

IS YOUR CURRENT CML MEDICATION NOT A GOOD FIT?

Talk With Your Doctor About Your
Experience and Treatment Options

CML, chronic myeloid leukemia

What About **MY CML**

ONE SIZE DOESN'T FIT ALL IN TREATING CML

For more than 20 years, medications have helped make chronic myeloid leukemia (CML) more manageable for many people. Today, doctors have several treatment options. But a CML medication that works for one person may not work for another. So how do you know if your current medication is a good fit? While your doctor is the best resource, this guide is designed to help.

Not Responding or Struggling With Side Effects?

A CML medication that worked at one time may no longer fit—whether it's because you're falling short of your treatment goals or you're experiencing unmanageable side effects. **To help provide an understanding of CML and when it may be time to discuss treatment options with your doctor, the following pages include:**

- Background on the disease, CML medications, blood testing, and treatment goals
- Information about treatment challenges in CML, including drug resistance and unmanageable side effects
- A Doctor Discussion Guide that can help patients have a productive conversation about their CML and treatment options
- Resources that provide support for patients and caregivers who are living with CML

Review this information and discuss it with your doctor. You can also learn more at [whataboutmycml.com](https://www.whataboutmycml.com)



DOES THE IDEA OF A “GOOD CANCER” NOT FIT?



You may have heard others refer to CML as the “good cancer.” That’s because medications have helped make CML more manageable for many people.

But the CML journey doesn’t turn out to be quite as “good” for some people. Along the way, some patients find that their medication is not working as well as it did early on, or they experience unmanageable side effects.

To help you have productive conversations with your doctor, review the following section to learn more about the cause of CML, targeted therapies, and treatment goals.

UNDERSTANDING CML

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

What Causes CML?

CML occurs when:

- The blood-forming cells of the bone marrow create too many white blood cells
- These damaged white blood cells crowd out healthy red blood cells, white blood cells, and platelets
- This can lead to health problems

Most people with CML have Philadelphia chromosome-positive chronic myeloid leukemia (Ph+ CML).

- It is caused by an abnormal fusion gene, called *BCR-ABL1*, which results from a change in chromosomes in the body
- In CML, pieces of chromosomes 9 and 22 break off and trade places
- This change 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

Review this information and discuss it with your doctor. You can also learn more at whataboutmycml.com

CML Has 3 Phases

CML is classified into 3 phases: chronic phase, accelerated phase, and blast phase. Most adults are diagnosed in chronic phase and most people respond to treatment.

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.

Former Oncology Nurse Shares Her CML Story

Watch this video about Gail, who offers a unique perspective as both a patient with CML and a health care professional. A retired oncology nurse, Gail discusses the challenges of being diagnosed when her 2 children were young, and she was the sole breadwinner. Gail is currently on her fourth CML medication and talks about the importance of working with a CML specialist. [Watch Gail's story](#)



CML MEDICATIONS AND WHERE YOU FIT IN

Since 2001, medications called tyrosine kinase inhibitors (TKIs) have played an increasingly important role in managing CML. TKIs are thought to work by blocking the signals that cause cancer cells to grow and spread.

Take an Active Role in Helping to Choose Your Medication

When you have CML, it's important to be your own advocate. That means playing an active role with your doctor in your treatment plan. If you're interested in a specific medication, be sure to mention it to your doctor.

Keep Up With Your Treatment

Once your doctor prescribes a TKI, you have to do your part to help set yourself up for success. **To help you manage your CML, be sure to:**

- Take your CML medication as prescribed
- Keep up with your blood work, so your doctor can see if you are responding to treatment
- Go to all of your doctor appointments and speak up about any issues you may be having, whether you're struggling with side effects or not reaching your CML milestones

Review this information and discuss it with your doctor. You can also learn more at whataboutmycml.com

What If Your CML Medication Isn't a Good Fit?

If you're not reaching your CML milestones (see pages 7-8) or you're struggling with side effects, you may find the Doctor Discussion Guide on pages 12-13 to be helpful. You can also visit whataboutmycml.com and take a quiz that can help you tell your doctor how CML is affecting your daily life.

Don Talks About Being Open With Your Doctor

Don learned he had CML after a visit to the emergency room. Since his diagnosis, his medication has been switched multiple times. In this video, Don discusses the impact of CML on his life, finding doctors he can talk to openly, and the support he receives from his family and others with CML. [Watch Don's story](#)



KNOW YOUR NUMBERS

Once you've been prescribed a medication to treat CML, your doctor may have you go for regular blood tests to see if you are responding to treatment and achieving your CML milestones. **Here are tests your doctor may order:**

Complete Blood Count (CBC)

- Measures the amount of red blood cells, white blood cells, and platelets in the blood

Standard 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

qPCR Test for Tracking *BCR-ABL1* Levels

- qPCR testing is sensitive enough to detect the smallest amount of leukemic cells in the blood and bone marrow
- When you go for qPCR testing, be sure the lab uses a standardized scale called the International Scale to measure your *BCR-ABL1* level. It's a reliable way to measure progress toward your goals

qPCR, quantitative polymerase chain reaction

Gene Mutation Testing

- Looks for mutations in the *BCR-ABL1* gene that may cause certain medications to stop working
- Your doctor may call this a *BCR-ABL1* kinase domain mutation analysis

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 with your doctor.

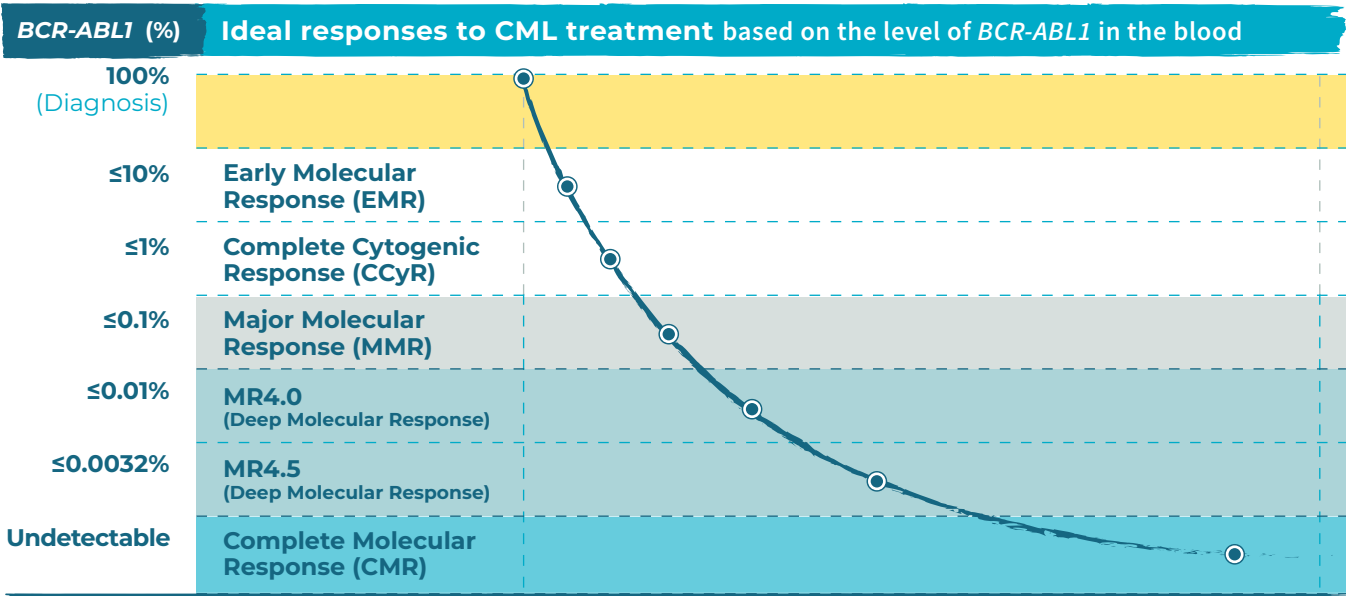
Your doctor may track your *BCR-ABL1* with a qPCR test. It's so sensitive it can detect **1 cancer cell** among anywhere from **100,000 to 1 million cells**

SETTING TREATMENT GOALS WITH YOUR DOCTOR

Your doctor may discuss treatment milestones in CML with you. Keep in mind, treatment goals may vary from patient to patient.

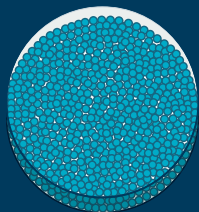
The chart below describes treatment milestones in CML. One goal is to reduce the number of cells with the *BCR-ABL1* gene to as close to zero as possible.

The Lower, the Better



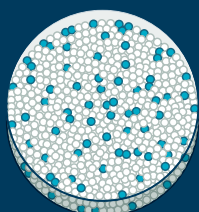
MILESTONES IN CML

The illustrations below can help you picture how the number of leukemic cells may come down over time with treatment. The blue dots represent the amount of *BCR-ABL1* in the body.



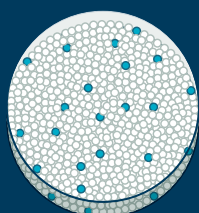
At Diagnosis: Baseline

- 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%



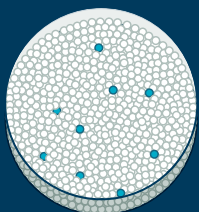
Early Molecular Response (EMR) or Complete Hematologic Response (CHR)

- Blood counts for red blood cells, white blood cells, and platelets return to normal
- With EMR, *BCR-ABL1* is $\leq 10\%$ of all the cells in your blood



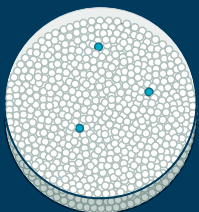
Complete Cytogenetic Response (CCyR)

- 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 $\leq 1\%$



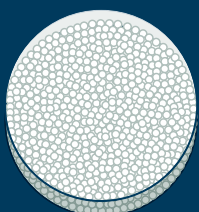
Major Molecular Response (MMR)

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



Deep Complete 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)
- These levels can only be detected by the most sensitive tests or cannot be detected



Complete Molecular Response (CMR)

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

SOMETIMES A CML MEDICATION DOESN'T FIT

Medications may work well for many patients with CML. But over time, some people may find that their medication no longer fits—whether it's because they do not reach their treatment goals or they experience unmanageable side effects.

You'll find a Doctor Discussion Guide on pages [12-13](#) that you can use to raise any concerns you may have about CML and your current medication. You can also take a quiz at whataboutmycml.com that can help you have a productive conversation with your doctor.

SOME PEOPLE STOP RESPONDING TO A MEDICATION OR HAVE UNMANAGEABLE SIDE EFFECTS

Most people with CML are treated with a type of targeted therapy called tyrosine kinase inhibitors (TKIs). These medications are thought to inhibit the BCR-ABL protein that leads to uncontrolled growth of leukemic cells.

Some People Have a Different Experience

As your doctor continues to treat CML, one goal is to see the number of leukemic cells in your blood go down. For some people, that may not happen. **These patients may experience any of the following:**

- **Drug intolerance:** Side effects of a medication become unacceptable and significantly affect daily life
- **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 medication worked for a time, but it no longer works as well. This is known as secondary drug resistance

If your doctor determines that you are not responding well to treatment or you're having unmanageable side effects, your doctor may decide if it's appropriate to adjust your dose or consider another medication. That's why it's important to have an open conversation with your doctor about any side effects and the results of your blood work.



HOW CAN YOUR DOCTOR TELL IF YOUR CML MEDICATION FITS?

Some people find that their CML medication no longer works as well as it did early on or they try to tough out side effects. If you're having issues with side effects, it's important to speak with your doctor. You may find it helpful to use the Doctor Discussion Guide on pages 12-13. There's also an interactive quiz at whataboutmycml.com, which may help give your doctor a better sense of how CML is affecting you on a daily basis.

Drug Resistance

Some patients with CML find that over time, the number of leukemic cells in their blood starts going up instead of going down. This may be due to drug resistance, which happens when cancer cells no longer respond to a medication.

In CML, one of the causes of resistance is a mutation in the *BCR-ABL1* gene. A mutation is a change in a cell's DNA.

The Role of Mutation Testing

To determine if you have a mutation, your doctor may order a gene mutation test. It looks for mutations in the *BCR-ABL1* gene that may cause certain medications to stop working.

Your doctor may decide to test for a mutation if you are:

- Not responding or no longer responding to medication
- Unable to reach a treatment milestone
- Progressing to the accelerated phase or blast phase

Dealing With Side Effects

Some people are hesitant to tell their doctor about side effects. That doesn't help the patient—or the doctor. Your doctor may be able to help you manage side effects—but only if you tell your doctor what issues you are dealing with.

If side effects are starting to interfere with your daily life, you should have a discussion with your doctor. For example, if side effects are getting in the way of doing your job, causing you to cancel plans, or simply requiring you to ask for help with day-to-day chores, these are sure signs that you need to speak up.

Have an Open Conversation With Your Doctor

If your CML medication doesn't seem to fit—whether it's because you're not responding to treatment or you're experiencing unmanageable side effects—talk with your doctor.

Fighting CML Together

Nancy learned she had CML after going for blood work prior to an unrelated surgery. In this video, Nancy and her husband Mark discuss how her diagnosis came as a complete shock. Now on her third medication for CML, Nancy talks about her experience and how helpful it's been to have Mark at every step of her journey with CML.

[Watch Nancy's story](#)



YOUR CML DOCTOR DISCUSSION GUIDE

(1 of 2)

If you're not reaching your treatment goals for CML or side effects are becoming unmanageable, don't keep it to yourself. Use this guide to have a productive conversation with your doctor. Note, Ph+ CML is often referred to broadly as CML.

1 Which medications have you taken for CML? (List all that apply.)

2 Which of the following common side effects of CML medications have you recently experienced? (Check all that apply.)

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

3 How often do you experience side effects, if any?

4 What impact have side effects had on your daily life? (Check all that apply.)

| | | |
|--|---|---|
| <input type="checkbox"/> Interfered with my work | <input type="checkbox"/> Interfered with my social activities | <input type="checkbox"/> I've needed help with routine chores |
|--|---|---|

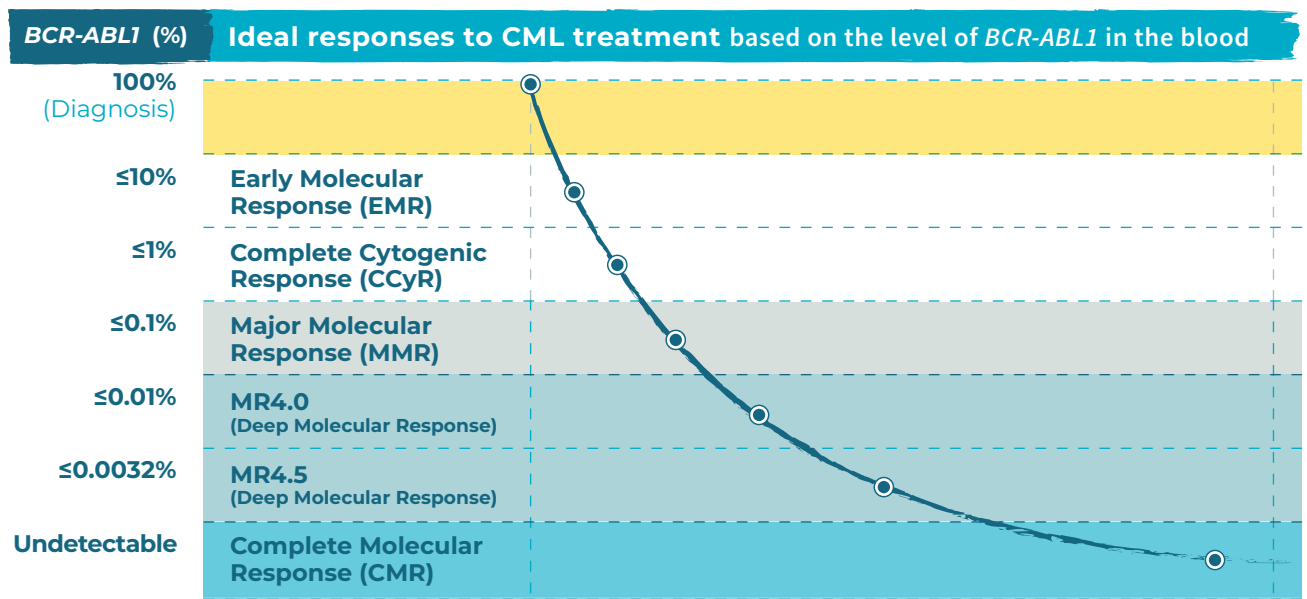
Provide your doctor with specific examples:

YOUR CML DOCTOR DISCUSSION GUIDE

(2 of 2)

5 What CML treatment goals have you discussed with your doctor?

6 Discuss with your doctor where your *BCR-ABL1* results stand on the chart below.



This chart shows an example of how your blood counts may decrease with medication. If your *BCR-ABL1* level increases, or you do not achieve your CML treatment goals, you may want to ask your doctor about other treatment options.

To learn more about the terms in the above chart, see page 8.

Treatment goals vary by patient. Not every patient will reach these CML milestones.

Take Our Online Quiz to Help Start a Conversation With Your Doctor

Your experience with CML may be affecting you in more ways than you realize. That's the purpose of the quiz at whataboutmycml.com

Sharing the results of your quiz with your doctor may help you bring up any issues you may be having. Of course, the quiz does not take the place of medical advice from your doctor. Be sure to see your doctor regularly about your CML.

CONNECT WITH US TO KEEP UP WITH THE LATEST IN CML

While today's medications help many people with CML, some patients do not do as well.

If this sounds a lot like what you're going through, sign up for patient support at whataboutmycml.com. You'll receive:

- Educational information about CML
- Tips to help you have a productive conversation with your doctor
- Information about the importance of keeping up with your blood work
- Access to videos about patients with CML whose experience may be similar to yours

Resources for CML

As a rare cancer, CML does not receive the same attention as some of the more common forms of cancer. You may find it helpful to reach out to organizations that provide support for those living with CML. You'll find 4 sources of information on the right and additional resources at whataboutmycml.com.

Leukemia & Lymphoma Society®

[LLS.org](https://lls.org)

1-800-955-4572

The National CML Society

nationalcmlsociety.org

American Cancer Society®

cancer.org

1-800-ACS-2345 (1-800-227-2345)

National Cancer Institute's Cancer Information Service

cancer.gov/contact

1-800-4CANCER (1-800-422-6237)

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Visit whataboutmycml.com
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