

Talking About Acute Myeloid Leukemia



A GUIDE TO TALKING ABOUT TREATMENT WITH YOUR TEAM

This guide can help you take control and have better discussions with your health care team after a diagnosis of Acute Myeloid Leukemia (AML). Inside you'll find a quick overview of treatment options, questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.

AML treatments can include chemotherapy, targeted therapy, and stem cell/bone marrow transplants. Due to the acute nature of AML, treatment may start as soon as you are diagnosed. Things may happen very suddenly, and it is normal to feel anxious and overwhelmed. You can learn more about coping and details on treatments in our *Frankly Speaking About Cancer: Acute Myeloid Leukemia* and *Treatment for AML* booklets (www.CancerSupportCommunity.org/AML or 888-793-9355).

AML TREATMENT TERMS

You will hear many words used to describe AML. However, there are some terms that you should become familiar with as you discuss treatment options with your health care team. Some key ones to know are:

Induction therapy: The term induction is often used in reference to high-dose chemotherapy given to treat AML.

Remission: When signs and symptoms of cancer have disappeared (although you may still have some cancer cells in your body). Remission after induction therapy is common in AML. Nearly all patients in remission after induction would relapse if they did not have further treatment.

Consolidation therapy: Treatment that is given after the cancer is put in remission by induction therapy. For AML, consolidation therapy is most often one to four cycles of chemotherapy after a rest and recovery from induction therapy. Consolidation is also called postremission therapy.

Chemotherapy: Uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

Targeted therapy: Targeted drugs aim to block cancer growth driven by changes in the cancer's genetics. They may be given in combination with chemotherapy or alone.

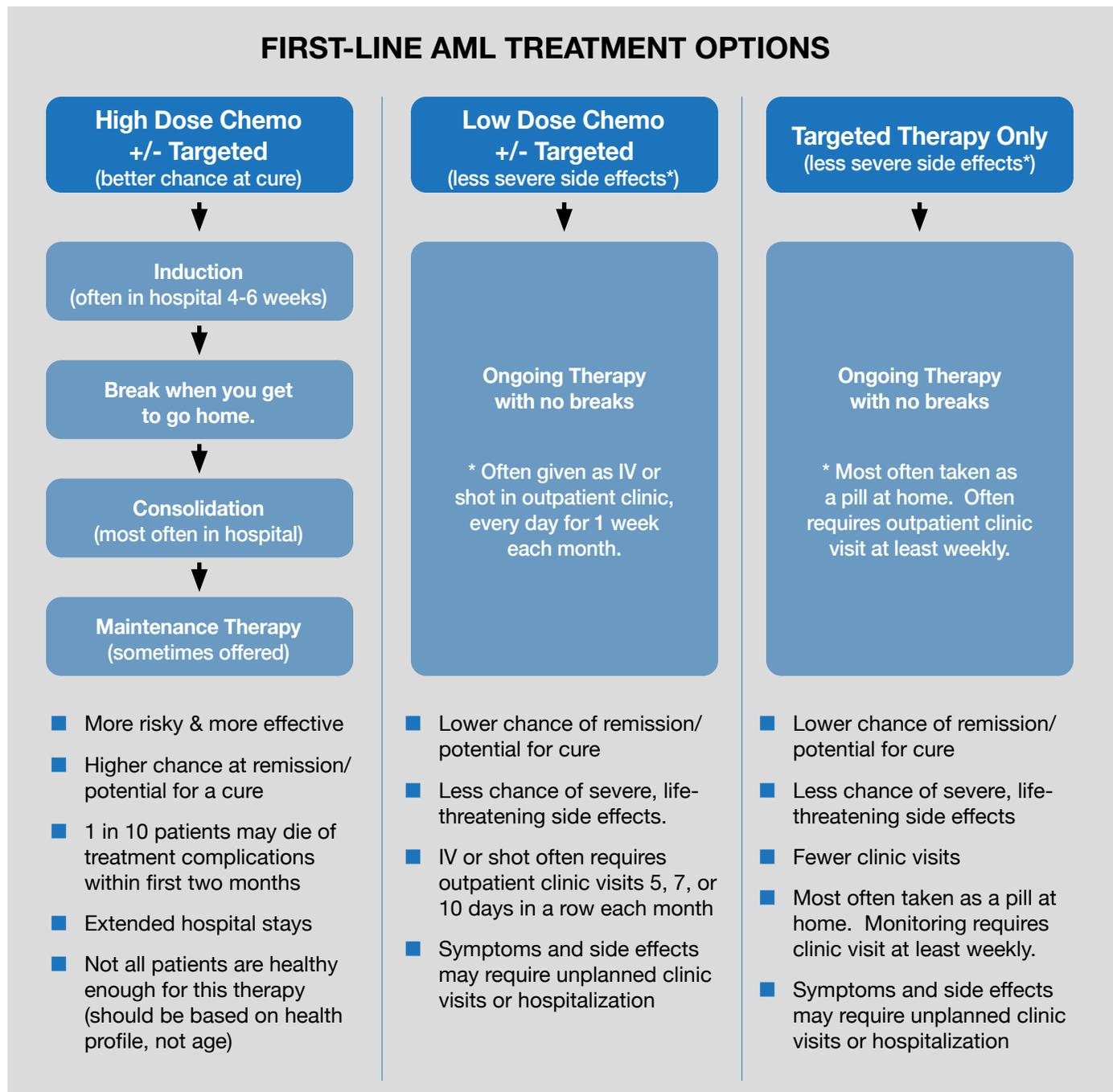
Stem cell/bone marrow transplant: Allows you to have high dose chemotherapy to kill any remaining cancer cells. Because high dose chemo also kills your normal blood-forming cells (stem cells), your cells are replaced with stem cells collected from the blood or bone marrow of a donor. A stem cell/bone marrow transplant gives you a better chance of a longer, durable remission.

Clinical trials: These studies are done to test new drugs, combinations of drugs, or different ways of doing stem cell/bone marrow transplant.

For more AML treatment terms, see Cancer Support Community's *Acute Myeloid Leukemia* and *Treatment for AML* booklets at www.CancerSupportCommunity.org/AML.

Overview of Treatment

Factors like your age, health, AML subtype, biomarker test results, and your risk of relapse help your doctor decide which treatments are best for you. Treatment options differ based on the patient. Before starting treatment, your health care team probably talked to you about the options of **high dose** and **low dose** treatment.



For more information on AML treatment, see Cancer Support Community's *Acute Myeloid Leukemia* and *Treatment for AML* booklets at www.CancerSupportCommunity.org/AML.

Your health care team may give you a choice on what treatment plan is best for you and best fits your goals and preferences. Make sure you ask questions and discuss any concerns with your health care team. See sample questions to ask your health care team starting on page 4.

THINK ABOUT TREATMENT AND PERSONAL GOALS

Whether you choose high or low dose therapy or choose to stop cancer treatment, it is important to be sure the goals of your care team’s treatment match up with your current personal goals. When you talk to your doctor about your treatment options, ask about the goals of treatment and how each treatment might affect the goals that you have for your life.

Possible goals may be to live as long as possible, to live as normally and as well as possible, to make it to a special event/milestone, or to contribute to progress by taking part in research. Let your health care team know about your treatment and personal goals. Here’s a worksheet to help you think through what goals are most important to you:

Physical Health and Well-being	What is most important for you to be able to do?
Family and Social Relationships	What’s going on in in the lives of others that is important to you?
Work/ School	Do you want to continue working? Can you adjust your schedule or responsibilities?
Personal/ Spiritual Growth	How is your confidence and self-esteem? Are you able to do things you enjoy?
Community/ Involvement	Are you getting the support you need from your community? Are you able to stay active/involved in your community?

GETTING SUPPORT

- You and your primary caregiver are going to need support. Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).
- Make a list of things you need (child care, meal prep, transportation, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support. You can also ask for a mentor or to be matched with another person with AML.
- AML survivors recommend having a caregiver take notes when you meet with your doctor.
- CSC and many other organizations have educational information, helplines, support groups, online discussion boards, and more ways to seek support from others who have AML.

FINANCIAL RESOURCES

- Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.
- Talk with your health care team, pharmacist, and treatment center about the cost of your treatment.
- Ask your team to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing the financial issues and costs.
- Reach out to your health insurance company to find out what resources they have that could help you. Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment is far away, ask if there are assistance programs that can help cover your travel costs. There are also housing/lodging programs that can provide temporary lodging throughout your treatment.
- The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment or applying for disability, visit:
www.CancerSupportCommunity.org/cost
or call our Helpline at 888-793-9355.

QUESTIONS FOR MY HEALTH CARE TEAM

Things might move quickly after your diagnosis and you may start treatment right after your diagnosis. You can always ask questions even if you are currently receiving treatment. Below are some questions that you might ask:

AT DIAGNOSIS/WHEN GETTING A SECOND OPINION

1. What type & subtype of AML do I have? Did I test positive for any biomarkers like FLT3, p53, IDH1, or IDH2?
2. What is your goal for my treatment? What would a cure look like for me?
3. If remission is not the goal, what is the goal for my treatment?
4. My top personal goals are *[Fill in your answers from the goals section, above]*: _____.
Is the treatment I am currently on the best treatment for me to meet my personal goals?
5. What other treatments are available to me based on my health profile?
6. Should I be thinking about a stem cell/bone marrow transplant? If so, when will the Transplant Team start looking for a donor?
7. What are the pros and cons of each treatment option that is available for me? What are the chances that this treatment may harm me? (Most patients overestimate the harm their treatment may do.) What are the chances that this treatment may cure me? (Most patients also overestimate their chance for a cure.)
8. Are there any new treatments or clinical trials that may be right for me?
9. What are my treatment options if I relapse?
10. What is my prognosis?
11. What treatment will I need next? Will that be given in the hospital? How much time will the therapy take?
12. How can I manage treatment costs? Will it be covered by my insurance? Is there a financial navigator or social worker that I can talk with? How do I apply for disability?
13. What side effects might I expect, and how can I prepare for them? What side effects should I be concerned with and monitoring? What side effects should I let you know about?
14. Will I need a full-time caregiver? Can I drive?

DURING TREATMENT

15. How many cycles of chemotherapy and/or targeted therapy will I have?
16. What are some side effects that I may experience? How will I feel after each cycle of treatment?
17. Is there anything I can do to lessen the side effects?
18. Are my blood counts returning to normal? If not, what are the next steps?
19. Are there any changes I can make to my lifestyle in order to improve my prognosis?
20. How do we know if I am in remission? When does this happen?

QUESTIONS FOR MY HEALTH CARE TEAM (CONTINUED)

21. How long will I receive this treatment? How much time will each treatment session take?
22. How long will I be hospitalized or need to stay away from crowds or public place?
23. What treatments will I need after induction therapy? Will that be given in the hospital? How much time will the therapy take?
24. What consolidation therapy do you recommend for me? Will that be given in the hospital? How much time will consolidation therapy take?
25. Do I need to change my other medications? Do I need to supplement my diet? Should I take vitamins?
26. How often will I need a stem cell/bone marrow transplant? Will I need more than one?
27. How often will I need a biopsy?

GENERAL QUESTIONS TO ASK ANY TIME

28. The symptoms and side effects that are bothering me the most are: _____.
They are affecting my daily life in these ways: _____.
What can we do to manage these symptoms? _____.
29. Could palliative (supportive) care help manage my symptoms and side effects? Can you refer me to a palliative care specialist?
30. How do I find out more about what foods to avoid, how to increase my appetite, etc.? Is there a nutritionist that I can meet with?
31. What activities do I need to avoid? Should I exercise or not? Can I drive?
32. What do I need to do to avoid infection? Avoid crowds? People with illnesses?
33. When can I go back to work/school? Can I play with my pets and/or kids? Can I work in my garden? Can I have dental work done?
34. How do I find a caregiver or support at home? Are there support services for caregivers?
35. How do I find a therapist or other help for coping with AML?
36. How do I find support groups or supportive online communities?
37. How can I manage pain? Do you recommend physical therapy?

MORE RESOURCES

For more information and key questions to ask about your treatment see our *Frankly Speaking About Cancer: Acute Myeloid Leukemia* and *Treatment for AML* booklets at www.CancerSupportCommunity.org/AML.

The Cancer Support Community's **Open to Options**[®] program can help you think through treatment options by preparing a list of personalized questions to share with your doctor. Our Open to Options[®] specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



AML Information, Survivorship & Support

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

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

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

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

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

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

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

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 9 am - 9 pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation

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

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



The Cancer Support Community provides 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 worksheet 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 or call 888-793-9355.

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