Talking About Chronic Myeloid Leukemia (CML)

A Guide for Discussions With Your Care Team

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A PROGRAM OF THE CANCER SUPPORT COMMUNITY

If you have chronic myeloid leukemia (CML), the information in this resource can help you talk with your care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

For more information on CML and additional resources, visit
www.CancerSupportCommunity.org/Chronic-Myeloid-Leukemia

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GILDA'S CLUB

YOUR CML CARE TEAM

Treatment for CML can be difficult to manage and require frequent visits. Your care team should include a group of healthcare professionals and specialists that you trust. Early and regular discussions with your care team are helpful for managing your CML diagnosis.

Your care team may include:

Medical oncologist or hematologist/oncologist − A medical oncologist diagnoses and treats cancer. A hematologist/oncologist (hem/onc) specializes in diagnosing and treating blood cancers. They will offer cancer treatment options and referrals to specialists. This includes chemotherapy, immunotherapy, and targeted therapy.

Nurse practitioner, nurse, or physician assistant − Nurse practitioners (NPs), physician assistants (PAs), and nurses (RNs) may work with the oncologist or hem/onc to help answer questions about your CML diagnosis. A nurse may administer treatments. These healthcare professionals are also a great resource to speak with about your mental health. They can connect you with social workers, counselors, psychiatrists, and others.

Nurse navigator, patient navigator, or nurse/care coordinator − Navigators help you manage your care. They help schedule appointments, get answers to your questions, recommend educational resources, and support you during your treatment.

Oncology social worker and therapist/counselor − A social worker, therapist, and counselor helps you and your caregiver find resources to cope with cancer and its treatment side effects. Social workers can help navigate costs and help with practical concerns. Social workers and therapists are trained mental health professionals who can help you address your emotions through individual or group therapy.

Financial navigator – Along with patient navigators and social workers, financial navigators can help you understand and manage costs and connect you with financial support resources. This includes both costs of treatment and other related needs — like travel, lodging, and leave benefits.

Oncology pharmacist − An oncology pharmacist is an expert on medicines used to treat cancer. They can educate you on any treatment side effects and how to manage them. They can also help you understand how best to take different medications if you have many at once.

Palliative care specialist − This person focuses on improving patients' quality of life. They can be helpful if you are having difficult symptoms, pain, or side effects. Palliative care is different from end-of-life care or hospice. You can see a palliative care doctor at any point during your treatment.

TIPS FOR TAKING CONTROL

- Take someone with you to appointments, for support and an extra set of eyes and ears.
- Talk to your care team or financial navigator about ways to manage treatment costs.
- Take your medicines as prescribed. Let your care team know if you have missed doses. Also let them know if certain side effects are causing you to miss or skip doses.
- You can always seek a second opinion at any time and for any reason during your care.
- Shared decision making is an important part of treating CML. You are a key member of the care team.
- Write down your questions before each doctor's visit. Keep a journal to take notes during your visit.
- Prepare in advance for your doctor's visit by filling out the rest of this discussion tool.
- Ask questions until you understand what is being said.
- You can ask for information in a different language or a drawing if you need it.
- Consider asking for permission to record the conversation. This can be a helpful way to revisit and remember complex information later.

QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

What phase is my CML?
What is the goal of treatment?
Can you recommend a CML specialist?
What are the next steps?

GETTING A SECOND OPINION

At any point in your care, you can ask for a second opinion. Many people may seek out a second or third opinion to confirm their diagnosis and review all available treatment options. Another hospital or doctor may offer different treatment options — including clinical trials — or more useful support services. They may be a better fit for you in other ways, such as being closer to your home. Do not worry about hurting feelings. You can always return to the first doctor if you want. You are entitled to decide what is best for you and your goals. Remember, timely cancer treatment is key. Read more about seeking a second opinion at **www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion**.

CML SIDE EFFECTS

Below are some of the things people with CML may experience. Think about how often they affect you. Talk to your care team about how best to manage them.

	Rarely	Sometimes	All the time
Feeling very tired			
Pain, joint pain, muscle aches, cramps, or trouble moving around			
Fluid retention			
Difficulty thinking clearly or remembering			
Feeling anxious, overwhelmed, or depressed			
Fear of disease progression or upcoming appointments			
Issues with vision or eye bleeds			
Skin problems, rash, or sensitive skin			
Nausea, diarrhea, vomiting, or mouth sores			
Weight loss or gain			
Loss of sexual desire or problems with intimacy			
Other:			

How often are cancer symptoms or treatment side effects interfering with your life?

	Rarely	Sometimes	All the time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities I normally enjoy (e.g., traveling, socializing, hobbies)			
Confidence/self-image			
Sleep			
Social relationships			
Sexual relationships			
Eating and/or exercise			
Others:			

For more information about how to manage treatment side effects, visit **www.CancerSupportCommunity.org/Managing-Side-Effects**.

THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

When you talk to your care team about your treatment options, ask how each one might impact your personal life and goals. If you choose not to receive treatment, think about what kind of care will help you feel comfortable and meet your goals.

Some personal goals may be to:

- Be there for a special event/milestone
- Live as long and as well as you can
- Become an advocate and help others by sharing your experience
- Take part in research

Tell all the members of your care team about your treatment choices and personal goals. Your goals may change over time, and that is OK. Let your care team know if changes happen, so that they can support you in the best way possible.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

Here are some questions for you to consider and discuss with your doctor, as you think about your personal and treatment goals. You may also find it helpful to discuss your goals with your family and loved ones first.

Physical, Emotional, & Sexual Health and Well-Being

- What is most important for you to be able to do and feel?
- What do you want to be able to do physically during or after treatment?
- What symptoms or side effects do you want to avoid or manage?
- What does feeling "emotionally well" look like for you?

Family and Social Relationships

- What is going on in the lives of others that are important to you?
- Are there people in your life that you want to spend more time with or support?
- Are there upcoming family milestones or events you want to be present for?
- How can you maintain meaningful relationships during treatment?
- Who do you want to make medical decisions for yourself if you are unable?

Work/School/Home

- Do you want or need to continue working or attending school? What kind of support or changes will help you with this?
- What changes could help you balance treatment with your responsibilities?
- What kind of help do you need at home or with daily tasks?

Social Support & Community Involvement

- Are you getting the support you need from friends, family, or community?
- What would good support look like for you right now?
- Is getting or staying involved in your community, advocacy, or support groups important?

Personal and Spiritual Growth

- Are you taking care of yourself spiritually and emotionally?
- What spiritual and wellness practices are important to you? Are there spiritual practices or beliefs that bring you comfort?
- What helps you feel connected to something bigger than yourself?
- What personal or emotional goals do you want to focus on?

Other

- What else is important to you?

CAREGIVING FOR CML

Caring for someone with CML can be both rewarding and challenging. Every caregiver experience is different. It is normal to feel overwhelmed, stressed, or even frustrated as you balance your own life with your loved one's needs. **You are not alone in feeling these emotions.** It is completely natural to feel overwhelmed, frustrated, and tired.
As a caregiver, you might:

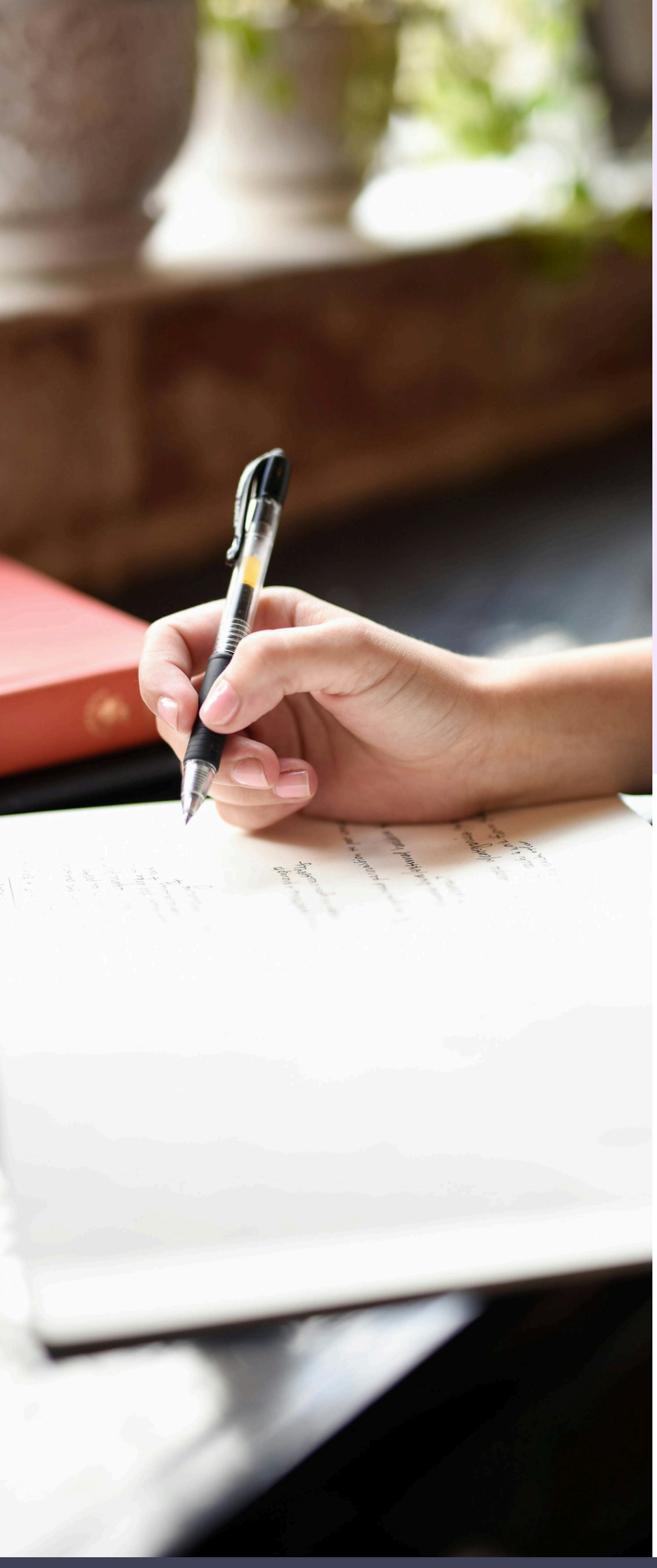
- Help with making decisions about treatment and finances.
- Drive your loved one to appointments.
- Assist with everyday activities like managing medications, preparing meals, or keeping track of symptoms.

During this time, you may want to do all you can to support your loved one. **Taking care of yourself is not selfish; it is essential.** Seek out the support that is helpful for you. This could be through a family member or friend or a professional such as a licensed therapist or social worker. If you are looking for peer support, consider joining a support group for CML caregivers. Talk with your care team about the support options available for you.

For more information on caregiving, visit **www.CancerSupportCommunity.org/Caregivers**.

QUESTIONS TO ASK YOUR DOCTOR ABOUT TREATMENT & YOUR GOALS

What are my treatment options?
What are the benefits and risks of each treatment option that is available for me? What side effects should I watch out for during, immediately after, and long-term during or after treatment?
Are there other treatments options that work just as well but would cost less money?
Will a stem cell transplant be needed? If so, will it use my own healthy cells (autologous) or cells from a donor (allogenic)?
How will we know if treatment is working? Is remission possible? What would that look like? Could I ever stop treatment?
Are there clinical trials that could help me?
Will my ability to have sex or have children change during treatment?
The symptoms and side effects that are bothering me the most are (see answers from above): • These side effects are affecting my daily life in these ways: • What can we do to manage these side effects?
Can my medication doses be adjusted and still be effective?
My top goals for treatment are (see answers from above):
Can I keep working or attending school during treatment?
How can I manage treatment costs? Is there a financial navigator I can speak with?
What can I do to stay active and feel better?
Is there a support group or social worker I can talk to about my experiences?
What resources or support groups are available for my loved ones/caregiver(s)?
Who can I talk to if I am feeling overwhelmed or depressed?



GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers). Make a list of things you need (childcare, meal prep, laundry, etc.) and who can help with each task. Ask your care team about resources for social, emotional, and practical support. Let them know about your concerns. If you search for information online, make sure that you are using trusted websites. Turn to the back page of this publication to see a list of trusted organizations. CSC and many of these organizations have helplines, online discussion boards, and more ways to seek support from others who have CML.

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. The cost of prescription medications to treat CML may make up a significant portion of your medical expenses. However, there are many resources to help cover these costs. Talk with your care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, financial navigator, or to a nonprofit organization for help managing the financial issues and costs.

To learn more about ways to manage the cost of treatment, visit: **www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment**

RESOURCES

CHRONIC MYELOID LEUKEMIA RESOURCES

Cancer Support Community
CSC-867-5309 (or outside the U.S., toll-free 888-793-9355)
www.CancerSupportCommunity.org/Chronic-Myeloid-Leukemia

Blood Cancer United
1-800-955-4572
BloodCancerUnited.org/Blood-Cancer/Leukemia/Chronic-Myeloid-Leukemia-CML

American Cancer Society
800-227-2345
www.Cancer.org/Cancer/Types/Chronic-Myeloid-Leukemia.html

FINANCIAL SUPPORT RESOURCES

Cancer Support Community
CSC-867-5309 (or outside the U.S., toll-free 888-793-9355)
www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment

Blood Cancer United - Financial Support
1-800-955-4572 | BloodCancerUnited.org/Finances

National CML Society
www.NationalCMLSociety.org/

Patient Advocate Foundation
1-800-532-5274 | www.PatientAdvocate.org/

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline at CSC-867-5309 (or outside the U.S., toll-free 888-793-9355), available in 200 languages.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more **www.CancerSupportCommunity.org/FindLocation**.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Chronic-Myeloid-Leukemia**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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