

Caring for a loved one, caring for yourself

**A GUIDE TO SUPPORTING THOSE
WITH ACUTE MYELOID LEUKEMIA**

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

As a caregiver, you may have the important and often challenging role of providing emotional and physical support for someone with 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 how you can help play a role. Know that you and your loved one are never alone, and that, in addition to this guide, there are resources and organizations to provide help each step of the way.

Here's what you'll find inside:

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Understanding AML is an important part of being a caregiver

An overview of AML

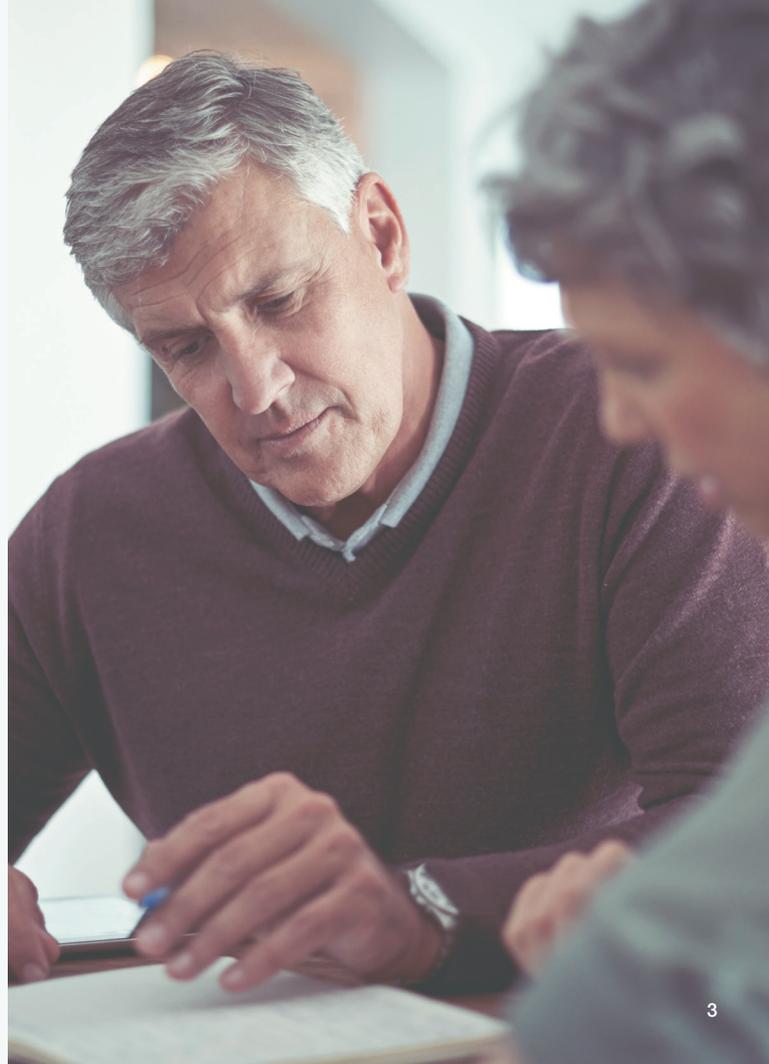
If you have experience being a caregiver for someone with AML, you are likely familiar with the disease and its causes. If you are new to being a caregiver, a good first step is to understand some of the science behind AML. The following information will provide a brief overview of AML and why it occurs.

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

The bone marrow is a soft tissue found within the bones. Bone marrow normally produces **stem cells** which then form **platelets** (help with blood clotting), **red blood cells** (transport oxygen throughout the body), and **white blood cells** (help fight infection). With AML, white blood cells don't mature properly. These immature white blood cells are called **leukemic blasts** and they are unable to fight infections the way healthy, mature white blood cells can.

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

Treatment for a person with AML typically starts as soon as possible. Depending on factors like age or the type of AML, they may receive a few cycles of treatment before they start to feel better. Treatment can even continue after a person is in remission, in order to help them stay in remission longer.





Why AML happens

Understanding the causes of AML

In some cases, people with AML may have known risk factors. However, others may develop AML without any known risk factors at all. A risk factor is something that may increase the chance of someone developing AML.

Risk factors include:

- Older age
- Male gender
- Smoking and chemical exposure
- History of another blood disorder
- Prior treatment for cancer
- **Genetics** or family history

In addition, changes (or mutations) in **DNA** may cause normal cells to turn into cancerous cells. DNA makes up our **genes**, which control the way cells function. Certain mutations are more likely to cause too many leukemic blasts to form in the bone marrow and may lead to AML.

The healthcare team looks at all of this information before determining what the best treatment options are for your loved one.

AML and its impact on your loved one

Although AML is a cancer of the blood, it affects the entire body. Be sure that your loved one is comfortable sharing how they are feeling. Make a note of changes in their 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 all of the treatment options that are available. This will allow you to stay informed about your loved one's care, and help make decisions.



Signs and symptoms associated with AML

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

- Cytopenias
- Weight loss
- Tiredness
- Excess bleeding
- Fever
- Night sweats
- Loss of appetite
- Bruising

AML signs can occur due to high numbers of leukemic blasts in the bone marrow. When the blast count gets very high, patients may notice bone or joint pain, a feeling of fullness, or small red-purple spots that may look like a common rash.

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

TYPES OF CYTOPENIAS	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) Fever and night sweats
Thrombocytopenia	A low number of platelets	Bruising and bleeding Frequent nosebleeds Bleeding of the gums Rash-like spots

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

Treatment goals for AML

A main goal of treatment for AML is to eliminate leukemic blasts in the blood and bone marrow. A number of treatment options are available and patients may receive more than one treatment at a time. Treatment plans depend on their age, health, and other factors. These options typically fall into 2 phases of treatment: induction and consolidation.

The goal of **induction therapy** is to get rid of as many leukemic blasts as possible. This therapy is generally more intensive, typically requiring a hospital stay, and several chemotherapy (or “chemo”) drugs may be used. Some patients may receive non-intensive induction therapy.

After induction therapy, the doctor will use a bone marrow test to see how many leukemic blasts remain. Depending on the results, a patient may receive another round of chemo or other treatment. A patient is considered in remission once few or no leukemic blasts remain.

After remission, **consolidation therapy** may be given as a limited course of treatment to destroy any remaining leukemic blasts and make the leukemia less likely to return.

Consolidation therapy may include one of the following options or a combination of them:

- **Chemotherapy:** Use of similar drugs given during induction and may be given at lower doses
- **Hematopoietic stem cell transplant (HSCT):** Transfer of healthy stem cells to a person with AML from either a donor or from the person with AML. This treatment is also known as bone marrow transplant

Another post-remission treatment option is **continued treatment**. It is usually a medication of lower intensity than what is used during induction or consolidation therapy. This treatment may be given for an extended period of time.

Patients who do not respond to therapies or treatments that are currently on the market can take part in clinical trials as an alternative option. This allows qualified patients an opportunity to receive treatment that has not yet been FDA approved but may work for them. However, if further treatment or clinical trials are not options, the focus may shift to controlling symptoms caused by leukemia, rather than trying to cure it.

Treatment options and goals may vary from person to person. It is important to discuss an individualized treatment plan with the healthcare team so you understand the risks and benefits of all the options and your loved one can make the decision that is right for them.



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 and if they are in remission. Consider learning about 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 the healthcare team so you and your loved one can make an informed decision about which treatment option is best.



CHEMOTHERAPY

Chemotherapy is the use of drugs that eliminate cancer cells. These medications can also affect healthy cells in the body.

Chemo may be given at various points in a person's treatment:

- As initial treatment (induction)
- Before HSCT
- After initial treatment (consolidation)

Doctors will consider if a person is healthy enough to tolerate high-intensity chemo, and if not, a low-intensity type of chemo may be prescribed.



HEMATOPOIETIC STEM CELL TRANSPLANTATION (HSCT)

HSCT is sometimes used to treat AML.

This type of transplant involves transferring healthy stem cells to the patient from either a donor or from the patient with AML. This treatment helps restore the patient's own bone marrow to produce normal healthy red blood cells, white blood cells, and platelets, in an effort to fight the disease. Stem cell transplantation is typically done when the patient is in remission.



CONTINUED TREATMENT

The healthcare team may recommend **continued treatment** after your loved one has achieved first remission. This treatment is typically given over an extended period of time.

Continued treatment may be an option for people with AML in first remission or who choose not to move forward with HSCT.



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. There are targeted therapies currently approved for the treatment of specific AML mutations.



WATCH AND WAIT

Once a person completes treatment or stem cell transplant, the healthcare team may choose to **watch and wait**.

Watch and wait represents the follow-up period after a person is in remission, when the signs and symptoms of AML are monitored. During this time, your loved one may return for office visits where their blood and bone marrow are examined. This period of time may vary from person to person, spanning a few weeks to years.



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 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.



The roles of 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 with AML, 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 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

A diagnosis of and/or treatment for AML can be stressful for both patients and caregivers. You and your loved one may be nervous or fearful about what to expect. 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 during the treatment process.

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 they are no longer able to do something
- Help your loved one find a support group if they want to join

Helping with daily activities

AML can often impact a person'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 your loved one with AML feels by helping them 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 meal preparation
- Helping to figure out medical expenses and insurance coverage
- Monitoring and/or giving medicines
- Encouraging them to eat nutritious foods, drink plenty of water, and get enough rest
- Reminding them to avoid contact with sick people and practice good hygiene methods (such as frequent hand washing) to help decrease the chance of infection

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 overwhelming.

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 your loved one's symptoms and treatment side effects that you have noticed
- A list of questions
- A notepad for taking down new information
- A list of current medications

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, family, and local support groups

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. Local healthcare organizations, government agencies, and community groups may offer services to help as well.

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**
— caregiving.org
- **Caregiver Action Network**
— caregiveraction.org
- **Well Spouse Association**
— wellspouse.org

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

- **United States Department of Labor: Office of Disability Employment Policy**
— dol.gov/odep
- **Meals on Wheels America**
— mowaa.org
- **Air Care Alliance**
— 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**
— aamds.org
- **American Cancer Society's "WhatNext" Support Network**
— whatnext.com
- **Cancer Support Community**
— cancersupportcommunity.org/find-support
- **Leukemia & Lymphoma Society**
— lls.org/support/support-groups
- **MDS Foundation (You and AML)**
— youandAML.com
- 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
- **Anemia** – Low red blood cell count
- **Blasts** – Young, immature cells that build up in the bone marrow. They are unable to fight infections the way healthy, mature white blood cells can. Also known as myeloblasts
- **Bone marrow** – The soft interior of the bones where new blood cells are created
- **Complete remission/remission** – The absence of signs and symptoms of AML
- **Consolidation therapy** – Additional chemotherapy treatment that may be given after induction. Consolidation therapy consists of other therapies that can be used in combination with drugs used during induction, however, at different doses
- **Continued treatment** – Medication used in a person with AML in remission, after the first phase of cancer treatment, over an extended period of time
- **Cytopenia** – A low number of healthy cells
- **DNA** – Found inside the cells, DNA contains genetic information and makes up genes, which control the way cells function
- **Genes** – Part of the DNA, genes control the way cells function
- **Genetics** – Inherited family history
- **Hematopoietic stem cell transplantation** – This type of transplant involves transferring healthy stem cells from a donor to the patient
- **Induction therapy** – The first phase of treatment a person with AML receives. This treatment is usually the strongest against blast cells
- **Leukemic blasts** – Immature white blood cells that are unable to fight infections the way healthy, mature white blood cells can
- **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 (help with blood clotting)
- **Post-remission treatment** – Treatment that is given to continue to keep a person with AML in remission and can help prevent AML from returning
- **Red blood cells** – Carry oxygen from the lungs to all cells in the body
- **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

