

**FREE** take one

3rd Edition

# ACUTE MYELOID LEUKEMIA

*A treatment guide for  
patients and their families*



**FLIP  
OVER!**

For guide to  
**MYELOFIBROSIS**

  
**CONTENT  
REVIEWED BY  
A DISTINGUISHED  
MEDICAL  
ADVISORY  
BOARD**

# Join the search for potential, new post-transplant acute myeloid leukemia (AML) maintenance therapy

Help researchers determine if they can help extend the time post-transplant patients with AML stay in remission

If you have been diagnosed with AML and are planning to have a transplant or have just had a transplant, you may qualify for the VIALE-T clinical research study.

**You, your child, or someone you know may be able to participate if you or they meet the following requirements:**

- At least 12 years old
- Diagnosed with AML
- Planning to have an allogeneic stem cell transplant (SCT) or have had one in the past 45 days

The treatment being studied in the clinic with patients with AML is not approved for use by regulatory health authorities. Safety and efficacy are under evaluation.



## Viale-t

There are other requirements to participate.  
To find out more about VIALE-T, visit

[https:// www.AML-VialeStudy.com](https://www.AML-VialeStudy.com)

ClinicalTrials.gov Identifier: NCT04161885  
EudraCT Number: 2019-002621-30  
M19-063\_Patient Resource Guide Ad\_12Sep2022\_V1.0\_US





3rd Edition

# ACUTE MYELOID LEUKEMIA



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# Understanding your diagnosis helps guide the path forward

**P**eople whose lives are affected by acute myeloid leukemia (AML), an aggressive hematologic (blood) cancer, have reason to be optimistic about the future. Advances in the last decade have led to several new treatment approvals by the U.S. Food and Drug Administration (FDA). Immense effort toward understanding specific chromosome changes and molecular alterations, and the development of therapies and treatment combinations targeting these abnormalities, have fueled the progress.

AML is a rare disorder. Depending on the unique characteristics of your diagnosis, you may have to make treatment decisions quickly. To ensure you feel informed, consult with an AML specialist or a cancer center known for treating it. You will benefit from their experience. If a specialist is not nearby and traveling for treatment is not an option, look for one who will provide a second opinion and/or consult with your doctor. A second opinion can confirm the diagnosis, prognosis and suggested treatment plan or add other information to consider.

## ABOUT AML

AML is a type of leukemia that begins in early myeloid cells, which normally mature to become white blood cells (with the exception of lymphocytes), red blood cells or platelets. Instead of developing into these normal blood elements, they grow uncontrollably, creating an excess of abnormal myeloid cells that crowd out healthy blood-forming cells in the bone marrow. The few healthy blood-forming cells cannot keep up, resulting in low numbers of healthy white blood cells, red blood cells and platelets. This increases the risk for infection, anemia and excessive bruising and/or bleeding.

The “acute” in AML means it grows quickly. Other forms of leukemia are categorized as “chronic,” which means slow growing. AML is sometimes referred to as acute myeloid, myelocytic or myeloblastic leukemia and is described as untreated, in remission or recurrent.

## DIAGNOSING AML

Your doctor will order tests to diagnose your condition and recommend the best treatment plan. You may have blood tests, bone marrow aspiration and biopsy, a lumbar puncture and/or imaging tests. Specialized tests, such as flow cytometry, fluorescence in situ hybridization (FISH), next-generation sequencing and reverse transcription-polymerase chain reaction (RT-PCR), will likely be used to identify the proteins, chromosomes, genes and other factors involved in leukemia, as well as determine the subtype.

Your doctor will refer to the World Health Organization (WHO) Classification System (see Table 1). It classifies AML into subtypes based on the appearance of the leukemia cells under a microscope, as well as the presence or absence of certain chromosome (cytogenetic) abnormalities and/or molecular (genetic) mutations found in the leukemia cells. This distinction is important because each subtype has specific symptoms and can behave differently after treatment.

These abnormalities can be numerical or structural. A numerical abnormality is when a different number of chromosomes in the cells than is normal is present. For example, instead of the typical 46 chromosomes in each cell of the body, there may be 45 or 47 chromosomes. A structural abnormality means the chromosome’s structure has been altered in one of several ways.

Some of the molecular genetic changes linked to AML include *ASXL1*, *CEBP alpha*, *FLT3*, *IDH1*, *IDH2*, *NPM1*, *RUNX1* and

## TABLE 1 WHO CLASSIFICATION SYSTEM

### AML with recurrent genetic abnormalities

Subtypes:

- Acute promyelocytic leukemia with *PML::RARA* fusion
- Acute myeloid leukemia with *RUNX1::RUNX1T1* fusion
- Acute myeloid leukemia with *CBFB::MYH11* fusion
- Acute myeloid leukemia with *DEK::NUP214* fusion
- Acute myeloid leukemia with *RBM15::MRTFA* fusion
- Acute myeloid leukemia with *BCR::ABL1* fusion
- Acute myeloid leukemia with *KMT2A* rearrangement
- Acute myeloid leukemia with *MECOM* rearrangement
- Acute myeloid leukemia with *NUP98* rearrangement
- Acute myeloid leukemia with *NPM1* mutation
- Acute myeloid leukemia with *CEBPA* mutation
- Acute myeloid leukemia with other defined genetic alterations

### AML with myelodysplasia-related changes

#### Therapy-related myeloid neoplasms

### AML not otherwise specified

(includes cases that do not fall into any other group; similar to the FAB classification system)

Subtypes:

- AML with minimal differentiation (M0)
- AML without maturation (M1)
- AML with maturation (M2)
- Acute myelomonocytic leukemia (M4)
- Acute monoblastic/monocytic leukemia (M5)
- Pure erythroid leukemia (M6)
- Acute megakaryoblastic leukemia (M7)
- Acute basophilic leukemia
- Acute panmyelosis with myelofibrosis

### Myeloid sarcoma

**Undifferentiated or biphenotypic acute leukemias** (leukemias that have both lymphocytic and myeloid features; also called ALL with myeloid markers, AML with lymphoid markers, or mixed lineage leukemia)

*Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.*

*TP53* (see Table 1 for additional mutations). Targeted therapies are approved to treat certain AML genetic mutations. Not all genetic mutations are always present during diagnostic testing, so your doctor will likely retest if the disease relapses (returns).

Certain genetic mutations are associated with a better prognosis than others. Some mutations respond better to certain types and dosages of drug therapy. Still others may influence the timing of, or need for, a stem cell transplant. ■

## ACUTE MYELOID LEUKEMIA SUPPORT RESOURCES

- ▶ **Alex’s Lemonade Stand Foundation for Childhood Cancer:** [www.alexlemonade.org/cancer-research-category/leukemia-aml](http://www.alexlemonade.org/cancer-research-category/leukemia-aml), 866-333-1213
- ▶ **American Society of Hematology:** [www.hematology.org](http://www.hematology.org)
- ▶ **The Angiogenesis Foundation:** [www.angio.org/about-angiogenesis](http://www.angio.org/about-angiogenesis)
- ▶ **Asian American Donor Program:** [www.aadp.org](http://www.aadp.org)
- ▶ **Be The Match:** [www.bethematch.org](http://www.bethematch.org)
- ▶ **Blood & Marrow Transplant Information Network:** [www.bmtinfonet.org](http://www.bmtinfonet.org)
- ▶ **Cancer Support Community:** [www.cancersupportcommunity.org/acute-myeloid-leukemia](http://www.cancersupportcommunity.org/acute-myeloid-leukemia)
- ▶ **HEADstrong Foundation:** [www.headstrong.org](http://www.headstrong.org)
- ▶ **The Leukemia & Lymphoma Society:** [www.lls.org](http://www.lls.org)

**Kathleen Packard, 58, resolved to be in control of her acute myeloid leukemia (AML) journey. Surrounded by an incredible support system and a trusted medical team, she reached remission and is living a healthy, joyful life. She hopes the lessons she learned will help other people facing AML.**



Kathleen and her husband, Mark

## *It's okay to have a down day, just don't unpack and stay there*

➔ **Acute myeloid leukemia (AML) is terrifying** because it comes on so quickly. I went to the emergency room with what I thought was indigestion, and I left with a very serious blood cancer diagnosis.

The “acute” in AML is what makes it so hard to absorb. I had to make treatment decisions so quickly. Fortunately, I had a trusted cancer center in my backyard. Though I felt it was the right place for me, my niece who is a nurse practitioner had my blood test results sent to another hospital to confirm the diagnosis and recommended treatment.

After the second opinion confirmed the diagnosis and treatment plan, I began chemotherapy. I felt fine the first week. On the 8<sup>th</sup> day, the chemotherapy kicked in like a thunderbolt. I developed nearly every side effect possible, including painful sores in my mouth and on my esophagus. I lost every bit of my hair. I also lost a lot of weight and then gained back even more. I discovered adding cranberry juice to water took away the metallic taste and made it bearable to drink the water I needed.

Fortunately, I went into remission after chemotherapy. However, additional treatment would be required to keep the AML from coming back. A stem cell transplant provided the best chance at curing my leukemia. We found a perfect match in a wonderful young man from Germany and began to prepare for it.

My husband Mark found a new apartment that became my home for a year. We'd lived in our home for 27 years and raised our three children there, but it was big and old and a fresh, clean environment was preferable for the transplant.

The transplant itself was easy. But, pre-transplant blood work showed I had a genetic mutation known as *FLT3*. My doctor explained that it was the reason my AML was so aggressive. She was involved in a clinical trial that was testing a tyrosine kinase inhibitor designed to inhibit the mutated cells from growing, and I decided to join after finishing the transplant.

I wasn't scared to try the trial because I knew scientists had spent a great deal of time cultivating the drug. I trusted my doctor and was confident she wouldn't offer me an option that wasn't worth considering. And, my grandkids were my inspiration. I had waited a long time for grandkids, and I'd made up my mind that we were going to have Sunday dinners. I would fight to be around for those.

I was on the trial for a year, and it was successful. My last bone marrow biopsy showed no signs of the *FLT3* mutation.

Getting into the right mindset set the pace for how things went for me. I had ups and downs, but I learned not to look too far ahead and just take one day at a time. I told myself that the calmer I stayed, the better it would go, and it was true.

Like my anniversary, the date I was diagnosed is something I'll never forget. But it's like giving birth. I don't remember the pain. Instead, I remember the kindness of others. I remember that Mark, our family and five of my dearest friends gave up so much of their lives to help me survive. I think about how their lives intertwined because of me, and how they gave me the courage to know that even though it was a very tough battle, it was one I could win. And I did. ■

### » *Lessons from Kathleen*

**Lesson #1: It's okay to have a down day, just don't unpack and stay there.** Keep a journal, and write down one good thing that happens each day. When you need it, look back and see what made that day better.

**Lesson #2: How you react to certain challenges makes a huge difference.** Getting involved in finding solutions keeps your mind occupied.

**Lesson #3: You can have your test results sent to another provider** at a specialized cancer center for a second opinion. Your current doctor should be more than happy to comply with your request.

**Lesson #4: Surround yourself with support.** Mark and I have been together since we were 17 and married for more than four decades. We genuinely love and care about each other. When we found out I had AML, he sat down on the floor and cried at the thought of losing his best friend. He's been by my side through it all, from not caring about how different I look because of treatment to being trained to give me pre-transplant chemotherapy at home.

**Lesson #5: Consider a clinical trial for yourself and for future generations.** Search your soul and find something that you love more than yourself. Something you want to live for. You might do it for that grandbaby you will have one day.



# Tailoring a plan for your unique diagnosis

**A**dvances in treating acute myeloid leukemia (AML) are leading to improved quality of life and longer survival times. Many of these treatments target the unique chromosome and genetic abnormalities found in AML. Discuss your subtype with your doctor and ask about available treatment options.

## PHASES OF TREATMENT

Every diagnosis is unique, but AML treatment generally begins quickly with two phases of chemotherapy: remission induction therapy and post-remission therapy.

The goal of remission induction therapy is to destroy the leukemia cells in the blood and bone marrow, putting the AML into complete remission. Complete remission is defined as having blood counts that are back to normal, the elimination of leukemia cells in blood and bone marrow samples that are examined under a microscope, and no signs or symptoms of the disease.

Post-remission therapy, also called consolidation therapy, is then started to kill remaining leukemia cells that could cause a relapse.

After additional test results are examined, your doctor will consider your age, general health, ability to manage certain therapies and your preferences for daily living. The following options may be used alone or in combination.

**Chemotherapy** kills cancer cells and some healthy cells. It may be used for remission induction therapy or post-remission therapy, or followed by stem cell transplantation. Many factors contribute to the choice of chemotherapy drug that will be most effective for you, including your age (whether you are younger or older than 60), risk factors and prognosis (predicted outcome after treatment). Sometimes chemotherapy requires a lengthy hospital stay so blood counts can be closely managed. When AML has spread to the brain and spinal cord, intrathecal chemotherapy that is injected into the fluid-filled space between the thin layers of tissue that cover the brain and the spinal cord may be used.

**Stem cell transplantation** may be curative. An allogeneic transplant is most commonly used for AML. It involves stem cells donated by a family member or an unrelated donor. To reduce the risk of Graft-versus-Host Disease (GvHD), a serious condition in which transplanted donor immune cells attack the patient, it is important the patient's and donor's tissues match as closely as possible.

An allogeneic transplant can work directly against the cancer through the graft-versus-tumor effect (also referred to as graft-versus-leukemia or graft-versus-cancer-cell). This may occur when the donor's white blood cells (the graft) attack any cancer cells (the tumor) remaining. The graft-versus-tumor effect can be key to a successful outcome.

The assistance of a caregiver post-transplant will be invaluable. Talk with your doctor about how a caregiver can help and for how long.

**Targeted therapy** uses drugs or other substances to identify and attack specific cancer cells. Targets include gene mutations, chromosome alterations and proteins on the cell surface. Targeted therapy is intended to affect

only cancer cells. It may be given alone or in combination with chemotherapy, depending on the presence of certain gene mutations (alterations) or specific proteins on the surface of the leukemia cells. Some targeted therapies are approved to treat the CD33 protein and the *FLT3* (pronounced "flit-three"), *IDH1* and *IDH2* gene mutations.

**Radiation therapy** uses high-energy radiation to destroy cancer cells. It may be used if the cancer has spread to the brain, spinal fluid or testicles. It may also be used to shrink a collection of leukemia cells that has formed a mass. Some people with localized disease (disease in a specific area of the body) or bone pain that does not lessen with chemotherapy may receive radiation therapy to specific parts of the body. Total body irradiation may be given to the entire body before stem cell transplantation to make space for the new cells (graft) to replace the diseased blood system.

**Leukapheresis** may be used temporarily to help immediately lower white blood cell counts when leukostasis occurs. Leukostasis is a very high number of leukemia cells in the blood that can affect normal blood circulation. During leukapheresis, blood is removed to eliminate leukemia cells and then the remaining blood is returned to the body.

## Make medication adherence a priority

**Taking the right treatment in the right dose at the right time – every time – is referred to as medication adherence. Whether you are taking oral therapy (pills) or getting intravenous (IV) treatments, you are responsible for taking your treatment just as your doctor intends to get the maximum benefit. The consequences of not doing so can be serious.**

**Set yourself up to succeed. These suggestions may help:**

- ▶ **Ask your pharmacist to explain how to take your medicine and about possible drug interactions.**
- ▶ **Keep a treatment diary. Track each treatment, including missed doses or appointments, and detail any side effects. If you miss a dose or appointment, let your health care team know so they can determine whether you should make it up immediately or wait until your next scheduled time.**
- ▶ **Set up reminders for taking your medicine and scheduling refills. A reminder can be an alarm on your clock or phone.**

## REIMBURSEMENT & PATIENT ASSISTANCE RESOURCES

- ▶ **myAbbVie Assist:** [abbvie.com/patients/patient-assistance](http://abbvie.com/patients/patient-assistance), 800-222-6885
- ▶ **Astellas Pharma Support Solutions:** [astellaspharmasupportsolutions.com/patient](http://astellaspharmasupportsolutions.com/patient), 800-477-6472
- ▶ **Bristol-Myers Squibb Access Support:** [bmsaccesssupport.bmscustomerconnect.com/patient](http://bmsaccesssupport.bmscustomerconnect.com/patient), 800-861-0048
- ▶ **Bristol-Myers Squibb Patient Assistance Foundation:** [bmspaf.org](http://bmspaf.org), 800-736-0003
- ▶ **Genentech Access Solutions:** [genentech-access.com/patient](http://genentech-access.com/patient), 877-436-3683
- ▶ **Genentech Oncology Co-pay Assistance Program:** [copayassistancenow.com/patients](http://copayassistancenow.com/patients), 855-692-6729
- ▶ **Genentech Patient Foundation:** [gene.com/patients/patient-foundation](http://gene.com/patients/patient-foundation), 888-941-3331
- ▶ **Idhifa BMS Access Support:** [bmsaccesssupport.bmscustomerconnect.com/patient/financial-support](http://bmsaccesssupport.bmscustomerconnect.com/patient/financial-support), 800-861-0048
- ▶ **JazzCares:** [jazzcares.com](http://jazzcares.com), 833-533-5299

**Growth factors** are sometimes given to increase the number of white blood cells that are decreased by treatment, which can increase the risk of infection. Growth factors may be given before stem cells are collected or after chemotherapy once remission is reached.

**Clinical trials** may be considered at any time. Many strategies are being researched, including new targeted therapies, immune therapies and combinations. In chimeric antigen receptor (CAR) T-cell therapy, for example, the patient's T-cells are removed during remission, engineered to express a CAR that targets remaining AML cells, and infused back into the body.

#### REFRACTORY AND RELAPSED AML

AML can become resistant at any time in the treatment process. This is called refractory AML. When it returns, it is called relapsed AML. In these cases, your doctor may perform new tests and recommend a new treatment plan. ■

#### COMMON DRUG THERAPIES FOR AML

*These drugs may be used alone or in combination.*

- ▶ azacitidine (Vidaza)
- ▶ azacitidine (oral) (Onureg)
- ▶ cytarabine
- ▶ daunorubicin hydrochloride
- ▶ daunorubicin/cytarabine liposomal (Vyxeos)
- ▶ doxorubicin hydrochloride (Adriamycin)
- ▶ enasidenib (Idhifa)
- ▶ gemtuzumab ozogamicin (Mylotarg)
- ▶ gilteritinib (Xospata)
- ▶ ivosidenib (Tibsovo)

#### POSSIBLE COMBINATION THERAPIES

- ▶ ADE: cytarabine (Ara-C), daunorubicin hydrochloride, etoposide phosphate (Etopophos)
- ▶ cytarabine with other approved anti-cancer drugs
- ▶ glasdegib (Daurismo) with low-dose cytarabine
- ▶ idarubicin (Idamycin, Idamycin PFS) with other approved anti-leukemic drugs
- ▶ ivosidenib (Tibsovo) with azacitidine (Onureg)
- ▶ midostaurin (Rydapt) with cytarabine and daunorubicin induction and cytarabine consolidation
- ▶ venetoclax (Venclexta) with azacitidine (Vidaza) or decitabine (Dacogen) or low-dose cytarabine

*As of 10/3/22*

# Coping with the emotions of your child's diagnosis

**M**oving forward after your child receives an AML diagnosis will feel more manageable if you take advantage of the support options available. Members of your child's medical care team, advocacy groups and other families whose lives have been affected by AML can help you navigate what seems like an impossible road ahead. These suggestions may also help.

**Help for parents:** You may feel overwhelmed and ill-equipped

to manage such a serious medical condition and worry about how all the aspects of your lives will be affected. Learn all you can about your child's diagnosis, and try your best to focus on the now.

Draw on the experience of your child's nurse navigator and medical team to provide guidance, education and training. Pharmacists are another trusted source who can offer guidance on safely handling and dispensing your child's medications and managing side effects.

Keep your family routine as close as you can to what it was before. Consistency helps everyone feel as normal as possible.

Find an outlet for your feelings. Consider sharing your concerns with a therapist, social worker, member of your spiritual community or pediatric AML support group.



**Help for your child:** Enlist the aid of your child's nurse navigator, a psychologist, social worker or child-life specialist to explain AML and its treatment to your child. They will make the discussion age-appropriate to ensure the right information is shared.

Be honest with your child about hair loss. Chemotherapy is often part of AML treatment, so think about hats, caps and wigs. Be aware that losing their hair may be very upsetting. The social worker or child-life specialist on your child's medical team can offer support and resources for dealing with hair loss.

**Help for siblings:** It is important to recognize they may be feeling the same fear, anger and stress as you. Help them cope by reminding them that you're there for them. Assure them their feelings are valid. Continue to parent, love and discipline as you normally would. Again, consistency is key.

**Help for friends:** Encourage your child to keep up with friendships. They may be extra fatigued, which may prevent them from picking up with their social activities as quickly as you might expect. If in-person visits are an infection risk, encourage kids to connect through video games, social media and by phone. ■

- ▶ **Novartis Oncology Universal Co-pay Program:** [copay.novartisoncology.com](http://copay.novartisoncology.com), 877-577-7756
- ▶ **Novartis Patient Assistance NOW Oncology (PANO):** [patient.novartisoncology.com/financial-assistance/pano](http://patient.novartisoncology.com/financial-assistance/pano), 800-282-7630
- ▶ **Onureg BMS Access Support:** [bmsaccesssupport.bmscustomerconnect.com/patient/financial-support](http://bmsaccesssupport.bmscustomerconnect.com/patient/financial-support), 800-736-0003
- ▶ **Pfizer Oncology Together:** [pfizeroncologytogether.com/patient](http://pfizeroncologytogether.com/patient), 877-744-5675
- ▶ **Rydapt Financial Resources:** [us.rydapt.com/acute-myeloid-leukemia/patient-support/financial-resources](http://us.rydapt.com/acute-myeloid-leukemia/patient-support/financial-resources), 800-282-7630
- ▶ **Tibsovo Servier One:** [servierone.com/s/patient/tibsovo](http://servierone.com/s/patient/tibsovo), 844-409-1141
- ▶ **Venclexta Access Solutions:** [genentech-access.com/patient/brands/venclexta](http://genentech-access.com/patient/brands/venclexta), 877-436-3683
- ▶ **Vidaza BMS Access Support:** [bmsaccesssupport.bmscustomerconnect.com/patient/financial-support](http://bmsaccesssupport.bmscustomerconnect.com/patient/financial-support), 800-861-0048
- ▶ **Vyxeos Jazz Cares:** [jazzcares.com/patients/vyxeos](http://jazzcares.com/patients/vyxeos), 833-533-5299
- ▶ **Xospata Support Solutions:** [astellaspharmasupportsolutions.com/patient/xospata](http://astellaspharmasupportsolutions.com/patient/xospata), 844-632-9272

# Make a plan for managing side effects

**C**ancer treatments are typically accompanied by a range of side effects. Knowing what to expect and how to manage them should they occur will help you feel more in control. Your multidisciplinary health care team will introduce you to supportive care services that can address the physical, emotional, practical, spiritual, financial and family-related challenges of having cancer.

Some side effects are simply an inconvenience, while others can disrupt your quality of life. Still others have the potential to be life-threatening, making it critical that you know what to do if one occurs. Your health care team will rely on you to communicate openly about how you feel.

## POTENTIALLY SEVERE SIDE EFFECTS

Ask your doctor whether you are at risk for serious side effects. If you are, find out how to identify the symptoms and report them immediately if they occur.

- **Infection** can occur as a result of a low white blood cell count (neutropenia) or other factors. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4 °F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching. If you cannot reach your doctor, go to the emergency room.
- **Cytokine release syndrome** can occur with CAR T-cell therapies if immune cells affected by treatment rapidly release large amounts of cytokines, which are a type of protein, into the bloodstream. Symptoms may include headache, fever, nausea, rash, low blood pressure, rapid heartbeat and difficulty breathing.

- **Infusion-related reactions** may occur with some intravenous (IV) treatments. Most reactions are mild with symptoms such as chills, fever, nausea, headache and skin rash. Some can be serious and even fatal without medical intervention. Symptoms such as shaking, chills, low blood pressure, dizziness, breathing difficulties or irregular heartbeat can be serious or even fatal without medical intervention.
- **Tumor lysis syndrome (TLS)** may occur after treatment. Symptoms may include vomiting, diarrhea, muscle cramps or twitches, neuropathy (numbness or tingling in your fingers, toes, arms or legs) and decreased urination.
- **Graft-versus-Host Disease (GvHD)** may occur with an allogeneic stem cell transplant. Call your doctor immediately if you have dryness of the eyes and mouth;

tightening, blistering or burning of the skin; jaundice; fever; sudden weight loss; or abdominal pain, bloating or diarrhea.

## COMMON SIDE EFFECTS

Many people begin by getting help to manage side effects and pain. You may receive these services from an advanced practice nurse, physical therapist, dietitian or palliative medicine specialist who has extra training in symptom management. They may be available at your hospital, cancer center or medical clinic and are often covered by individual insurance plans, Medicare and Medicaid. To learn more, you can talk with the hospital's social worker, financial counselor or your health insurance representative.

Table 1 on page 7 lists several common side effects from AML and its treatments. Keep in mind that not every person reacts in the same way. Some side effects may be more intense when more than one therapy is given.

Contact your medical team by phone or the online portal when a physical or emotional side effect or symptom begins so it can be treated or managed immediately.

## Prepare for a Range of Emotions

*Receiving a cancer diagnosis is shocking, and acknowledging your feelings is necessary for your well-being. The following are common emotions you may have and suggestions for working through them.*

**Anxiety** can begin as soon as you receive your diagnosis. Moderate to severe anxiety may be treated with medication, therapy or both. Explore calming techniques, such as meditation, muscle relaxation, yoga or guided imagery.

**Depression** is a psychological reaction to your situation as a whole. Do not avoid talking to your doctor about it because you think depression is just part of having cancer. Talk with your doctor if you feel hopeless, helpless or numb. If you have

thoughts of death or of attempting suicide, seek medical attention immediately.

**Doubt** can lead to questions about the meaning of life and its purpose. Some people find strength in support from family, friends, the community or spirituality. It may also help to open up to a counselor or support group.

**Fear** is common, especially when you think about the future. Do your best to stay focused on the present.

**Guilt** may occur if you feel you are a burden to loved ones or if you wonder why you are surviving when others did not. Talk with a therapist about these feelings.

**Scanxiety** can happen when you are awaiting results from imaging scans, laboratory tests or follow-up exams. It is normal to be nervous. Talk with your doctor or nurse so you can know when to expect results. Keep your mind occupied with things you enjoy, such as reading, playing games or gardening.

## PATIENT & CAREGIVER SUPPORT RESOURCES

- ▶ **American Psychosocial Oncology Society Helpline:** 866-276-7443
- ▶ **Cactus Cancer Society:** [www.cactuscancer.org](http://www.cactuscancer.org)
- ▶ **CanCare:** [www.cancare.org](http://www.cancare.org)
- ▶ **CANCER101:** [www.cancer101.org](http://www.cancer101.org)
- ▶ **Cancer Care:** [www.cancercare.org](http://www.cancercare.org)
- ▶ **Cancer Connection:** [www.cancer-connection.org](http://www.cancer-connection.org)
- ▶ **Cancer Hope Network:** [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)
- ▶ **Cancer Support Community (AML):** [www.cancersupportcommunity.org/acute-myeloid-leukemia](http://www.cancersupportcommunity.org/acute-myeloid-leukemia)
- ▶ **Cancer Support Community Helpline:** 888-793-9355
- ▶ **Cancer Survivors Network:** [csn.cancer.org](http://csn.cancer.org)
- ▶ **Caregiver Action Network:** [www.caregiveraction.org](http://www.caregiveraction.org)
- ▶ **CaringBridge:** [www.caringbridge.org](http://www.caringbridge.org)
- ▶ **Center to Advance Palliative Care:** [www.capc.org](http://www.capc.org)
- ▶ **Chemo Angels:** [www.chemoangels.com](http://www.chemoangels.com)



## OTHER TYPES OF SUPPORT

Supportive care extends to other areas and is also available to your children, family members, caregivers and others close to you. Ask your health care team for referrals to trusted sources. You do not have to go through this alone.

**Social support** is available in many forms. You may choose to speak with a therapist or attend an online, telephone or in-person support group. Participants openly share what they have learned from challenges with treatments, in their relationships or careers and in other areas. Many advocacy programs offer one-on-one buddy programs that pair you with another person who has the same type of cancer. It can be extremely helpful to

share your feelings with people who understand what you are going through.

**Spiritual guidance**, even if you do not consider yourself a religious person, is available from a chaplain at the hospital or from your religious community.

**Financial counseling** can help relieve the stress and anxiety of paying for treatment and other related expenses. Knowing the costs of treatment and related expenses and making a plan may help you feel more in control. Counseling about nutrition, fitness, mental health, physical/occupational therapy, speech therapy, complementary medicine and other areas is also available. ■

▲ **TABLE 1**  
**COMMON SIDE EFFECTS**

Side Effect	Symptoms
<b>Anemia</b>	Low energy, weakness, dizziness, light-headedness, shortness of breath, rapid heartbeat
<b>Bone loss</b>	Weakened bone caused by the cancer or treatment
<b>Bruising and bleeding</b> (thrombocytopenia)	Low number of platelets in the blood, which can lead to bruising and bleeding
<b>Cardiotoxicity</b>	Heart damage that may arise from some cancer treatments. Ask your doctor whether you are at risk and the symptoms that require immediate attention.
<b>Chemo brain</b> (cognitive dysfunction)	Brain fog, confusion and/or memory problems
<b>Constipation</b>	Difficulty passing stools or less frequent bowel movements compared to usual bowel habits
<b>Decreased appetite</b>	Eating less than usual, feeling full after minimal eating, not feeling hungry
<b>Diarrhea</b>	Frequent loose or watery bowel movements
<b>Fatigue</b>	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
<b>Fever</b>	Raised body temperature that could signal an infection
<b>Hair loss</b> (alopecia)	Hair loss on the head, face and body
<b>Headache</b>	Pain or discomfort in the head
<b>Leukocytosis</b>	Elevated white blood cell count that may involve fever, fatigue, weakness, dizziness or nausea
<b>Mouth sores</b>	Tiny sores in the lining of the mouth and gums, tongue, roof of mouth and/or lips
<b>Nausea and vomiting</b>	The feeling of needing to throw up and/or throwing up
<b>Neuropathy</b>	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
<b>Neutropenia</b>	Low white blood cell count that increases the risk of infection
<b>Pain</b>	Pain and aches that occur in the muscles, bones, tendons, ligaments or nerves
<b>Respiratory problems</b>	Shortness of breath (dyspnea) with or without cough, upper respiratory infections
<b>Skin reactions</b>	Rash, redness and irritation, or dry, flaky or peeling skin that may itch

## FOR THE CAREGIVER



### 5 Key Caregiving Responsibilities

Your role as a caregiver will change as your loved one's needs change. These steps will get you started:

- 1 Get the OK to receive medical information.** Make sure you are authorized to communicate with your loved one's medical team, access medical information, use the online portal, renew prescriptions and more.
- 2 Set up a system for managing treatments.** Keep track of when medications and treatments are given. Note any side effects that occur and whether anything helps relieve them.
- 3 Ensure you have reliable transportation.** Plan for taking your loved one to and from appointments, running errands and more. Ask if telehealth appointments are an option.
- 4 Ask questions and take notes.** Keep a running list of questions for your loved one's medical team that you can ask during or between appointments as necessary.
- 5 Practice self-care.** Keep up with your medical appointments, social relationships, hobbies and exercise plan. Share your feelings with friends, a therapist or spiritual leader. Consider connecting with other caregivers.

- ▶ **The Children's Treehouse Foundation:** [www.childrenstreehousefdn.org](http://www.childrenstreehousefdn.org) ▶ **Cleaning for a Reason:** [www.cleaningforareason.org](http://www.cleaningforareason.org)
- ▶ **Connect Thru Cancer:** [www.connectthrucancer.org](http://www.connectthrucancer.org) ▶ **Family Caregiver Alliance:** [www.caregiver.org](http://www.caregiver.org) ▶ **Friend for Life Cancer Support Network:** [www.friend4life.org](http://www.friend4life.org)
- ▶ **The Gathering Place:** [www.touchedbycancer.org](http://www.touchedbycancer.org) ▶ **Imerman Angels:** [www.imermanangels.org](http://www.imermanangels.org) ▶ **Livestrong Foundation:** [www.livestrong.org](http://www.livestrong.org)
- ▶ **LivingWell Cancer Resource Center:** [www.livingwellcrc.org](http://www.livingwellcrc.org) ▶ **Lotsa Helping Hands:** [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)
- ▶ **National LGBT Cancer Project:** [www.lgbtcancer.org](http://www.lgbtcancer.org) ▶ **Patient Empowerment Network:** [www.powerfulpatients.org](http://www.powerfulpatients.org)
- ▶ **SHARE Caregiver Circle:** [www.sharecancersupport.org/caregivers-support](http://www.sharecancersupport.org/caregivers-support) ▶ **Triage Cancer:** [www.triagecancer.org](http://www.triagecancer.org)
- ▶ **Well Spouse Association:** [www.wellspouse.org](http://www.wellspouse.org) ▶ **weSPARK Cancer Support Center:** [www.wespark.org](http://www.wespark.org)

# Advocate for yourself when searching for a trial

**B**eing involved in your own care includes understanding all of the treatment options available to you, including clinical trials. These medical research studies are conducted to evaluate whether a new treatment, such as a drug or vaccine, drug combination, surgical procedure, type of radiation therapy or a combination of therapies, is more effective or better in some way than the current standard-of-care available.

Depending on your diagnosis and other factors, the therapy used in a clinical trial may be suitable as a first-line treatment (before any other treatment is given) or at another time during care.

If you are interested in exploring a clinical trial, let your medical team know. While they look for one that may fit into your treatment plan, you can search, too.

Start one of these two ways:

- 1. Request assistance by phone.** This is a convenient option for people who are not tech-savvy, do not have access to the tools necessary to search online or simply prefer to talk to a person.
- 2. Search online.** Some clinical trial search websites are customized to a certain cancer type; others are much broader. Generally,

these sites are hosted by the government, the National Cancer Institute, cancer advocacy groups, pharmaceutical companies and industry trade organizations, academic medical centers and major hospitals. No single list contains every open clinical trial, and new trials are continually being added, so check back often. You can start your search with the *Clinical Trial Resources* listed at the bottom of this page.

It is possible that hundreds of clinical trials may appear to apply to your diagnosis. Looking at them thoroughly is time-consuming, so consider asking friends and family members to help. ■



## Getting Started

Whether you are on the phone or online, your search will likely begin with several questions to help steer you to clinical trials that may best meet your needs, such as the cancer type, your age, your location and the distance you are willing to travel. Traveling is not always necessary, and virtual visits may be available for certain portions of the trial. Clinical trials happen in many places, from big cities to small towns. Some may even be accessible through your doctor's office.

### STEP 1:

#### Get prepared

Have your exact diagnosis, pathology report and details of your previous cancer treatments on hand to help determine whether you meet the basic eligibility criteria. Every participant in a specific trial must meet the same eligibility criteria. That typically includes cancer type, subtype, stage, biomarker status and treatment history. Your age, gender and other health conditions may also be factors. For example, if a trial requires that you have already had a specific treatment and you have not, you will not be eligible.

### STEP 2:

#### Fill in your information

This customizes your search.

**Your Diagnosis:** Enter "AML." To further customize your search, enter applicable criteria such as age and previous treatments on the Results screen.

**Desired Location:** If you prefer a clinical trial close to home, enter your home address. Enter additional locations if you are willing and able to travel for treatment.

**Other Terms:** You can refine your search even more by adding a particular treatment type or genetic mutation. You can also add a National Clinical Trial identifier, which is a unique eight-digit code preceded by "NCT" that is assigned to each trial.

### STEP 3:

#### Read your search results

A list of clinical trials that match your search terms will populate and generally includes the following.

**Recruitment Status:** This indicates whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. The status will change, so check for updates.

**Summary of Study:** This details the purpose of the clinical trial and the treatment being studied. This section is usually written for health care providers, so ask your doctor about anything you do not understand.

**Eligibility Criteria:** This outlines the criteria you must meet to be eligible for the trial, such as the stage of disease, sites of metastasis, overall health requirements and previous treatments.

**Contacts and Locations:** Contact information for the clinical trial investigators, staff or sponsors who may be able to provide more details about the study is provided.

**Sponsor:** This is the entity responsible for the clinical trial.

### STEP 4:

#### Learn more

Once you find a potential trial, talk with your doctor. Keep in mind that some may be closed, and you may not qualify for every trial that interests you.

## CLINICAL TRIAL RESOURCES

- ▶ **AbbVie Clinical Trials:** [abbvieclinicaltrials.com](http://abbvieclinicaltrials.com)
- ▶ **Be the Match | Jason Carter Clinical Trials Program:** [www.ctsearchsupport.org](http://www.ctsearchsupport.org), 888-814-8610
- ▶ **Cancer Support Community:** [www.cancersupportcommunity.org/find-clinical-trial](http://www.cancersupportcommunity.org/find-clinical-trial), 888-793-9355
- ▶ **Center for Information & Study on Clinical Research Participation:** [www.searchclinicaltrials.org](http://www.searchclinicaltrials.org)
- ▶ **ClinicalTrials.gov:** [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- ▶ **Lazarex Cancer Foundation:** [www.lazarex.org](http://www.lazarex.org), 877-866-9523
- ▶ **The Leukemia & Lymphoma Society:** [www.lls.org/treatment/types-of-treatment/clinical-trials/finding-a-clinical-trial](http://www.lls.org/treatment/types-of-treatment/clinical-trials/finding-a-clinical-trial), 800-955-4572
- ▶ **National Cancer Institute:** [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)
- ▶ **NCI Cancer Information Service:** 800-422-6237
- ▶ **WCG CenterWatch:** [www.centerwatch.com](http://www.centerwatch.com), 866-219-3440

P A T I E N T  
R E S O U R C E

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*Where information equals hope*