

Terms to Know For Empowered Care

Health Literacy: Understanding your disease and treatment options helps you make informed decisions.

Shared Decision-Making (SDM): A collaborative process where you and your care team make treatment decisions together, based on your goals and values.

Patient Empowerment: not a one-time event, but a continuous practice of learning, asking, and engaging in your care.

Understanding Your AML Diagnosis

- Ask your care team to explain your AML subtype and prognosis.
- Request genetic sequencing of your leukemia cells. This helps identify targeted treatment options. Ask, "Have all the necessary genetic tests been done to guide my treatment options?" Even if results take 2–3 weeks, waiting for molecular data can lead to better-informed treatment choices.
- Know the difference between acquired mutations (in cancer cells) and inherited mutations (germline).
- Share your full medical history, including prior cancer treatments and family cancer history.

Access Targeted Therapies & Clinical Trials

- Clinical trial criteria may unintentionally exclude some populations, but don't assume, ask, "Are there any clinical trials or targeted therapies I should consider for my AML subtype?" Don't hesitate to seek a second opinion from an AML specialist.
- Trials are increasingly flexible: shared care models allow local testing and remote participation.
- Organizations like Blood Cancer United (formerly Leukemia and Lymphoma Society) offer free trial-matching services.
- Targeted therapies depend on knowing your leukemia's genetic profile. Testing is key. [Source](#)

Supporting Your Emotional & Mental Health

- Share emotional struggles with your oncologist early on. They can help with these struggles before they escalate, so don't wait to speak up. Ask, "What mental health or emotional support services are available for me and my family?" so they can connect you to resources.
- Normalize life during treatment: bring hobbies, music, or creative outlets into your care space.
- Adolescent and young adult (AYA) patients may benefit from age-specific support teams.
- Caregivers need support too; ask about resources for family mental health and stress management.

Navigating Logistics & Social Support

- Be transparent about social barriers: childcare, work, housing, insurance, immigration.
- Ask your care team, "Can we review what support services are available to help me complete treatment successfully?"
 - Your circumstances shape your care plan so be sure to make them known.
- Engage with social determinants surveys honestly because they unlock access to grants and support.
- Ask about FMLA (Family and Medical Leave Act), disability, transportation, home health services, and insurance coverage.
- If you are a caregiver, explore all available resources early. Don't wait until it's overwhelming. [Source](#)

[ACT]IVATED is brought to you by the Patient Empowerment Network. Funding is made possible through support from AbbVie and generous donations from people like you.