

YOUR TREATMENT, YOUR VOICE

A RESOURCE & DISCUSSION QUICK-GUIDE FOR PEOPLE LIVING WITH CML

Picking a treatment for chronic myeloid leukemia (CML) is not only about test results—it's also about your and your care partners' daily life, goals, and comfort. When you share what matters to you, your doctor can try to tailor care that fits. **This teamwork with your doctor is called "Shared Decision-Making (SDM)."**

This guide is for informational purposes only and does not constitute medical advice. Patients should consult their healthcare provider for personalized recommendations.



WHY SPEAK UP?

By taking an active role in treatment decision-making, you gain more than just information—you gain a sense of **control, confidence, and care** that more closely fits your lifestyle.

CARE THAT FITS YOUR LIFE

When you share your goals and concerns with your care team, they can help identify treatments that better fit your needs, which may make it easier to stay on track with work, family, and daily life.

UNDERSTAND MORE, WORRY LESS

Asking questions helps you understand your condition and treatment options. When things are clear, you may feel less anxious and more confident about your choices.

BUILD TRUST WITH YOUR CARE TEAM

Honest conversations help you and your care team work together as partners, ensuring you and your loved ones feel heard and respected.

SIMPLE STEPS TO SHARED DECISION-MAKING

1. UNDERSTAND YOUR CML DIAGNOSIS

Make sure your care team explains your diagnosis clearly. Ask about key details like stage, risk factors, and test results. Patient groups (listed below) can also offer useful resources and support.

2. SHARE WHAT MATTERS MOST

Tell your care team about your priorities—such as managing side effects, staying at work, or spending time with loved ones.

3. KNOW ALL YOUR OPTIONS

Ask your care team to explain each treatment option, outlining potential risks and benefits. Request written materials or decision tools, and keep asking questions until you fully understand.

4. DISCUSS RISKS & BENEFITS

Ask what you can expect from each option, including possible side effects and how these may affect your daily life.

5. TAKE YOUR TIME

Let your care team know if you want time to think or discuss options with family or friends before deciding. Bringing someone to appointments can also provide support.

6. CHECK IN REGULARLY

Your needs and situation can change. Keep talking with your care team and update your care plan as needed.

7. ASK ABOUT COSTS

Speak with your care team or a financial navigator about ways to manage the costs of your CML care.

QUICK-ACCESS SUPPORT AT YOUR FINGERTIPS

These organizations can help you at no cost. **Scan the QR codes** to open links on your phone.

ORGANIZATION	SCAN	DECISION-MAKING HELP & MORE	CONTACT
Blood Cancer United		<ul style="list-style-type: none">• Expert CML information & resources• Personalized 1:1 support• Financial help & trial navigation	1-800-955-4572 bloodcancerunited.org
CML BUSTER FOUNDATION		<ul style="list-style-type: none">• CML-specific support groups• Monthly meetings (in-person & virtual)• Peer-to-peer connections & mentorship	1-714-319-3193 cmlbf.org
Leukemia Research Foundation		<ul style="list-style-type: none">• Plain-language CML guides• Peer mentoring• Research updates & education program	1-847-424-0600 leukemiarf.org
CANCER SUPPORT COMMUNITY		<ul style="list-style-type: none">• "Open to Options®" doctor visit prep• "Frankly Speaking About Cancer" tools• 200 in-person locations	1-888-793-9355 cancersupportcommunity.org
CML ADVOCATES NETWORK		<ul style="list-style-type: none">• Global network of news & rights info• Patient groups & webinars	cmladvocates.net info@cmladvocates.net

WHERE TO FIND **HELP**

Many organizations offer **free resources** and **personalized support** to help you and your loved ones manage life with CML. Reach out directly using the contact details or QR codes provided in this guide.

REAL STORIES: LEARNING FROM OTHERS

CANCER SUPPORT COMMUNITY

Communicating with Your Healthcare Team – Patient Testimonial:
See how a patient practiced open communication and how it made a difference. tinyurl.com/CML-guide20

Finding a Medication That Works for You – CML Patient Testimonial:
A patient shares their experience finding the right treatment with their care team tinyurl.com/CML-guide21

Three-Part Podcast Series – Real Patient and Expert Conversations:
Listen to patients and experts discuss diagnosis, staying on top of care, and the importance of communication.

Part 1: The Beginning – Diagnosis and Selecting Your Doctor
tinyurl.com/CML-guide22

Part 2: The Journey – Staying on Top of Your Cancer
tinyurl.com/CML-guide23

Part 3: Lessons Learned – Managing Financial Costs and Resources
tinyurl.com/CML-guide24

Accompanying Paper
(Future Oncology, 2023)
tinyurl.com/CML-guide34

FINANCIAL CONCERN

CANCER SUPPORT COMMUNITY

Resource Navigation
tinyurl.com/CML-guide16

BLOOD CANCER UNITED

Financial Assistance
tinyurl.com/CML-guide17

"Cancer and Your Finances" booklet
tinyurl.com/CML-guide18

TREATMENT OPTIONS

CML ADVOCATES NETWORK

Patient-Friendly Summaries:
Easy-to-understand expert recommendations in multiple languages. tinyurl.com/CML-guide33

Updates on global clinical trials and patient stories.
tinyurl.com/CML-guide27

CML Quality of Life Tracker - SDM Tool for Patients: Co-created in partnership with Novartis.

tinyurl.com/CML-guide26

CANCER SUPPORT COMMUNITY

Coping with CML & Treatment:
Coping with CML and treatment through shared experiences and tips.
tinyurl.com/CML-guide28

BLOOD CANCER UNITED

Clinical Trials Support Center:
Nurse navigators assist with finding and understanding clinical trial options.
tinyurl.com/CML-guide29

Education on Treatments: Simple explanations of chemotherapy, targeted therapies, stem cell transplants, and more. tinyurl.com/CML-guide5

Shared Decision Making in Chronic Leukemias Videos: Short videos to help you play an active role in choosing treatments and talking with your care team. tinyurl.com/CML-guide32

Shared Decision-Making Discussion Guide for Patients: A guide to clarify your goals, list questions, and prepare for appointments.
tinyurl.com/CML-guide7

LEUKEMIA RESEARCH FOUNDATION

New & Emerging Treatments Series:
Videos featuring experts discussing the latest treatment options and research.
tinyurl.com/CML-guide8

PSYCHOSOCIAL SUPPORT

CML BUSTER FOUNDATION

Peer Support Groups: Connect for shared experiences and encouragement.
tinyurl.com/CML-guide31

CANCER SUPPORT COMMUNITY

"Preparing for Your Doctor's Visit"
Discussion Tool: Organize your questions before appointments and discuss emotional and practical needs.
tinyurl.com/CML-guide11

Frankly Speaking About Cancer – Treatment Decision Making Program:
Advice and real stories about treatment decisions and coping with cancer.
tinyurl.com/CML-guide12

Open to Options® Counseling Program:
Free, evidence-based counseling to clarify your goals and prepare for treatment discussions.
tinyurl.com/CML-guide13

LEUKEMIA RESEARCH FOUNDATION

Peer/Emotional Support: Online community for patients and caregivers, mentor program and other resources.
tinyurl.com/CML-guide14

BLOOD CANCER UNITED

Information Specialists: Receive one-on-one support and education from oncology social workers and nurses.
tinyurl.com/CML-guide15



SCAN TO LEARN MORE AND ACCESS RESOURCE LINKS ONLINE

Blood Cancer United

 CML
BUSTER
FOUNDATION

 Leukemia
Research
Foundation

 CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

 CML
ADVOCATES
NETWORK

 NOVARTIS

Developed by advocates for the CML community, this document embodies their collective ambition to improve patient outcomes in CML and serve as an accompanying guide to treatment decision-making discussions with your doctor. The CML Shared Decision-Making Council was convened by Novartis with the goal of bringing CML patient organizations together to align on needs of CML patients and generate collaborative action. Individual members of the CML Decision-Making Council are paid consultants for Novartis Pharmaceuticals Corporation Inc.