



Patient and physician portrayals

Community Perspectives on the Chronic Myeloid Leukemia (CML) Patient Experience

CML patient advocates and medical experts came together to discuss how to improve the CML experience, from prediagnosis to ongoing management. This is a summary of those discussions and suggestions for how HCPs and patients can partner to improve care and treatment.*

01. Before Diagnosis

Patients and care partners are often unprepared for a CML diagnosis. A referral to a specialist can cause concern, but if no one has mentioned the possibility of "cancer," being sent to a cancer treatment center can be a shock, making it more difficult to process information

Patient & Care Partner

- Write down your questions so you can get the information you need to determine next steps with your physician

Health Care Team

- Consider a longer discussion or a call to explain the specialist referral process and discuss their potential outcomes
- These initial interactions show the importance of open conversations and help build trust with patients

02. Diagnosis & Initial Treatment Plan

“I try to reduce the power of words like ‘cancer’ and ‘leukemia’ by explaining CML is a type we can treat and sometimes cure. We need to see and be talking with the patient more frequently at this stage to give them opportunities to ask questions and become informed.”

– **Christopher Benton, MD**
Rocky Mountain Cancer Center

Patient & Care Partner

- Take notes during your visit to better understand lab results and diagnosis
- Care partners should join visits and help take notes, asking questions during appointments for additional support
- Ask CML specialists for trusted resources to learn more about CML and treatment
- Ask providers about support groups and mental health resources

Health Care Team

- Meet people where they are by asking what they know already, and be sure to explain treatment goals and the care and communication plan
- Avoid rushing to make a treatment decision immediately upon diagnosis to allow time to discuss and consider appropriate options
- Ensure patients are active in the decision-making process and share how individuals can follow up post-appointments
- Provide resources that meet the needs of CML patients, and consider sharing information about CML community advocacy organizations, including:[†]
 - [CML Advocates Network](#)
 - [CML Buster Foundation](#)
 - [CancerCare](#)
 - [Cancer Support Community](#)
 - [Leukemia & Lymphoma Society](#)



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03. Starting Treatment

“We know that patient navigators and good care coordination help support patients. These supports also help reduce health inequities.”

– **Claire Saxton, MBA**
Cancer Support Community

“The physician has to be empathetic. I was told I had ‘the good cancer,’ and that was a punch in the gut. Sharing information can help establish a relationship based on understanding and trust. It helps calm the patient and helps them deal with their new situation.”

– **Joannie Clements, Living with CML**
CML Buster Foundation

Patient & Care Partner

- Use a journal to keep track of any potential side effects during treatment
- Continue to talk to your cancer care team throughout treatment about how you're feeling
- Engage with your support network while adjusting to new routines

Health Care Team

- Schedule frequent clinic visits to see how patients are adjusting to their new reality
- Ensure they feel fully educated on the treatment plan and address any of their questions
- Continue to ask about their emotional and mental health during treatment
- Suggest keeping a log to use during visits for more personalized care

04. Initial Monitoring & Ongoing Management

“Patients often don’t want to annoy us with questions, or we get complacent about asking how they’re really doing after the first 2-3 years of treatment. Both parties must be willing to have a dialogue.”

– **Ehab Atallah, MD**
Medical College of Wisconsin



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Patient & Care Partner

- Be honest with your care team about any missed doses and if side effects are affecting your daily life
- Be sure you clearly understand your lab results and any changes to your treatment from your care team before you leave the appointment
- Tell your care team how your treatment is fitting into your lifestyle, even after several years on the same treatment
- Ask your care partners for support when adjusting to new treatments and lifestyle changes

Health Care Team

- Continue to check in with patients over time, even after years of treatment to ensure they still feel supported
- Regularly ask them about any changes in tolerability, and discuss potential treatment updates so they are prepared if a switch becomes necessary
- If there is need for a change in treatment, ensure the patient is fully educated and part of the shared decision-making

*Content stems from CML Patient Advocate and Medical Expert Leadership Summit at ASCO, on May 30th 2024 attended by: Ehab Atallah, MD (Medical College of Wisconsin); Christopher Benton, MD (Rocky Mountain Cancer Centers); Jerry Clements (CML Network); Joannie Clements (CML Buster Foundation); Jorge Cortes, MD (Georgia Cancer Center); Marissa Fors, LCSW, OSW-C, CCM (Cancer Care); Thomas Leblanc, MD, MA (Duke University); Michael Mauro, MD (Memorial Sloan Kettering Cancer Center); Cristina Ruiz (CML Buster Foundation); Claire Saxton, MBA (Cancer Support Community); Stephen Strickland, MD (SCRI at TriStar Centennial) and Novartis employees. Patient Advocate and Medical Expert attendees were compensated for their participation by Novartis Pharmaceuticals Corporation.

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