

FRANKLY SPEAKING

ABOUT CANCER

Acute Myeloid Leukemia



If you or a loved one has acute myeloid leukemia, or AML, you may be feeling overwhelmed. You may be reeling from how fast everything is happening. You will have a lot of information to process. You may have to make quick decisions about your treatment. You may even have to check into a hospital right away. It helps to know what to expect. This booklet gives an overview of AML diagnosis,

treatment, and strategies for how to cope. We hope this will help you learn more about your options, know what questions to ask, and start to feel empowered to take control of your life.



CANCER SUPPORT
COMMUNITY



Coping with AML

Living through AML diagnosis and treatment can be difficult. Treatment often begins suddenly, even though you might have felt fine or thought you had a minor illness.

You may need to be in a hospital for long periods of time. Treatment may require you to stay away from crowds or public places because your immune system is weakened. You may feel isolated because you can't go to work, school, the grocery store, or do activities you enjoy. People with AML often

say that they feel like the illness has taken over their life very suddenly with no time to prepare.

AML can also be difficult for loved ones who are helping as caregivers. For caregiver resources, visit www.CancerSupportCommunity.org/Caregivers.

Here are some coping strategies recommended by survivors and health care providers.

PREPARING FOR IN-HOSPITAL TREATMENT

Talk through your choices with your family, friends, and health care team. They can help you think about the pros and cons of different treatments. Ask how likely it is for the treatment to work. Also:

- Consider travel arrangements if the nearest treatment center is far away, or if you decide to join a clinical trial.
- Anticipate long stays in the hospital, for weeks to months. A hospital social worker or financial counselor can aid you in researching and coordinating insurance, travel, and housing.
- Often patients with AML will not be able to work during treatment. Talk to your hospital social worker and workplace Human Resources right away about how to apply for short- and long-term disability benefits. It can take up to six months for long-term benefits to begin.
- Start thinking about how friends and family can help. You can expect to need six to nine months of help with household tasks, cooking, cleaning, errands, rides, childcare, financial support, etc.

WHILE IN THE HOSPITAL

Once you are in the hospital, your full-time job is getting healthier. You will need help from your treatment team, social workers, friends, family, and the community.

ASK FOR RESOURCES



Ask to talk to a social worker or patient advocate. Ask what resources are available at the hospital and local community for support.

EXPAND YOUR HEALTH CARE TEAM



Expand your health care team to include useful specialists such as: a nutritionist, a psychologist or therapist, a physical therapist, a palliative care specialist, and a financial advisor to plan for costs. Ask who to talk to and how to contact them about any issues or side effects. If stem cell transplant is a next step, connect with a transplant team.

GETTING SUPPORT



If you are trying to run your household or work from your hospital bed, you are not focusing on your full-time job of getting healthier. Instead, ask for the specific support you need from friends and loved ones. Accept help when it is offered. Consider using an online scheduler, such as www.MyLifeLine.org, to get the help you need.

REACH OUT



Reach out to others with AML. It can help to find people who understand what you are going through. For accurate information on the internet, seek out chat rooms that are monitored by professionals. (See the list of AML resources on the back page.)

STAYING CONNECTED



Find ways to stay involved with your community. For example, your place of worship may offer podcasts or live-streaming of services. They may also offer visits from parishioners or clergy.

AFTER YOU ARE HOME FROM THE HOSPITAL

When you are home, or if you are staying near your treatment center on an out-patient basis, you may continue to feel isolated because you will likely be required to stay away from crowds and public spaces.

.....

1 STAY CONNECTED You likely won't be able to go out in public for a while. Find ways to keep in contact with those you care about through phone calls or internet chats.

2 ASK ABOUT PATIENT HOUSING Ask your social worker about patient housing for you and your caregiver, transportation and meal services, in-home health aides, and other options to help you manage outside the hospital.

3 TAKE CARE OF YOUR BODY Talk with your health care team about nutrition and exercise. Focus on eating well and staying active. If you smoke, try to stop.

4 SEEK OUT LOCAL RESOURCES such as those offered by CSC's and Gilda's Clubs, who may have blood cancer support groups. See the back page for more resources.

5 GET HELP IF YOU NEED If you feel sad or depressed, talk with your health care team and seek medical help. Know who to contact on your care team during and after hours, if you have problems.

6 BE AN ACTIVE PARTNER IN YOUR TREATMENT You can prepare for your medical visits by using our "Preparing for Your Doctor's Visit" worksheet, available at www.CancerSupportCommunity.org/AML.

7 KEEP TRACK OF YOUR SYMPTOMS and ask questions. Let your health care team know if you have any new symptoms.

What is AML?

AML begins in the bone marrow, the soft inner part of certain bones, where new blood cells are made. Changes happen in some of these cells that make them grow out of control. AML usually grows and moves into the blood quickly.

There isn't a known cause for most cases of AML, but research has shown that some things may increase your risk. These risk factors include: exposure to certain chemicals (such as benzene), smoking, and some genetic disorders or family history of leukemia. AML is sometimes a secondary cancer caused by radiation or chemotherapy for other cancers.

Diagnosis and Subtyping

Your health care team will run tests to learn as much as they can about the leukemia. This process is called diagnosis and subtyping.

Diagnosis = Do you have AML?

Subtyping = Does the AML have any special markers that will help doctors decide which treatment might work best for you?

GETTING A DIAGNOSIS

If your doctor suspects AML, they will order tests, including:

- Blood tests—specialized test to determine how many white blood cells you have and to see if these cells look abnormal. For information on normal results for

TALKING ABOUT AML

You will hear many words used to describe AML. Some key ones to know are:

ACUTE: Develops quickly. If not treated immediately, will progress rapidly and likely be fatal.

BLASTS: Short for “myeloblasts.” These are the immature blood-forming cells that normally appear in bone marrow. AML occurs when a blast is “stuck” in its immature state and multiplies.

LEUKEMIA: A cancer of the blood cells, which grow out of control and crowd out healthy cells.

MYELOID: Describes the type of cells that would normally turn into more specific, mature kinds of white blood cells, red blood cells, or platelets.

RELAPSE/RECURRENCE: When leukemia reappears in the marrow after treatment.

See the following page for additional information on types of blood cells.

TYPES OF BLOOD CELLS

RED BLOOD CELLS (also called RBCs and erythrocytes) contain the protein hemoglobin, which carries oxygen from the lungs to the rest of the body. Having low red blood cells is called anemia.

PLATELETS (also called thrombocytes) help form blood clots to slow or stop bleeding and to help wounds heal. Having low platelets is called thrombocytopenia (*THROM-boh-sy-toh-PEE-nee-uh*). This makes it hard for your blood to clot and easy to develop bleeding and bruising.

WHITE BLOOD CELLS (also called WBCs and leukocytes) are part of the body's immune system. They help the body fight infection and other disease. Having low white blood cells is called leukopenia (*LOO-koh-PEE-nee-uh*) and makes it hard for your body to fight off infection.

COMPLETE BLOOD COUNT (CBC) is a blood test that measures the number of different types of blood cells in a sample of your blood.

Complete Blood Count (CBC) tests, visit www.CancerSupportCommunity.org/CBC.

- Bone marrow biopsy/aspiration — These tests take both solid and liquid portions of the marrow, usually from the pelvis. If 20 percent of the cells in the bone marrow are immature “blast” cells, the diagnosis is usually AML. In normal bone marrow, the blast count is 5 percent or less.

FINDING YOUR SUBTYPE USING BIOMARKER TESTS

Biomarker tests can be used to diagnose the specific subtype of AML you have, if any. The results can help your doctors decide which treatments may work best against your specific type of AML. The three main types of tests that look at changes (“mutations”) in the cancer's genes are:

- Cytogenetics (also called chromosome tests)
- Fluorescence in situ hybridization (FISH)
- Other molecular/genomic tests, such as:
 - polymerase chain reaction (PCR)
 - DNA sequencing and microarray technologies
 - next generation sequencing - looks for a number of specific genetic changes to the cancer cells at once

Your doctors use these tests to look for mutations in the AML cells (changes in the cancer cell's DNA). Nearly two-thirds of people with AML have these changes.

Biomarkers that can help your doctors decide your AML treatment include:

- FLT3 (pronounced “flit3”)
- IDH1 and IDH2
- p53 (TP53)
- NPM1
- CEBPA

Ask your doctor if you have been tested for these and other, newer biomarkers that may help decide which treatment is best for you.

SUBTYPES

AML is not just one disease. It is a set of diseases that are divided into subtypes. This information helps doctors to estimate how the disease will progress and what treatment will work best. Your doctor should tell you which subtype you have and which treatment is recommended.

Treatment Planning

After you find out you have AML, your doctor will tell you which treatments are best for you. Your doctor may ask you what you want to do. This is called **Treatment Planning**. Due to the acute nature of AML, treatment may start as soon as you are diagnosed. There are often more treatment choices to be made after your first treatment is finished. For example, once you are in remission, you may have the option to get a stem cell transplant.

TREATMENT RECOMENDATIONS

Some of the factors that help your doctor and health team decide what treatment to recommend include:

.....



Your values, goals, and preferences



Your age



Your medical history



Your overall health



The subtype of AML you have

TIPS FOR TREATMENT PLANNING:

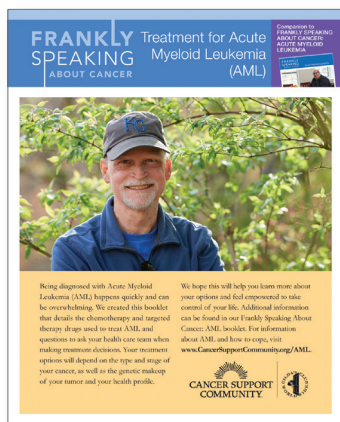
- Ask questions. Your health care team will give you a lot of information in a short amount of time. Listen closely and ask questions until you understand what is being said. Write down as much as possible. Bring a friend or relative to take notes, or request a patient navigator or social worker, if available.
- Feel free to ask follow-up questions after appointments by email or through your hospital's patient portal. Ask who you can contact with questions and concerns. This may be your doctor, a nurse practitioner, or fellow/resident.
- Communicate with your health care team. Report any side effects or symptoms you experience.

- Use a notebook to keep track of side effects, take notes when talking with your health care team, track appointments and treatments, and keep financial and insurance details. A detailed medical record will help you apply for disability claims.

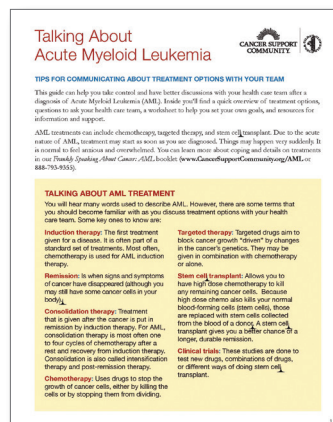
GETTING A "SECOND OPINION"

Since AML usually grows quickly, treatment often begins as soon as possible after diagnosis. However, a second opinion can give you more information and help you feel more confident about your treatment specialists, but you may have to ask. AML is an uncommon disease, so it is best to be treated by a doctor who specializes in treating patients with blood cancers.

You can learn more about treatments in our *Frankly Speaking About Cancer: Treatment for Acute Myeloid Leukemia (AML)* booklet.



To improve communication with your cancer care team, use our *Talking About Acute Myeloid Leukemia* booklet.



To download or order these materials, visit www.CancerSupportCommunity.org/AML or call our Helpline at 888-793-9355.



QUESTIONS FOR TREATMENT PLANNING

To help you through the whirlwind of information, decisions, and life adjustments of an AML diagnosis, it helps to have specific questions answered at each stage.

- What subtype do I have?
- Does my cancer test positive for any biomarkers that help make treatment decisions, such as FLT3, TP53, IDH1, IDH2, NPM1, and CEBPA?
- What are my different treatment options?
- Are there any clinical trials that would be right for me? How do I find out more about them?
- Am I healthy enough for high-dose chemotherapy?
- Should I be thinking about a stem cell transplant? If so, when will the Transplant Team start looking for a donor?
- Can my leukemia be cured? What would a “cure” look like for me?
- What treatment do you recommend for me, and why?
- What are the risks of this treatment? What are the benefits?
- What are the side effects (short and long term)? What can I do to prepare for them?
- Do I need to go to an academic medical center for my treatment?
- How long will I be in the hospital?
- Do I need to go get dental work done before beginning treatment?
- How will treatment affect my everyday life? Will I need to miss work/school?
- How much will this treatment cost? Will it be covered by my insurance? Is there a social worker or financial counselor that I could meet with?
- How do I apply for disability?

Questions for you to think about and tell your health care team

- What are my goals for my treatment?
- What is most important to me right now?



QUESTIONS FOR TREATMENT PLANNING (Continued)

- What am I willing to go through to achieve my goals?
- What am I worried about?

Questions During Treatment (these will vary depending on whether you have high-dose chemotherapy in a hospital, low-dose in a clinic or supportive care only):

- What side effects should I be looking for? When do I need to contact my medical team?
- Whom should I call if I have questions or problems during office hours? After hours and weekends?
- How long will I receive this treatment? How much time will each treatment session take?
- How do we know if I am in remission? When does this happen?

Questions When Heading Home from the Hospital or Finishing Treatment

- After I leave the hospital, will I need to come back for additional treatment?
- How often will I come in for future appointments? How much time will I need for these?
- How do I find out more about what foods to avoid, how to increase appetite, etc.? Is there a nutritionist that I can meet with?
- What activities do I need to avoid? Should I exercise or not? Can I drive?
- What do I need to do to avoid infection? Avoid crowds? People with illnesses? Can I play with my pets and/or kids? Can I work in my garden? Can I have dental work done?
- When can I go back to work/school?
- How do I find a therapist?
- How do I find a caregiver or support at home? Are there support services for caregivers?
- How do I find supportive online communities?

Treatment for AML

AML is an aggressive cancer. If possible, you should have your treatments at a major cancer center or university hospital to find the most up-to-date care.

Usually, the first goal of treatment is to get the patient into complete remission (CR). This means that most of the AML has been eliminated from the patient's blood or bone marrow. The long-term goal is to cure the disease. A cure means that the cancer will never return. This can be difficult to determine, because AML can return after many years. A complete remission (CR) is the first step towards a possible cure.

The main types of treatment for AML are:

- Clinical trials
- Chemotherapy
- Targeted therapy
- Stem cell transplant

CLINICAL TRIALS

To learn more about AML treatment, download or order our *Frankly Speaking About Cancer: Treatment for AML* booklet at www.CancerSupportCommunity.org/AML.

Researchers are finding new ways to treat AML. This means that the rates of cure are improving. Still, much more research is needed to fully understand the disease and how best to treat it. A clinical trial may be the only way to get certain treatments, including some that are very promising.

KEY THINGS TO KNOW:

- Clinical trials for AML are done to test new drugs, combinations of drugs, or different ways of doing stem cell transplant.
- A doctor experienced in treating AML should be able to recommend specific trials.
- The U.S. Food and Drug Administration and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Most often, the trial pays the costs of the drug being studied. Then your health insurance and your copay cover “standard” treatment costs. Be sure to ask what costs you may incur.

See the resources on the back page for help finding clinical trials that might be right for you.

CHEMOTHERAPY

Induction

Most people with AML will receive chemotherapy treatment. The first phase of chemotherapy is induction therapy. It will usually begin right away.

The goal of induction therapy is to bring on (“induce”) a complete remission (CR). This means:

- you have less than 5 percent blast cells in your bone marrow,
- your blood counts have returned to normal (or mostly normal), and
- you have no signs or symptoms of AML.

Getting to a complete remission can take three to six weeks. Partial remission (PR) is when cancerous cells are reduced but still detectable.

There are several chemotherapy drugs that may be used to treat AML. Two or more of these drugs are usually combined at a time. These drugs are given through an IV (into a vein) at the hospital. Younger patients can sometimes receive higher doses of these drugs than older patients can.

Low-dose Treatment

Some people may not be able to have the standard therapy due to other serious health conditions and increased risk from intensive therapy. Others choose not to receive intensive therapy because of the required time in the hospital or the serious side effects and risks. For these people, less intensive chemotherapy drugs may be used. Low-dose



treatment may also be used when the AML has a p53 mutation.

Consolidation or Postremission

Nearly all patients in complete remission after induction would relapse if they did not have further treatment. For this reason, it is usually followed by one to four more cycles of chemotherapy, called consolidation (postremission) therapy. This uses a variety of drugs, usually given in the hospital. However, most of your recovery time can be spent at home. Sometimes a stem cell transplant is used as post-remission therapy.

Maintenance/Continuing Therapy

Once you reach CR, your care team may use maintenance/continuing therapy to prolong AML remission. Most often it uses a drug given as a pill at home. People on maintenance therapy tend to have lower blood counts.

SIDE EFFECTS OF CHEMOTHERAPY

Even when you are getting better, cancer treatment for AML can make you feel worse. Coping with the side effects of treatment can

be one of the hardest parts of cancer. It helps to talk with your health care team about your side effects and how you are feeling. There are many remedies available for side effects.

With high-dose chemotherapy (induction), patients often experience severe side effects. You may have physical symptoms, such as hair loss, mouth sores, and digestive problems. You may have low blood cell counts. This could be low red blood cells (anemia) or low white blood cell count (leukopenia). Both can be treated.

Most patients receiving induction chemotherapy require frequent transfusions for a few weeks in the hospital. Fevers and infections can also occur during the hospital stay that require IV antibiotics.

Chemotherapy for AML can also have long-term side effects that last for months or years. It may also cause “late effects” that may not show up until years after treatment ends. To manage any of these effects you may have, it is critical to see your doctor for follow-up care.

Low-dose chemotherapies and consolidation therapy have less significant side effects.

TARGETED THERAPY

Targeted therapy may be an option for some patients at different points of their treatment. Some targeted therapies are used only based on the findings of biomarker tests, including genetic testing of your cancer cells. Others are helpful for most cases of AML, and do not require specific testing. Targeted drugs aim to block cancer growth “driven” by changes in the cancer’s genetics.

AML targets that have therapies currently are: FLT3 mutations, IDH1 or IDH2 mutations, Hedgehog signaling pathway, and proteins called BCL-2 and CD33. For some of these drugs you need to be tested for the target. Ask your health care team if you have been tested for all the targets that have current therapies, including FLT3, IDH1 or IDH2.



“If I could go back in time, the one thing I would have done is more research on what a stem cell transplant entails. It wouldn’t have changed what I did, but it would have given me more information on what was to follow and what to expect.”

—Peter, acute myeloid leukemia patient

SIDE EFFECTS OF TARGETED THERAPY

Each targeted therapy can cause different side effects. Some of them can be very serious. The most common ones are: fatigue, nausea, vomiting, fever, diarrhea, respiratory infections, low blood counts, and mouth sores. Your health care team should monitor you closely for side effects. There are drugs that may prevent or reduce these side effects.

STEM CELL TRANSPLANT (SCT)

Your health care team may recommend a stem cell transplant (SCT). This treatment allows you to have high dose chemotherapy to kill any remaining cancerous cells. Because high dose chemo also kills your normal blood-forming cells (stem cells), those are replaced with stem cells collected from the blood of a donor. Bone marrow transplant (BMT) is similar, but the donor's stem cells are collected from their bone marrow.

This process works best if only small amounts of leukemia remain. That's why it often isn't used as a first treatment. It is most often used after you have achieved remission, when your doctor thinks there's a good chance the AML will come back. For patients healthy enough, a stem cell transplant can offer a chance for a much longer or permanent remission than chemotherapy alone.

If your doctor thinks a stem cell transplant may work for you after induction therapy, it is important to start a search as soon as possible to identify a matching donor. You will work with a new team—a transplant team—to find a donor and coordinate the transplant.

For more detailed information about stem cell transplant and its side effects, visit www.CancerSupportCommunity.org/SCT.

REFRACTORY & RELAPSED LEUKEMIA

If the AML is still present after you finish standard therapy (refractory leukemia) or it has returned (relapsed), you may be treated again. Different drugs or stem cell transplantation may be used. There are several targeted therapies that are approved for patients with refractory or relapsed AML.

Palliative (Supportive) Care

Palliative care (also called supportive care) focuses on providing patients with relief from symptoms, pain, and stress of a cancer diagnosis. Palliative care may be available to patients at any point in their treatment.

Palliative care is not the same as hospice, which focuses on supportive care in the final days, weeks, or months. Ask your health care team if there is someone who specializes in palliative care on your team.

Palliative treatments for AML include:

- Drugs to help with symptoms such as pain or nausea
- Blood transfusions that help relieve fatigue
- Medications to prevent and treat infections
- Nutritional counseling
- Physical therapy
- Exercise coaching
- Mental health services



Jen's Story

Diagnosis and Fear

Jen had been sick for weeks before her diagnosis with AML at age 38. Her white blood cell count got so low that her doctor had an ambulance take her to a cancer center where she was admitted for what became a 30-day stay.

In the ambulance, Jen still didn't completely understand what was going on. "My darkest night was that first night in the hospital. It took me by surprise. I didn't have any prior experience with cancer. It was terrifying."

Her leukemia responded to chemo, but her remission was brief. Jen had spent her months in remission worrying about relapse. "I was waiting for the other shoe to drop. When I relapsed, I was devastated but also relieved. The shoe had dropped and now we could deal with it."

Jen offers this advice to others who are diagnosed with AML: "You really do need to trust the process. The days are dark, and it's scary. But trust the process and learn from it. There are beautiful things happening, and it's up to you as the patient to see that."

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

Cancer.net • 888-651-3038 • www.cancer.net/AML

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

National Cancer Institute's Clinical Trials Information • 800-422-6237 • www.cancer.gov/clinicaltrials

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

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.

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

MyLifeLine — CSC's private, online community platform allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. You can also connect with other people facing cancer by joining the Living With AML online discussion board. Sign up at www.MyLifeLine.org.

Open to Options® — Need help making a cancer treatment decision? 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.

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.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.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/policy-advocacy/become-advocate.

FRANKLY SPEAKING ABOUT CANCER: ACUTE MYELOID LEUKEMIA WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



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

© March 2021 Cancer Support Community. All rights reserved. Photographs by Ed Cunicelli.