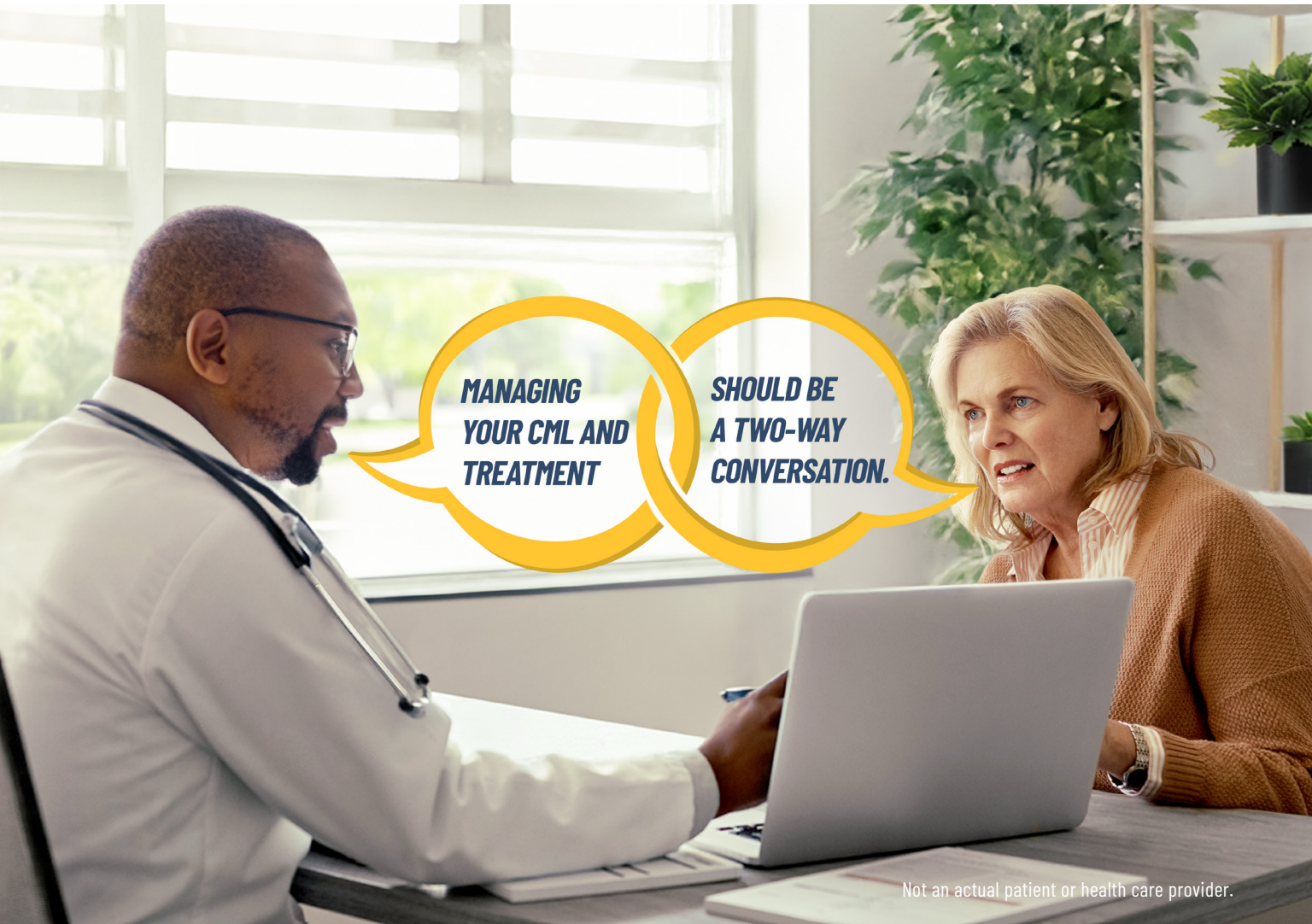


YOUR GUIDE TO CHRONIC MYELOID LEUKEMIA



**MANAGING
YOUR CML AND
TREATMENT**

**SHOULD BE
A TWO-WAY
CONVERSATION.**

Not an actual patient or health care provider.

CML, chronic myeloid leukemia.

SPEAKUP
CML

WHEN IT COMES TO YOUR CML AND TREATMENT, YOUR VOICE MATTERS

SPEAKUP
CML

You're an important source of information for your health care team as they evaluate your goals and determine an appropriate treatment for you. So, it's important to actively participate in conversations about your chronic myeloid leukemia (CML) and treatment.

Here you'll find resources, information about treatment goals, and see how other people with CML have taken action. To learn more, visit [SpeakUpCML.com](https://www.speakupcml.com).



Patient portrayals.



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THE MORE I LEARN ABOUT CML, THE MORE COMFORTABLE I FEEL TALKING WITH MY HEALTH CARE TEAM

YOUR HEALTH CARE TEAM CAN PROVIDE INFORMATION AND HELP YOU NAVIGATE OPTIONS

A diagnosis of chronic myeloid leukemia (CML) can be overwhelming. There's a lot to learn about this rare cancer and its treatment. There are many ways your life may change. But you and your health care team should approach it together. They need to know how you're really feeling, so don't keep questions to yourself. Speaking up helps you participate in a treatment option that may be right for you.

You are the best advocate for yourself.

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.

A "GOOD" CANCER?

For more than 20 years, medications have helped make CML more manageable for many people. Thanks to advances in treatment, most people who have CML can anticipate having a life expectancy that's close to normal.

WHAT CAUSES CML?

CML occurs when the blood-forming cells of bone marrow mistakenly create too many white blood cells. These damaged white blood cells crowd out healthy red blood cells, white blood cells, and platelets.

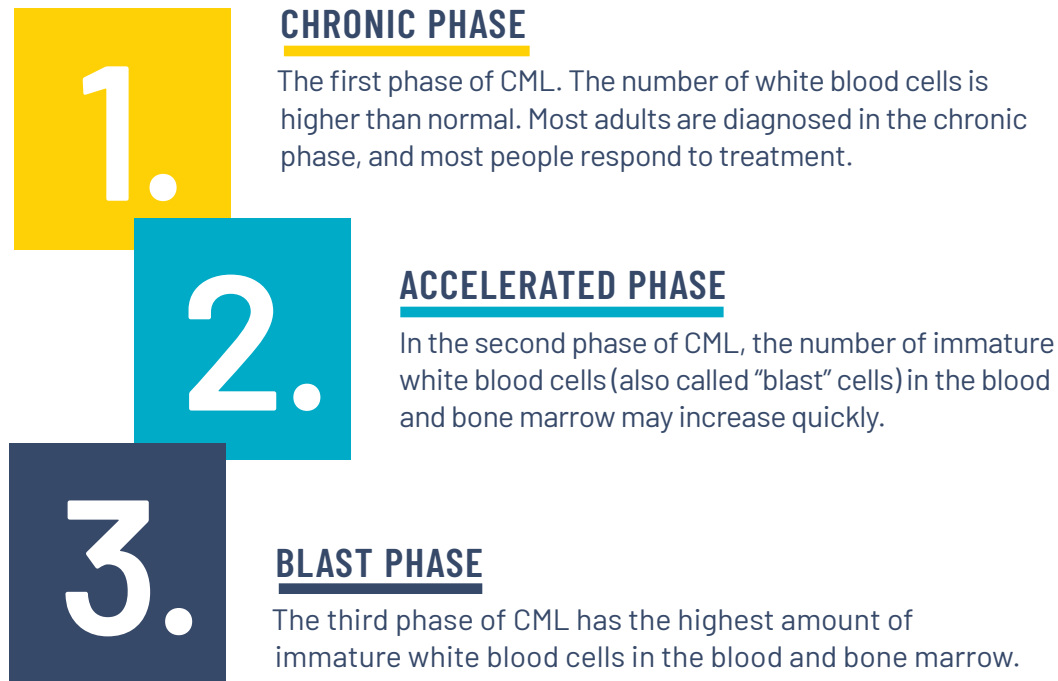
SIGNS AND SYMPTOMS OF CML

Some people may encounter symptoms before diagnosis. These can include:

- Feeling unusually tired
- Shortness of breath during everyday activities
- Fever
- Bone pain
- Unexplained weight loss
- Pain or a feeling of fullness on the upper-left side of the belly (abdomen area), below 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:

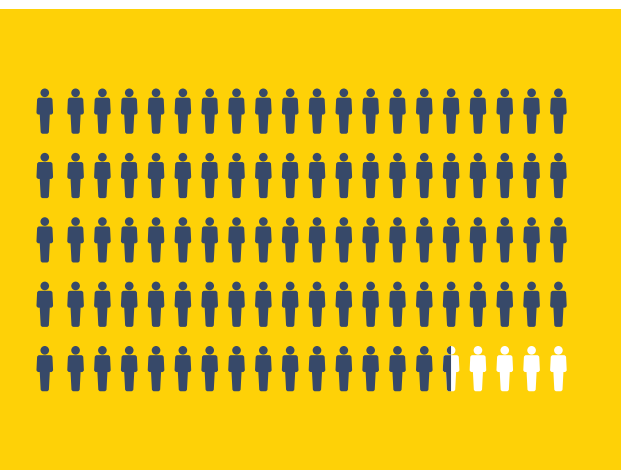


Your health care team may talk to you about the importance of keeping CML from progressing from the chronic phase to the more advanced accelerated or blast phases. If CML is left untreated, it is more likely to progress.

MOST PEOPLE DIAGNOSED WITH CML HAVE Ph+ CML

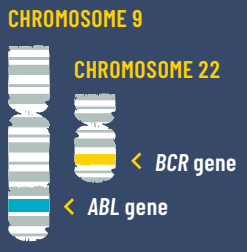
More than 95% of people with CML are diagnosed with Philadelphia chromosome-positive chronic myeloid leukemia (Ph+ CML).

Ph+ CML is caused by an abnormal fusion gene, called *BCR::ABL1*, which results from a change in chromosomes in the body

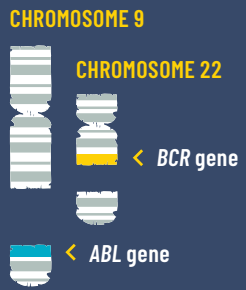


- Each cell in the human body has 23 pairs of chromosomes
- In CML, pieces of chromosomes 9 and 22 break off and trade places
- This can create a new abnormal chromosome: the Philadelphia (Ph+) chromosome
- This abnormal chromosome then produces the defective *BCR::ABL1* gene, which makes an abnormal protein called BCR-ABL

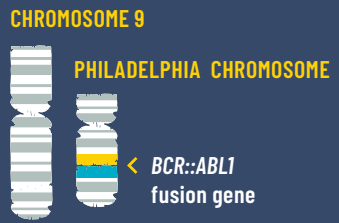
NORMAL CHROMOSOMES



CHROMOSOMES BREAK



CHROMOSOMES CHANGE





WHAT HAPPENS IN YOUR BODY WHEN YOU HAVE CML?

- **Blood-forming cells** of bone marrow mistakenly 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

ROLE OF CML MEDICATIONS

Not all CML treatments are the same—or work the same way.

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



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

It's important to set a clear treatment plan from the start. Work with your health care team to find a treatment that combines effectiveness with side effects that may be manageable for you.

The Questions to Ask Your Doctor on page 16 can help you start a conversation that includes your needs and what may be right for you.

SETTING TREATMENT GOALS IS IMPORTANT

It may be daunting at first, but it is important to speak up and work closely with your health care team to discuss treatment goals. You can help determine an appropriate treatment plan from the start by voicing your questions and preferences. Some common goals include:

- **Getting blood cell counts** back within a normal range
- **Reducing the number of leukemic cells** in the body
- **Reducing the amount of BCR-ABL protein** in the body to an undetectable level
- **Keeping chronic myeloid leukemia (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. Milestones are measured by the level of *BCR::ABL1* gene in your blood.

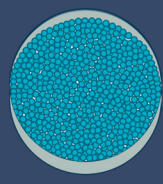
The illustrations on the next page show different milestones and how the amount of *BCR::ABL1* gene may decrease over time with treatment. The blue dots represent the amount of *BCR::ABL1* in the body.

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.

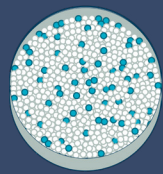
The Questions to Ask Your Doctor on page 16 can help you make the most of your doctor's appointments.

GOALS OR MILESTONES IN CML



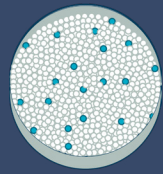
AT DIAGNOSIS

- At the time of a CML diagnosis, the abnormal *BCR::ABL1* gene level in the blood is different for everyone. Your health care team will determine your *BCR::ABL1* gene level at diagnosis, which will be your baseline level and typically will be considered as 100%. Your baseline level will be compared to future levels to determine whether you are reaching treatment milestones



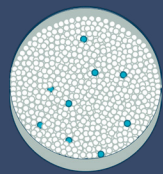
EARLY MOLECULAR RESPONSE (EMR)

- With EMR, the level of *BCR::ABL1* in the blood is between 10% and 1% at 3 to 6 months



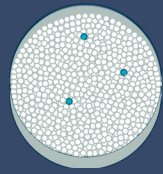
COMPLETE CYTOGENETIC RESPONSE (CCyR)

- With CCyR, the level of *BCR::ABL1* in the blood is $\leq 1\%$
- Your health care team may say you have a CCyR if there are no Philadelphia chromosome-positive (Ph+) cells detected in the bone marrow



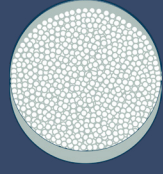
MAJOR MOLECULAR RESPONSE (MMR)

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



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

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



COMPLETE MOLECULAR RESPONSE (CMR)

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

GOALS OR MILESTONES IN CML

(CONT)

If your *BCR::ABL1* increases, or you do not achieve your CML treatment goals, you may want to ask your health care team about other treatment options.

The table below summarizes the milestones that may be achieved in response to treatment. Not all those living with CML can achieve these milestones or goals described.

<i>BCR::ABL1</i> LEVEL COMPARED TO LEVEL AT DIAGNOSIS	MILESTONE
>10%	Sign of TKI-resistant CML
≤10%	Early Molecular Response (EMR)
≤1%	Complete Cytogenetic Response (CCyR)
≤0.1%	Major Molecular Response (MMR)
≤0.01%	MR4.0, Deep Molecular Response (DMR)
≤0.0032%	MR4.5, DMR
Not detectable	Complete Molecular Response (CMR)

Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Chronic Myeloid Leukemia V.1.2026. ©National Comprehensive Cancer Network, Inc. 2025. All rights reserved. Accessed March 23, 2026. To view the most recent and complete version of the guideline, go online to [NCCN.org](https://www.nccn.org). NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.

See link to web for further guidance, if needed:
<https://www.speakupcml.com/setting-treatment-goals>

SPEAKING UP ABOUT SIDE EFFECTS

Have side effects from your medication interfered with some of your daily activities?

Don't keep it to yourself. Your health care team needs to know.

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 health care team. There can be other side effects with different types of CML treatments.

- 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

Be sure to tell your health care team about anything you experience that may be a side effect, sign, or symptom, including how it may be interfering with your daily activities or your emotional health.

If side effects are becoming so bothersome that you're not able to take your CML medication as prescribed, tell your health care team. Missing doses can make your medication less effective.

BEING A “GOOD PATIENT” DOESN’T HAVE TO MEAN PUTTING UP WITH SIDE EFFECTS

Some people with CML feel they don’t want to bother their health care team by bringing up side effects. But, in order for your health care team to provide you with the best treatment, they need to know how you are truly feeling.

CML requires teamwork. Your health care team knows medicine, but only you know how you feel when you take your CML medication.

DRUG RESISTANCE MAY HAPPEN

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 at all. This is known as primary drug resistance
- **Treatment works at first, but stops:** This is known as secondary drug resistance

That’s why it’s important to work with your health care team to find a treatment that may work and one you may be able to stay with.

MONITORING YOUR BLOOD

Your health care team may want you to go for blood tests at specific time points such as 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 health care team. That’s why it’s important to go for any blood tests prescribed 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 Philadelphia 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 Philadelphia 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
- **Gene Mutation Testing:** Looks for mutations in the *BCR::ABL1* gene that may cause certain medications to stop working. Your health care team may call this a *BCR::ABL1* kinase domain mutation analysis

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

1 CANCER CELL AMONG

100,000 TO 1 MILLION CELLS

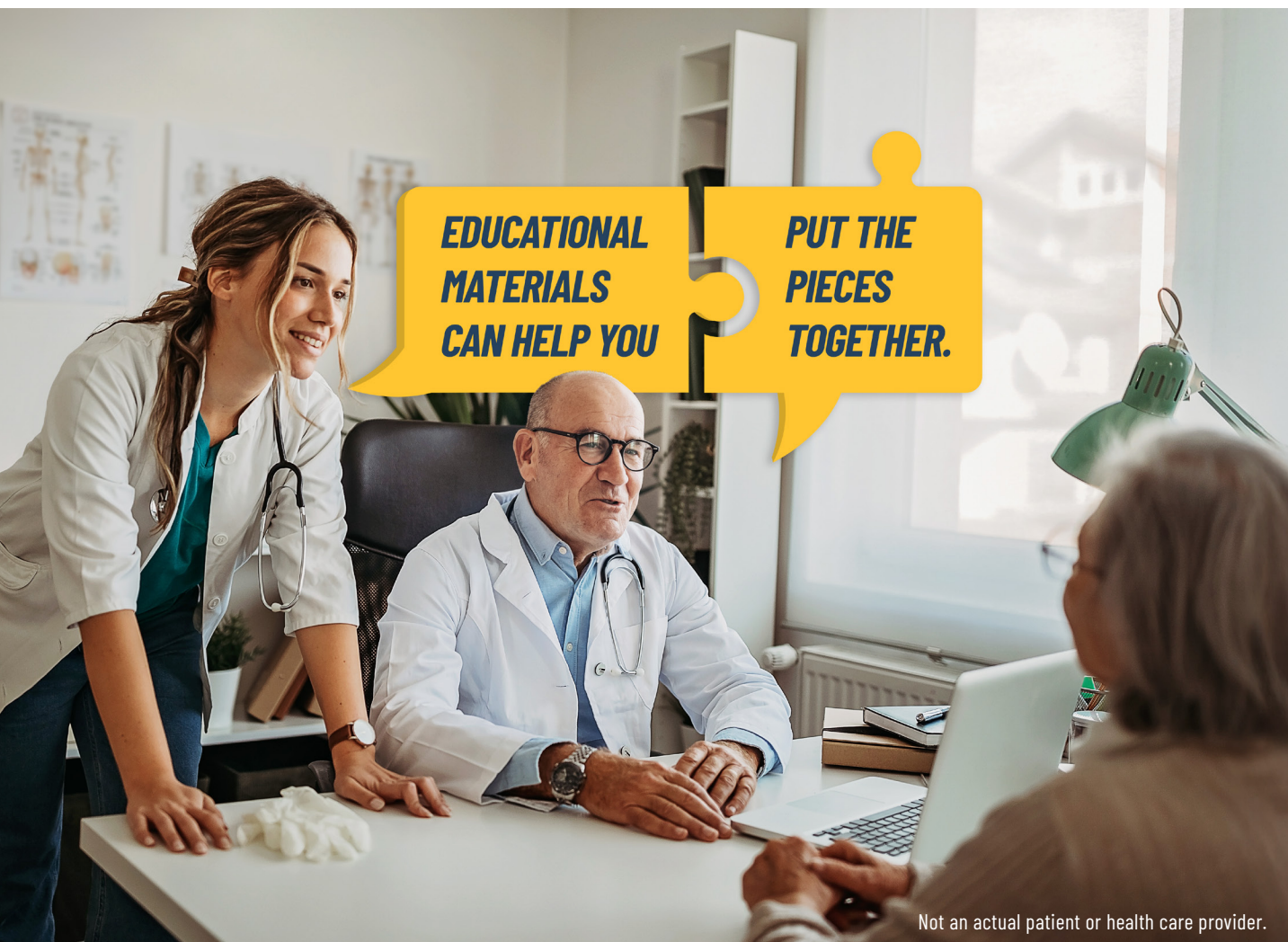
COMMUNICATING WITH YOUR DOCTOR

SEE A CML SPECIALIST—EVEN IF ONLY ONCE

While your local doctor is someone you need to rely on, you may find it helpful to see a CML specialist. A specialist can work together with your local health care team to help guide your treatment.

**EDUCATIONAL
MATERIALS
CAN HELP YOU**

**PUT THE
PIECES
TOGETHER.**



Not an actual patient or health care provider.

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 WITH CML

- Does my CML diagnosis impact my life expectancy?
- What treatments are available to treat CML? How do they work?
- Are there any treatment goals that I should try to reach?
- When do most patients reach these goals?

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 (check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Fever | <input type="checkbox"/> Rash/itching |
| <input type="checkbox"/> Diarrhea/nausea/vomiting | <input type="checkbox"/> Headache |
| <input type="checkbox"/> Muscle and joint pain | <input type="checkbox"/> Confusion |
| <input type="checkbox"/> Difficulty breathing/
shortness of breath | <input type="checkbox"/> Weight gain |
| <input type="checkbox"/> Bone pain | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Fluid retention/swelling | |
| <input type="checkbox"/> Fatigue | |
| <input type="checkbox"/> Bleeding/gastrointestinal
bleeding | |
| <input type="checkbox"/> Increased blood pressure | |

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
- I need help with routine chores
- Other: _____

RESOURCES TO HELP YOU MANAGE CML

Being diagnosed with chronic myeloid leukemia (CML) can be daunting. Your health care team can tell you about your options and help find a medication that may work for you.

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 through 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.

■ **Blood Cancer United®**
bloodcancerunited.org
1-800-955-4572

■ **The Max Foundation**
themaxfoundation.org
1-425-778-8660

■ **CancerCare®**
cancercares.org
1-800-813-HOPE
(1-800-813-4673)

■ **American Cancer Society®**
cancer.org
1-800-ACS-2345
(1-800-227-2345)

■ **Cancer Support Community**
CancerSupportCommunity.org
1-CSC-867-5309
(1-272-867-5309)

■ **CML Buster Foundation**
CMLBF.org
1-714-393-9399

The organizations and websites listed on this page are maintained by third parties over whom Novartis Pharmaceuticals Corporation has no control. As such, Novartis Pharmaceuticals Corporation makes no representation as to the accuracy or any other aspect of the information supplied by these organizations or contained in these websites.

Visit SpeakUpCML.com

*IT'S NICE TO HAVE
RESOURCES AVAILABLE
WHEN I NEED THEM.*

Patient portrayal

SPEAKUP
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