



10 Tips for Living Well with Acute Myeloid Leukemia

❶ TAKE ONE STEP AT A TIME AND MAKE ONE DECISION AT A TIME

Life with Acute Myeloid Leukemia (AML) can feel overwhelming. Yet, with small steps you can find your best path. Learn about AML by talking with doctors and patient navigators. Reach out to AML organizations. Don't trust everything you read online. Ask all your questions. In time, you can collect the information and support you need to make good financial, medical, and personal decisions.

❷ FIND A HEALTH CARE TEAM YOU TRUST

AML is an aggressive or fast-growing cancer. It is important to find a knowledgeable health care team that knows the most up-to-date care. It is important to find a doctor who is experienced in diagnosing and treating AML. The short-term goal of treatment is complete remission (CR). This means that most of the cancer is gone from your blood or bone marrow. The long-term goal is to cure AML, meaning that your cancer will not return. Some types of AML are easier to cure, while others are more difficult. Talk with your doctor about the goals of any recommended treatment options.

The main types of treatment include clinical trials, chemotherapy, targeted therapy, and stem cell transplant. Trust comes from being able to talk openly with your health care team and believing they can help. Ask about clinical trials that might be right for you. Treat finding a health care team like an interview to find the best experts for the job. If you don't feel your health care team is addressing your concerns, consider getting a second opinion. Don't worry about hurt feelings! Your team should help you care for your mind, body, and spirit.

❸ USE A NOTEBOOK TO KEEP TRACK OF YOUR DIAGNOSIS, SYMPTOMS, ANSWERS TO QUESTIONS, AND NEXT STEPS

Be sure to write down any symptoms you may experience. Coping with the side effects of treatment can be one of the hardest parts of cancer. AML patients who are being treated with high-dose chemotherapy may experience physical symptoms such as hair loss, mouth sores, and digestive problems. Treatment can also result in long-term side effects that may not show up for years after treatment. Make sure that you talk with your health care team. Take notes or ask someone to help you take notes during appointments.

Write down any questions, concerns, or needs you would like the doctor to address during the appointment. You may hear new words to describe AML. Ask your doctor to spell them out and define them. Write down this information and go back to it as needed.

④ ACCEPT HELP WHEN IT IS OFFERED

Day-to-day life and tasks can become harder. Ask others for the help you want and need. Often, your friends and family will feel good offering assistance. An online scheduler can help you and your loved ones stay organized and informed. **MyLifeLine.org** is a tool that can help you stay organized and connect your friends and family to any help you may need.

⑤ REACH OUT TO OTHER PEOPLE WITH AML

It's comforting to talk with others who understand what you're going through. People with AML can also be a good source of knowledge. You and your loved ones don't have to feel lonely, helpless, confused, or hopeless. You can connect with others through the internet or a local support group. To find an in-person location near you for support, go to www.CancerSupportCommunity.org/FindLocation.

⑥ SEEK SUPPORT FROM A PATIENT ADVOCATE

A trained advocate can help you navigate through many parts of the cancer journey. They can help manage insurance issues, find resources, and help with legal documents such as your will, medical directives, and estate plans. Many cancer centers offer, or can refer you to, a skilled advocate or patient navigator.

⑦ LEARN TO RELAX AND FIND A NEW PERSPECTIVE

An AML diagnosis is life changing. Be aware of your feelings and how you handle them. You can calm yourself with deep breathing, journaling, exercise, or creative activities. Having someone to talk to can affect how you look at things. Talking with a counselor or a therapist can help you cope with anxiety and depression. This can help you find or maintain the energy you need to get through treatment and take the best possible care of yourself.

⑧ FIND WAYS TO FEEL IN CHARGE OF YOUR LIFE

At times you may feel frustrated by changes to your work, school, and family life. Take action. Work with your health care team to come up with a plan that gives you as much control as possible over your treatment and care.





⑨ FOCUS ON NUTRITION AND EXERCISE

Every small step you take to eat better, get more exercise, and find more humor in life can make you feel better. Eating well will give you more energy and nutrients to help your body. You may feel tired but try to find times when you have energy to be active. Physical activity can lift your spirits, boost your energy, and reduce stress. Even when you feel tired, you can set reachable goals for healthy eating and physical activity (example: a 10-minute walk).

⑩ REMEMBER THAT HOPE IS POSSIBLE

It may help to focus on family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, hope can still make each new day better in some way. Plan to do something that makes you smile. Accept that some days will be better than others, but you can continue to enjoy the small, special moments.



AML INFORMATION, SURVIVORSHIP & SUPPORT

Cancer Support Community · 888-793-9355 · www.CancerSupportCommunity.org/AML

American Cancer Society · 800-227-2345 · www.cancer.org/cancer/acute-myeloid-leukemia

Be The Match · 800-627-7692 · www.bethematch.org

BMT Infonet · 888-597-7674 · www.bmtinfonet.org

Leukemia & Lymphoma Society · 800-955-4572 · www.lls.org/AML

Leukemia & Lymphoma Society First Connection Program · 800-955-4572 · www.lls.org/firstconnection

CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-8pm ET and Sat 9am-5pm ET.

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 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. 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 private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up 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.

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/AML. For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

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