

Preparing for Your Doctor's Visit

A WORKSHEET FOR PEOPLE WITH CHRONIC MYELOID LEUKEMIA



If you have **Chronic Myeloid Leukemia (CML)**, complete this worksheet to help you talk with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

ASK YOUR DOCTOR

- Ask about side effects and which ones you need to know about and report to your team.
- Talk to your health care team about how you are feeling.
- Ask about ways to manage your side effects.
- Ask about any symptoms or concerns you have.
- Ask about the latest information from clinical trials.
- 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.

TIPS FOR TAKING CONTROL

- Take someone with you to appointments, for support and an extra set of eyes and ears.
- Talk to your health care team or financial navigator about ways to manage treatment costs.
- It is important to take your medicine as prescribed. Let your health care team know if you have missed doses of therapy. Also let them know if certain side effects are causing you to miss or skip doses.
- If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- 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.

Below are some of the things people with CML may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.

	Rarely	Sometimes	All the Time
Feeling very tired or issues with mobility			
Pain, joint pain, muscle aches, or cramps			
Difficulty thinking clearly or remembering			
Feeling anxious, overwhelmed, or depressed			
Issues with vision or eye bleeds			
Skin problems, rash, or fragile skin			
Nausea, diarrhea, vomiting, or mouth sores			
Weight loss or gain			
Loss of sexual desire or problems with intimacy			
Others:			

How often are cancer or 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, such a traveling			
Confidence/self-image			
Sleep			
Social relationships			
Sexual relationships			
Eating and/or exercise			
Others:			

SETTING GOALS FOR TREATMENT

When you talk to your doctor about your treatment options, ask what the goal is. Also, think about your own values and tell your doctor what is important to you. Your goals may change over time.

Physical Health and Well-being	<i>What do you want to be able to do?</i>
Family and Social Relationships	<i>What's going on in the lives of others that is important to you?</i>
Work/School	<i>Do you want to continue working? Can you adjust your schedule or responsibilities?</i>
Personal and Spiritual Growth	<i>How is your confidence and self-esteem? Are you able to do things you enjoy?</i>
Community/ Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Other	<i>What else is important to you?</i>

PREPARING FOR YOUR NEXT HEALTH CARE VISIT

1. If you are feeling either better or worse today than at your last appointment, let your health care team know.

2. Have you been taking medication as it has been prescribed?

Let your health care team know if you have missed doses.

3. Write down your questions before each doctor's visit. Below are some suggested questions.

Concentrate on the issues that are most important to you.

■ Can you explain my test results to me? _____

■ The symptoms and side effects that are affecting me the most are: [fill in your answers from page 1].

These are interfering with my life in these ways: [fill in your answers from the top of page 2]. _____

What can we do to manage these symptoms? _____

■ My top goals for treatment are: [fill in your answers from page 2]. _____

Is the treatment that I am currently on the best treatment for me to meet these goals? _____

■ What other treatments are available to me? Are there any new treatments or clinical trials that may be right for me? _____

■ How can I manage treatment costs? Is there a financial navigator that I can talk with? _____

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 health 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 listing 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 represent a significant portion of your medical expenses. However, there are many resources to help cover these costs. Talk with your health care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, financial counselor, 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/cost

CML Information & Support

Leukemia & Lymphoma Society • 914-949-5213 • www.lls.org

American Cancer Society • 800-227-2345 • www.cancer.org

American Society of Clinical Oncology (ASCO) • 703-299-0158 • www.cancer.net/CML

Financial Support Resources

Leukemia & Lymphoma Society • 914-949-5213 • www.lls.org/financial-support

National CML Society • 877-431-2573 • www.nationalcmlsociety.org/resources/assistance-programs

CancerCare • 800-813-4673 • www.cancercare.org/financial_assistance

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org/help.php

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org

Cancer Support Helpline®

Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

Open to Options®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org, or by contacting your local CSC or Gilda's Club providing this service.

Services at Local CSCs and Gilda's Clubs

Almost 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

The Living Room, Online

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

Cancer Experience Registry®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing, and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

For more information and additional resources, please visit the CSC Leukemia page at <http://www.CancerSupportCommunity.org/leukemia>.

Share your experience and make your voice heard. Join the Cancer Experience Registry and participate in the special community of people facing chronic myeloid leukemia at www.CancerExperienceRegistry.org.

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www.CancerSupportCommunity.org 1-888-793-9355

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