



Caring for a loved one, caring for yourself

A GUIDE TO SUPPORTING THOSE WITH
RELAPSED/REFRACTORY ACUTE MYELOID LEUKEMIA

Caring for a loved one with relapsed/refractory acute myeloid leukemia (AML)

As a caregiver, you have the important and often challenging role of providing emotional and physical support for someone with relapsed/refractory AML. Whether you are caring for a partner, spouse, family member, or friend, this guide will provide advice and information about caregiving, including the importance of caring for yourself.

If you already have experience as a caregiver for someone with AML, you may notice that your role evolves as the disease changes. If this is your first time caring for someone with AML, you may be unsure of what your role is. Know that you and your loved one are never alone, and that support is there for you each step of the way.

Here's what you'll find inside:

- 03 Understanding AML
- 05 AML and its impact on your loved one
- 08 Getting to know the different treatment options
- 10 Your role as a caregiver
- 15 Caring for yourself
- 16 Organizations for caregivers
- 17 Glossary of terms

Understanding AML is an important part of being a caregiver

An overview of AML

If you have experience being a caregiver for someone with AML, you are likely familiar with the disease and its causes. If you are new to being a caregiver, a good first step is to understand some of the science behind AML. The following information will provide a brief overview of AML and why it occurs.

AML is a blood cancer of the **bone marrow**. “**Acute**” means that this disease can progress quickly if left untreated.

Bone marrow typically produces **platelets** (which help with blood clotting), **red blood cells** (which transport oxygen throughout the body), and **white blood cells** (which help fight infection). With AML, white blood cells don't form properly in the bone marrow and leukemia cells called **blasts** are produced instead. Blasts are unable to fight infections the way healthy white blood cells can.

As the bone marrow produces more and more blasts, there is no room for the production of normal red blood cells, white blood cells, or platelets. When there are too many blasts and not enough healthy cells, the symptoms of AML begin to occur.

When someone is initially treated for AML, he or she may feel better after treatment for a period of time. However, the signs and symptoms of AML may return. This means that a different course of treatment may be needed.





Why AML comes back

Understanding relapsed/refractory AML

After treatment, the signs and symptoms of AML may decrease or go away entirely. This is known as a **remission**. However, it is also possible that AML becomes **refractory**, which means that it does not respond to a particular treatment. Sometimes, after a period of remission, the signs and symptoms of AML return. This is known as a **relapse**.

If AML does return, it's important to discuss the various treatment options with your loved one and the healthcare team. Remember to consider how your loved one feels about next steps, and to understand what he or she can handle.

It is common for someone with AML to quickly move through periods of treatment, response, and relapse over time. However, the time between the different stages can vary among patients with this disease.

AML and its impact on your loved one

Although AML is a cancer of the blood, it affects the entire body. When AML returns, your loved one may have symptoms similar to those they had before remission. Each time AML returns, these symptoms may become stronger. Be sure that your loved one is comfortable sharing how he or she is feeling. Make a note of changes in his or her health and be ready to talk about these changes with the healthcare team.

Keep track of all the medicines and supplements your loved one is taking, and share these with the healthcare team so they can provide the best care.

Talk with the healthcare team about the options available at each stage of treatment. This will allow you to stay informed about your loved one's care and help make decisions.



Signs and symptoms associated with AML

Patients with AML generally have common signs of their disease, which may include:

- Cytopenia
- Weight loss
- Tiredness
- Fever
- Night sweats
- Loss of appetite

AML signs can occur due to high numbers of blast cells in the bone marrow. When the blast count gets very high, patients may notice bone or joint pain, swelling in the stomach, or what looks like a common rash.

Those living with AML often have a low number of healthy blood cells in their body because leukemia cells (blasts) multiply and crowd out the normal, healthy cells. Having a low number of healthy cells is known as a **cytopenia**. There are several different types of cytopenia, depending on what type of blood cell is affected.

TYPE OF CYTOPENIA	CAUSE	SYMPTOMS
Anemia	Low red blood cell count	Feeling tired Weakness Dizziness or lightheadedness Headaches Shortness of breath
Neutropenia Leukopenia	Low white blood cell count	More susceptible to infections (a weakened immune system)
Thrombocytopenia	A low number of platelets	Bruising and bleeding Frequent nosebleeds Bleeding of the gums

If you notice any of these symptoms, contact the doctor right away.

Encourage your loved one to eat and drink right, get enough rest, and reduce physical activity. To decrease the chance of infection, help them avoid contact with sick people and practice good hygiene.

Getting to know the different treatment options

There are several treatment options for those living with AML, and the options will vary based on different factors, including what stage of treatment your loved one is in. You will want to know all of the options so that you can better understand the recommendations of the healthcare team. This is not a complete list of options, but a list of common treatments used in AML.

Each treatment option has benefits and risks, so it is important to talk with your healthcare team so you and your loved one can make an informed decision about which treatment option is best.



CHEMOTHERAPY

Chemotherapy (sometimes referred to as “chemo”) is the use of drugs that kill cancer cells. Chemo is effective at killing rapidly dividing leukemia cells, but can also affect healthy cells in the body.

Doctors will consider if a patient is healthy enough to tolerate high-intensity chemo, and if not, he or she may choose to prescribe a low-intensity type of chemo.



ALLOGENEIC STEM CELL TRANSPLANTATION

Allogeneic stem cell transplantation (ASCT) is sometimes used to treat AML. This type of transplant involves transferring healthy stem cells from a donor to the patient. This treatment helps “jump start” the patient’s own bone marrow to produce a new supply of healthy red blood cells, white blood cells, and platelets in an effort to fight the disease. Stem cell transplantation can be done when the patient is in remission after treatment either at diagnosis or at relapse.



TARGETED THERAPIES

As researchers have learned more about the biology of cancer, they have been working to identify **mutations** associated with AML and to develop new treatments that target these mutations. Mutations may lead to changes inside a cell that cause it to become a cancer cell. Targeted therapies may act by correcting the inner workings of the blast, allowing it to act normally again. These therapies are called “targeted therapies” because they affect cancer cells that have a specific mutation while leaving cells without the mutation unaffected. There are targeted therapies currently approved for the treatment of specific AML mutations.



CLINICAL TRIALS

Clinical trials are research studies for which patients can volunteer if they meet certain requirements. These studies allow people with AML the chance to receive investigational medicines before they are proven safe or effective by the FDA. Ask your doctor about clinical trials that may be available.



PALLIATIVE TREATMENT

Palliative care, or supportive care, looks to increase comfort and quality of life for people with AML, but will not treat the disease. The goal of palliative care is to address the symptoms of a disease so that a patient can live his or her life as comfortably as possible.



Your role as a caregiver

As a caregiver, you will have many roles, and your roles change day-to-day. You may feel as though you are called upon to be a chauffeur, nurse, cheerleader, or counselor. If you have experience as a caregiver, you may already be aware of all these different responsibilities. If this is your first time caring for a loved one, or your first time caring for someone with a relapse, you may feel as though you don't know where to begin.

The following pages will offer advice on how you can best help in the care of someone with AML. Keep in mind that your role as a caregiver may change depending on what stage of treatment your loved one is in.

We will discuss:

- Providing emotional support
- Helping with daily activities
- Staying organized
- Working with the healthcare team

Providing emotional support

Finding out that AML has come back can be stressful for both a patient and their caregiver. The patient may feel as though he or she does not have the energy to go through another round of therapy. You may feel like you aren't sure what kind of emotional support your loved one needs. Staying positive, being patient, and having an open mind can help both of you cope with a tough diagnosis.

Here are some practical ways to provide emotional support:

- Be there to listen
- Let your loved one set the pace and tone of conversations
- Provide encouragement
- Be patient and understanding if he or she is no longer able to do something
- Help your loved one find a support group if he or she wants to join

Helping with daily activities

AML can often impact a patient's ability to perform simple tasks. Their daily routine may change, and they may need more help than they did in the past. As a caregiver, you can ease some of the pressure that someone with AML feels by helping him or her with everyday activities.

Some activities that you could help with include:

- Driving to appointments and running errands, such as grocery shopping
- Helping around the house
- Helping with personal care, such as bathing, dressing, and eating
- Helping to figure out medical expenses and insurance coverage
- Monitoring and/or giving medicines

Staying organized

Organization will help you keep track of all you need to do

Balancing your time being a caregiver with aspects of your daily activities and needs can feel like a full-time job. Doctor appointments, dosing schedules, and tasks around the house can quickly stack up, and may start to feel difficult to keep straight on top of all your typical activities.

You can make things easier for both yourself and your loved one by planning ahead. Keep a journal or daily planner and write down all that needs to be done. Often, just the act of writing down your to-do list can relieve some of the stress that you may be feeling.

Also, make sure that your loved one is organized and prepared for an upcoming doctor visit. It is very important to make the most of the time with the doctor and nurse. Here is a list of things that you should bring along as you sit down with the healthcare team:

- Your notes on the patient's symptoms and treatment side effects that you have noticed
- A list of questions
- A notepad for taking down new information

Working with the healthcare team

Communication is key

The healthcare team can be your most valuable ally. And, as a caregiver, you will be helpful to the entire healthcare team. Make sure that you have open conversations with the doctor and nurse, and that you are comfortable discussing all aspects of AML and your loved one's prescribed treatment.

Some questions you may want to ask the healthcare team:

- How will we know if there has been a change in his or her condition?
- How will we know if a treatment is working?
- What are common side effects of the treatment?
- What symptoms should we look out for?

Some questions that you will want to ask about the practice:

- When is the office open?
- Who should we contact outside of office hours or if there is an emergency?
- Who can we go to for questions when the doctor is unavailable?
- Can we get the results of lab tests on our computer?
- Do you know of any local support groups that we can contact?





Don't forget the importance of **caring for yourself**

While you are caring for someone with AML, you may tend to forget to take care of yourself. It is easy to become so focused on making your loved one more comfortable that you ignore your own well-being. This is not good for you or your loved one.

Take some time to do something for yourself. Each day, try to do something fun and relaxing, even if only for a short period of time.

And remember, do not feel guilty about taking occasional breaks from caregiving. No one can be a caregiver 24 hours a day, 7 days a week. A short break can help your physical and emotional well-being, and this can go a long way in supporting your loved one.

Here are some easy and effective ways to take care of yourself:

- Take time to walk outside, read a book, watch TV, or take part in your favorite hobby
- Be open to talking with other caregivers, as they can relate to how you are feeling
- Stay healthy. This means:
 - Get 8 hours of sleep a night
 - Maintain a balanced, healthy diet
 - Exercise regularly—go for a short walk, do yoga, or meditate
 - Visit your doctor for routine checkups—monitor your own health, particularly if you have your own medical issues

Reaching out for additional support

Seeking help from friends and family

If you are the primary caregiver for someone with AML, it is easy to feel as though you are handling everything yourself. Try not to feel guilty if you become overwhelmed, because feeling scared, sad, or lonely is normal. Don't be afraid to reach out to friends or family and ask for help, as this may be the best thing for you and your loved one.

Some tips that can help you to share caregiving responsibilities:

- Be honest about what you are able to do, and what you might need help with
- Be willing to accept help, no matter how big or small the offer
- Communicate with others about what they can do to help
- Make a plan with friends or family and organize the tasks that need to be done

Some tasks that others can help you with are:

- Chores such as shopping, cooking, cleaning, and childcare
- Being there to talk about how you are feeling
- Running errands
- Doing research on AML

Organizations for caregivers

Here are some websites and organizations that offer support and guidance to caregivers:

- **National Alliance for Caregiving**
— www.caregiving.org
- **Caregiver Action Network**
— www.caregiveraction.org
- **Well Spouse Association**
— www.wellspouse.org

The following is a list of resources that provide services for those living with a chronic illness:

- **United States Department of Labor: Disability Services**
— www.dol.gov/odep
- **Meals on Wheels Association of America**
— www.mealsonwheelsamerica.org
- **Air Care Alliance**
— www.aircarealliance.org

Patient advocacy groups that provide support to people with AML and their caregivers can be found here:

- **Aplastic Anemia and MDS International Foundation**
— www.aamds.org
- **American Cancer Society's "WhatNext" Support Network**
— www.cancer.org/treatment/supportprogramsservices/whatnext
- **Cancer Support Community**
— www.cancersupportcommunity.org
- **Leukemia & Lymphoma Society**
— www.lls.org/support/support-groups
- **MDS Foundation**
— www.mds-foundation.org/patient-caregiver-resources/
- Ask the healthcare team about local support groups that may offer services/assistance

Organizations, including some of the ones listed above, can provide help in finding ways to pay for medicines, transportation, and other types of support services. Depending on the treatment, the manufacturer may have a support program to help you.

Bristol Myers Squibb does not endorse any of these organizations or their communications.

Glossary

- **Acute** – An illness that will progress quickly if left untreated
- **Allogeneic stem cell transplantation** – This type of transplant involves transferring healthy stem cells from a donor to the patient
- **Anemia** – Low red blood cell count
- **Blasts** – Immature blood cells that are not usually found in the blood
- **Bone marrow** – The soft interior of the bones where new blood cells are created
- **Cytopenia** – A low number of healthy cells
- **Leukopenia** – Low white blood cell count
- **Mutation** – An abnormal change within a cell
- **Neutropenia** – A low number of neutrophils (a type of white blood cell)
- **Platelets** – Help prevent bleeding caused by cuts and bruises
- **Red blood cells** – Carry oxygen from the lungs to all cells in the body
- **Refractory** – The AML has not responded to any attempts at treatment
- **Relapse** – The signs and symptoms of AML have returned after a period of response to treatment
- **Remission** – The signs and symptoms of AML decrease or go away entirely
- **Thrombocytopenia** – A low number of platelets
- **White blood cells** – Help the body fight infections. They are a crucial part of the body's immune system

