath
- Fluid retention/swelling/weight gain
- Fatigue that disrupts daily activities
- Unusual bleeding/bruising
- Increased blood pressure
- Rash/itching
- Headache
- Brain fog/confusion

There may be other side effects with CML medications, and each medication has its own side effects. Some may be tolerable, some may not be. Tell your doctor about any side effects you experience.

WHY FIGHT 2 BATTLES?

Talk to your doctor about your treatment options so you can **focus on fighting CML, not only the side effects** from your medication.

Q.



MANAGING CML REQUIRES TEAMWORK

Your doctor knows medicine, **but only you know how you feel** when you take your medication. So don't keep side effects to yourself. Your doctor needs to know how you are truly feeling. **The Topics to Discuss With Your Doctor on page 26 can help you start a conversation.**

Of course, **it's important to do your part to manage CML.** That means **taking your medication exactly as prescribed** by your doctor.

If side effects are becoming so bothersome that you're not keeping up with your CML treatment as prescribed, tell your doctor. Missing doses can make your medication less effective.

It's also key to **go for any blood tests your doctor orders.** By staying on top of your results, you and your doctor can see if you are responding to treatment.

DRUG RESISTANCE CAN ALSO WEIGH ON YOU

One of the goals of treating CML is to see the number of leukemic cells in your blood decrease. For some people, this may not happen. If your numbers are going up, you may be experiencing drug resistance. There are 2 types of resistance in CML:

- **Treatment doesn't work:** The body does not respond to treatment. This is known as primary drug resistance
- **Treatment works at first, but stops:** The treatment worked for a time, but it no longer works as well. This is known as secondary drug resistance

If the results of your blood tests show that the number of leukemic cells are rising, your doctor may decide to adjust your dose or consider another treatment.

MEASURING YOUR RESPONSE TO TREATMENT

Your doctor may want you to go for blood tests every 3 months to see if you are responding to your medication.

An increase in your *BCR::ABL1* levels can be a red flag for your doctor. That's why it's important to go for any blood tests your doctor prescribes and discuss what your results mean.

TESTS YOUR DOCTOR MAY ORDER INCLUDE:

- **Complete Blood Count (CBC):** Measures the amount of red blood cells, white blood cells, and platelets in the blood
- **Cytogenetic Test:** Analyzes a small sample of bone marrow under a microscope to determine the number of cells with the Ph chromosome
- **Fluorescence In Situ Hybridization (FISH) Test:** A standard cytogenetic test may not detect all the CML cells in the blood. Your doctor may order a FISH test, which uses fluorescent dyes and a fluorescent microscope to measure the number of cells with the Ph chromosome
- **Quantitative Polymerase Chain Reaction (qPCR or molecular) Test:** qPCR testing is sensitive enough to detect the smallest amount of leukemic cells in the blood

THE **qPCR** TEST IS SO SENSITIVE IT CAN DETECT

1 CANCER CELL AMONG

100,000 TO 1 MILLION CELLS

COMMUNICATING WITH YOUR DOCTOR



Patient portrayal

SEE A CML SPECIALIST—EVEN IF ONLY ONCE

How many patients with CML has your doctor treated? That's a good question to ask because many doctors only treat a few patients who have CML. While your local doctor is someone you should feel comfortable relying on, you may also find it helpful to see a CML specialist. A specialist will have experience working with more CML patients and can collaborate with your local doctor to help guide your treatment.

WHO SHOULD BE ON YOUR CML TEAM?

There's no reason to fight CML alone. Here are some team members you should have in your corner as you start treatment and throughout your journey with CML.

- **Your local oncologist**
- **A CML specialist**
- **A mental health professional**, if you need assistance with the emotional toll of CML
- **Manufacturer Patient Support** for affordability questions
- **Family and friends**

5 TIPS

TO HELP YOU MAKE THE MOST
OF DOCTOR APPOINTMENTS

1. **Bring a list of any side effects you've been experiencing:** Write down how often you have side effects and when they happen
2. **Write down any questions you have for your doctor in advance,** including how your treatment is working
3. **Bring a buddy:** Bringing a family member or friend to your doctor's appointment can help you keep up with the information your doctor shares with you. And your buddy may be more comfortable asking the tougher questions
4. **Take notes:** It can be hard to remember everything your doctor says. Bring a pen and paper to take notes. If you have your phone, ask your doctor if you can record your appointment, so you can write down any notes later
5. **Ask your doctor to keep it simple:** Your doctor may use terms that are unfamiliar to you. Ask your doctor to explain any terms you don't understand



After enduring burdensome side effects from CML treatment for years, **Nicole learned about the importance of advocating for herself.** Hear how she worked with her doctor to find a treatment that worked for her. To watch Nicole's story, visit [SpeakUpCML.com](https://www.SpeakUpCML.com)

SPEAKUP
CML

QUESTIONS TO ASK YOUR DOCTOR AT YOUR APPOINTMENT

Depending on whether you're newly diagnosed with CML, or you're already on treatment, there are different questions you should consider asking your doctor.



QUESTIONS TO ASK IF YOU ARE NEWLY DIAGNOSED

- **Does my CML diagnosis impact my life expectancy?**
- **Are there different phases to CML?** Where do I stand?
- **What treatments are available to treat CML?** How do they differ?
- **When might I expect to see results** from a CML medication?
- **How will I know if the medication is working?**



QUESTIONS TO ASK DOWN THE ROAD

- **Are there any treatment goals** that I should try to reach?
- **What impact will CML and my medication have on my daily life?**
- **What are the side effects associated with each treatment?**
- **How long will I have to take medication for CML?**
- **What are some of the potential long-term effects** of treatment?
- **Can changes to my diet or exercise make a difference** to my treatment?

TOPICS TO DISCUSS IF YOU ARE ALREADY TAKING A CML TREATMENT

- **I'd like to discuss the following common side effects that I've recently experienced** from my current medication for CML or I'm currently experiencing. (Check all that apply)

<input type="checkbox"/> Fever	<input type="checkbox"/> Unusual bleeding/bruising
<input type="checkbox"/> Diarrhea	<input type="checkbox"/> Increased blood pressure
<input type="checkbox"/> Nausea/vomiting	<input type="checkbox"/> Rash/itching
<input type="checkbox"/> Bone, muscle, and joint pain	<input type="checkbox"/> Headache
<input type="checkbox"/> Difficulty breathing/shortness of breath	<input type="checkbox"/> Brain fog/confusion
<input type="checkbox"/> Fluid retention/swelling/weight gain	<input type="checkbox"/> Other (specify)
<input type="checkbox"/> Fatigue that disrupts daily activities	<input type="checkbox"/> None

These are not all the possible side effects of CML medications. Talk with your doctor about any side effects you may experience.

- **Here's how often I experience side effects:**

- **Here's how side effects are impacting my daily life:**
(Check all that apply)

- Interferes with my work**
- Interferes with my social activities**
- Interferes with physical activities or exercise**
- Affects my mental health and/or relationships**

Provide specific examples:

- **What CML treatment goals may be within my reach?**

CML CAN AFFECT YOU PHYSICALLY AND MENTALLY

Not only can CML take a toll on you physically, it can also affect your mental health. Many people with CML report suffering from depression. If you're having any mental health issues, be sure to talk with your doctor.



MENTAL HEALTH ADVOCACY GROUPS MAY BE HELPFUL

There are resources you can turn to for help with mental health, such as:

- Cancer Care at [cancercareservices.org](https://www.cancercareservices.org)



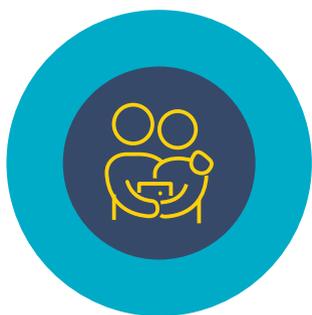
CANCERcare®

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ONGOING TREATMENT, ONGOING CHALLENGES

It is possible that issues related to CML can impact your emotions. Some may come up early in your treatment journey while others may arise later. It can be a good idea to seek guidance from your doctor, a mental health professional, or an advocacy group about the following topics:

- **How do you tell family and friends about your diagnosis?**
- **What should you tell your children?**
- **Should you inform your supervisor and colleagues at work?**
- **How do you manage relationships?** Some friends may draw closer when they learn your news, while others may pull back
- **If you're single, when do you tell someone you're dating** that you have CML?
- **How do you cope with going for blood work** every 3 months and waiting 1 or 2 weeks to get your results?
- **How do you deal with the "invisibility" of CML?** Since many people with CML look perfectly fine, others may forget that you have a chronic disease or think you have been cured



BUILD YOUR SUPPORT SYSTEM

It can be helpful to have your own support system. Ask a family member or friend to accompany you to your doctor appointments to help you take notes and remind you to ask questions.

Your doctor, mental health professionals, and advocacy groups can help you manage issues related to CML that are affecting your mental outlook.

You may find it helpful to connect with other CML patients, including on social media, who may be dealing with some of the same issues.

A CML DIAGNOSIS AT A YOUNGER AGE CAN AFFECT FAMILY PLANNING

Some people are diagnosed with CML when they may be considering starting or adding to their family. If this reflects your situation, you and your partner should talk with your doctor, and consider seeing a CML specialist, before you start treatment for CML.

WHAT IF YOU'RE PREGNANT AT DIAGNOSIS?

- **It can be a shock to get diagnosed with CML, but if you're already pregnant, the news can be even more concerning.** You're not just worried about yourself, but also about the impact of CML and potential treatment on your unborn child
- **Talk with your doctor about how to proceed.** Your doctor may take several factors into consideration, such as the phase of your CML and your due date

WHAT IF YOU'RE OF CHILD-BEARING AGE AT THE TIME OF DIAGNOSIS?

- **If you are a woman of child-bearing age and you're diagnosed with CML, your doctor may perform a pregnancy test** before you start on treatment. Your doctor may also recommend that you take steps to avoid pregnancy while you are taking a CML medication

CML TREATMENTS MAY AFFECT FERTILITY— IN MEN AND WOMEN

- **If you're taking a CML medication, you and your partner should speak with your doctor** before deciding to try to have children. Some CML medications may affect fertility in both men and women

WHAT IF YOU'RE ON TREATMENT AND YOU BECOME PREGNANT?

- **It's important to tell your doctor right away if you become pregnant or think you may be pregnant while on a CML medication.** Your doctor may decide to stop your CML medication.
- Do not breastfeed while you are taking a CML medication without specific direction from your doctor

TELL YOUR DOCTOR ALL THE MEDICINES YOU TAKE BEFORE STARTING TREATMENT

- **Before you start a CML medication, tell your doctor about all the prescription and over-the-counter medicines you take,** as well as any vitamins and herbal supplements
- **Certain CML medications may affect other drugs, vitamins, or supplements** you take and cause side effects
For example, common drug interactions may include proton pump inhibitors for acid reflux, heart medications, and antidepressant medications
- **Ask your doctor about foods to avoid** while taking a CML medication

6 TIPS

FOR TRAVELING WHEN YOU HAVE CML

1. **Depending on your destination, talk with your doctor to make sure you don't need medical clearance** or certain vaccines before you travel
2. **Pack your CML medication in your carry-on bag,** not your checked luggage
3. **Bring a list of all the medications you take**
4. **Keep up with your treatment:** Avoid taking a "vacation" from your CML medication
5. **Listen to your body:** CML medications can cause fatigue, so build in time to rest while on vacation
6. **Eat healthy and stay hydrated**

RESOURCES TO HELP YOU MANAGE CML

Being diagnosed with CML can be daunting. Your doctor can educate you about your options and work with you to find a treatment that can help manage your CML.

But if side effects from your medication are becoming more bothersome, you should speak up and tell your doctor.

Below are some resources that you may find helpful.



VISIT SpeakUpCML.com

To learn more about CML and hear from others who are fighting the disease, visit SpeakUpCML.com.

SIGN UP FOR SUPPORT

You shouldn't have to go it alone with CML. Sign up for ongoing support at SpeakUpCML.com.

You'll receive:

- Educational information about CML
- Tips to help you have a productive conversation with your doctor
- Information about the importance of telling your doctor about any side effects you may have

CONNECT WITH CML ADVOCACY GROUPS AND ORGANIZATIONS

As a rare cancer, CML often does not receive the same attention as some of the more common forms of cancer. You may find it helpful to reach out to the organizations listed below for information, support, or to connect with others who are living with CML.

■ **The Leukemia & Lymphoma Society®**

LLS.org
1-800-955-4572

■ **The National CML Society**

nationalcmlsociety.org

■ **The Max Foundation**

themaxfoundation.org
1-425-778-8660

■ **CancerCare®**

cancercares.org
1-800-813-HOPE
(1-800-813-4673)

■ **Leukemia Research Foundation**

leukemiarf.org
1-847-424-0600

■ **American Cancer Society®**

cancer.org
1-800-ACS-2345
(1-800-227-2345)

■ **National Cancer Institute's Cancer Information Service**

cancer.gov/contact
1-800-4-CANCER
(1-800-422-6237)

■ **National Patient Advocate Foundation**

npaf.org
1-202-347-8009

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LEARN TO “SPEAK” CML: A GLOSSARY OF TERMS

When you have CML, you may hear a lot of unfamiliar terms. The glossary below can be useful in speaking with your doctor—and explaining CML to family and friends.

- **Accelerated phase**
The second phase of CML, characterized by an increase in the number of damaged or immature white blood cells (also called blast cells)
- ***BCR::ABL1* gene**
An abnormal gene that forms when pieces of the 9 and 22 chromosomes swap places. This creates a damaged protein called BCR-ABL
- **Blast cell**
A white blood cell that is damaged or immature
- **Blast phase**
The third phase of CML, which can be difficult to treat. This phase has the highest number of immature blood cells (blast cells) in the blood and bone marrow
- **Bone marrow**
A sponge-like tissue in the center of most bones, responsible for creating different types of blood cells
- **Chromosome**
Bundles of coded instructions within cells for making and controlling cells
- **Chronic myeloid leukemia (CML)**
A cancer of the blood and bone marrow
- **Chronic phase**
The first phase of CML. Most people with CML are diagnosed in chronic phase. In this phase, the number of white blood cells is elevated but may not lead to symptoms
- **Complete blood count (CBC) test**
Measures the number of red blood cells, white blood cells, and platelets in your blood

LEARN TO “SPEAK” CML:

A GLOSSARY OF TERMS

(CONT)

- **Complete cytogenetic response (CCyR)**
Tests find no presence of the Philadelphia chromosome in a bone marrow sample
- **Cytogenetic testing**
This involves testing samples of tissue, blood, or bone marrow to identify changes in chromosomes
- **Gene**
Complex, coded instructions contained within cells for making new cells and controlling cell behavior
- **Gene mutation**
A change in the DNA of a cell
- **Intolerance**
When side effects of a certain drug become so unmanageable that the doctor decides to stop your medication
- **Leukemic cells**
Diseased white blood cells that grow abnormally
- **Major molecular response (MMR)**
An improvement related to treatment, MMR means that tests show a low amount of *BCR::ABL1* in the blood ($\leq 0.1\%$). This means 1 out of every 1000 cells has the *BCR::ABL1* gene
- **Milestone**
An optimal clinical treatment response within a certain timeframe
- **Molecular response**
A result of treatment, this reflects a decrease in the number of cells in the blood with the *BCR::ABL1* gene
- **Philadelphia chromosome (Ph)**
This abnormal chromosome is formed when parts of chromosomes 9 and 22 trade places, creating the *BCR::ABL1* gene. The presence of the Philadelphia chromosome shows that CML is in the body

LEARN TO “SPEAK” CML:

A GLOSSARY OF TERMS

(CONT)

- **Platelets**
Found in the blood and spleen, platelets help control or stop bleeding
- **Protein**
Essential for proper body function, a protein consists of amino acids
- **qPCR test (quantitative polymerase chain reaction test)**
The (qPCR) test (International Scale or IS) measures your *BCR::ABL1* level and is the standard for monitoring response to CML treatments
- **Red blood cells**
These blood cells contain a protein called hemoglobin, which carries oxygen from the lungs to other parts of the body
- **Resistance**
When you do not respond to a medication, or you stop responding to treatment
- **Tyrosine kinase inhibitors (TKIs)**
Doctors use this type of targeted medication to treat CML. The medication attaches to the BCR-ABL protein, helping to prevent it from sending growth signals
- **White blood cells**
A type of blood cell that helps the body fight infections. With CML, patients have too many immature leukemic white blood cells. These can crowd out healthy white blood cells, red blood cells, and platelets. These immature, leukemic cells are abnormal and do not become healthy white blood cells

Visit SpeakUpCML.com

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CML



Patient portrayal



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