

# FRANKLY SPEAKING ABOUT CANCER

## Treatment for Acute Myeloid Leukemia (AML)

Companion to  
FRANKLY SPEAKING  
ABOUT CANCER:  
ACUTE MYELOID  
LEUKEMIA



Being diagnosed with Acute Myeloid Leukemia (AML) happens quickly and can be overwhelming. We created this booklet that details the chemotherapy and targeted therapy drugs used to treat AML and questions to ask your health care team when making treatment decisions. Your treatment options will depend on the type and stage of your cancer, as well as the genetic makeup of your tumor and your health profile.

We hope this will help you learn more about your options and feel empowered to take control of your life. Additional information can be found in our *Frankly Speaking About Cancer: AML* booklet. For information about AML and how to cope, visit [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML).



## QUESTIONS FOR TREATMENT PLANNING

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

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

## QUESTIONS FOR TREATMENT PLANNING (CONTINUED)

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

- What are my goals for my treatment?
- What is most important to me right now?
- What am I willing to go through to achieve my goals?
- What am I worried about?

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

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

### Questions When Heading Home from the Hospital or Finishing Treatment

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

# CHEMOTHERAPY FOR AML

Chemotherapy (also called chemo) uses drugs to attack and kill cancer cells. These very strong drugs attack fast-growing cells like cancer. Chemotherapy can be given as a single drug or in combination with other drugs such as immunotherapy or targeted therapy.

Most chemotherapy drugs are given by IV (through a vein). Some drugs can be taken by injection or by mouth, as a pill. Because the drugs continue to work for days or weeks after they are taken, a period of rest and recovery follows each dose or cycle.

**These are the chemotherapy drugs that are available as of May 2020.** Keep in mind that you may not get any or even most of the possible side effects of a drug. New treatments become available all the time, so this may not be a complete list. You can download the most up-to-date list of targeted therapy drugs at [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML).

CATEGORY	DRUG/BRAND	COMMON SIDE EFFECTS
Anthracycline	<ul style="list-style-type: none"> <li>daunorubicin (Cerubidine®)</li> <li>idarubicin (Idamycin®, Idamycin PFS®)</li> <li>mitoxantrone (Novantrone®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Injection site pain</li> <li>Changes in urine color</li> <li>Nausea/vomiting</li> <li>Mouth sores</li> <li>Hair loss</li> <li>Diarrhea</li> <li>Liver problems (mitoxantrone)</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Heart problems</li> <li>Slight risk of developing blood cancer in the future (mitoxantrone)</li> </ul>
Alkylating Agent	<ul style="list-style-type: none"> <li>cyclophosphamide (Cytoxan®, Neosar®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Hair loss</li> <li>Nausea/vomiting</li> <li>Decreased appetite</li> <li>Discolored nails or skin</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Urinary/kidney problems</li> <li>Slight risk of developing blood cancer in the future</li> <li>Heart problems</li> </ul>
Antimetabolite— Miscellaneous	<ul style="list-style-type: none"> <li>hydroxyurea (Hydrea®, Droxia®, Mylocel®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Nausea/vomiting</li> <li>Mouth sores</li> <li>Diarrhea</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Slight risk of developing secondary cancer in the future</li> </ul>

# CHEMOTHERAPY FOR AML

Antimetabolite— Pyrimidine Analog	<ul style="list-style-type: none"> <li>cytarabine (Cytosar-U®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Headache</li> <li>Nausea/vomiting</li> <li>Mouth sores</li> <li>Liver problems</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Flu-like symptoms</li> <li>Eye inflammation</li> </ul>
Antimetabolite— Purine Analog	<ul style="list-style-type: none"> <li>cladribine (Leustatin®)</li> <li>fludarabine (Fludara®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Fatigue</li> <li>Cough</li> <li>Nausea/vomiting (fludarabine)</li> <li>Decreased appetite</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Kidney problems (cladribine)</li> <li>Liver problems (cladribine)</li> <li>Autoimmune disease (fludarabine)</li> <li>Neurologic problems</li> <li>Increased risk of developing secondary cancer in the future (cladribine)</li> <li>Reproductive problems</li> </ul>
Antimetabolite— Hypomethylating Agent	<ul style="list-style-type: none"> <li>azacitidine (Vidaza®)</li> <li>decitabine (Dacogen®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Nausea/vomiting</li> <li>Fatigue</li> <li>Cough</li> <li>Diarrhea or constipation</li> <li>High blood sugar (decitabine)</li> <li>Injection site pain (azacitidine)</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Kidney problems (azacitidine)</li> <li>Liver problems (azacitidine)</li> </ul>
Combination anthracycline and antimetabolite	<ul style="list-style-type: none"> <li>daunorubicin and cytarabine liposome (Vyxeos®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Diarrhea or constipation</li> <li>Nausea/vomiting</li> <li>Skin rash</li> <li>Swelling in hands, feet, ankles†</li> <li>Fatigue</li> <li>Muscle pain</li> <li>Headache</li> <li>Mouth sores</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Heart problems</li> </ul>
Plant alkaloids	<ul style="list-style-type: none"> <li>etoposide (Toposar®, VePesid®, Etopophos®)</li> </ul>	<ul style="list-style-type: none"> <li>Low blood counts*</li> <li>Nausea/vomiting</li> <li>Low blood pressure</li> <li>Menopause</li> <li>Loss of fertility</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>Slight risk of developing blood cancer in the future</li> </ul>

\*White and red blood cells, platelets

†Edema

# TARGETED THERAPY FOR AML

Targeted therapy is a newer form of cancer treatment that may be used to treat AML. Targeted therapies block the action of certain genes, proteins, or molecules that cause cancer to grow and spread. Biomarkers are features of your tumor that can be measured to help guide your therapy. Your doctor will need to test your tumor for biomarkers to find out if targeted therapy is right for you. This is called biomarker testing. Biomarker testing is often also called molecular testing, genetic testing, or genomic testing.

Most AML targeted therapies are taken by mouth as a pill. A few are given by IV (through a vein), sometimes in combination with chemotherapy.

**These are the targeted therapy drugs that are available as of May 2020.** Keep in mind that you may not get any or even most of the possible side effects of a drug. New treatments become available all the time, so this may not be a complete list. You can download the most up-to-date list of targeted therapy drugs at [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML).

CATEGORY	DRUG/BRAND	COMMON SIDE EFFECTS
FLT3 Inhibitor	<ul style="list-style-type: none"> <li>• midostaurin (Rydapt®)</li> <li>• gilteritinib (Xospata®)</li> </ul>	<ul style="list-style-type: none"> <li>• Low blood counts*</li> <li>• Nausea &amp; vomiting (midostaurin)</li> <li>• Diarrhea</li> <li>• Swelling of hands, feet, ankles†</li> <li>• Mouth sores (midostaurin)</li> <li>• Skin rash (gilteritinib)</li> <li>• Fatigue</li> <li>• Shortness of breath</li> <li>• Headache (midostaurin)</li> <li>• High blood sugar</li> <li>• Muscle, bone or joint pain</li> <li>• Liver problems</li> <li>• Kidney problems (gilteritinib)</li> <li>• Electrolyte imbalance‡</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>• Heart rhythm problems</li> <li>• Lung problems (midostaurin)</li> <li>• Pancreas problems (gilteritinib)</li> </ul>
IDH Inhibitor	<ul style="list-style-type: none"> <li>• ivosidenib (Tibsovo®)</li> <li>• enasidenib (Idhifa®)</li> </ul>	<ul style="list-style-type: none"> <li>• Electrolyte imbalance‡</li> <li>• Diarrhea</li> <li>• Nausea/vomiting</li> <li>• Decreased appetite (enasidenib)</li> <li>• Fatigue</li> <li>• Swelling of hands, feet, ankles†</li> <li>• High white blood cell count</li> <li>• Shortness of breath</li> <li>• Joint pain (ivosidenib)</li> </ul> <p><b>Rare but serious side effects</b></p> <ul style="list-style-type: none"> <li>• Differentiation syndrome</li> <li>• Heart rhythm problems</li> <li>• Liver problems (enasidenib)</li> </ul>

# TARGETED THERAPY FOR AML

Anti-CD33 Antibody-Drug Conjugate	<ul style="list-style-type: none"> <li>• gemtuzumab ozogamicin (Mylotarg™)</li> </ul>	<ul style="list-style-type: none"> <li>• Low blood counts*</li> <li>• Liver problems</li> <li>• Nausea/vomiting</li> <li>• Fatigue</li> <li>• Fever</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>• Heart rhythm problems</li> </ul>
BCL-2 Inhibitor	<ul style="list-style-type: none"> <li>• venetoclax (Venclexta®)</li> </ul>	<ul style="list-style-type: none"> <li>• Low blood counts*</li> <li>• Diarrhea</li> <li>• Nausea</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>• Tumor lysis syndrome (that can cause kidney problems)</li> </ul>
Hedgehog Pathway Inhibitor	<ul style="list-style-type: none"> <li>• glasdegib (Daurismo™)</li> </ul>	<ul style="list-style-type: none"> <li>• Low blood counts*</li> <li>• Fatigue</li> <li>• Nausea/vomiting</li> <li>• Electrolyte imbalance<sup>‡</sup></li> <li>• Swelling of hands, feet, ankles<sup>†</sup></li> <li>• Muscle or bone pain</li> </ul> <p><b>Rare but serious side effects:</b></p> <ul style="list-style-type: none"> <li>• Heart rhythm problems</li> <li>• Pregnancy problems</li> </ul>

\*White and red blood cells, platelets

<sup>†</sup>Edema

<sup>‡</sup>i.e. potassium, sodium, calcium, magnesium, etc.

You can learn more about treatments and coping in our *Frankly Speaking About Cancer: Acute Myeloid Leukemia* booklet.

*Talking About Acute Myeloid Leukemia* is an easy-to-use worksheet that helps to facilitate better communication about AML and its treatment, the effects on ones quality of life, and how to align treatment choices with personal goals.

To download or order these materials, visit [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML) or call our Helpline at 888-793-9355.



# AML Information, Survivorship & Support

**Cancer Support Community** • 888-793-9355 • [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML)

**American Cancer Society** • 800-227-2345 • [www.cancer.org/cancer/acute-myeloid-leukemia](http://www.cancer.org/cancer/acute-myeloid-leukemia)

**Cancer.net** • 888-651-3038 • [www.cancer.net/AML](http://www.cancer.net/AML)

**Be The Match** • 800-627-7692 • [www.bethematch.org](http://www.bethematch.org)

**BMT Infonet** • 888-597-7674 • [www.bmtinfonet.org](http://www.bmtinfonet.org)

**Leukemia & Lymphoma Society** • 800-955-4572 • [www.lls.org/AML](http://www.lls.org/AML)

**National Cancer Institute's Clinical Trials Information** • 800-422-6237 • [www.cancer.gov](http://www.cancer.gov)

**Patient Advocate Foundation** • 800-532-5274 • [www.patientadvocate.org](http://www.patientadvocate.org)

## CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

**Cancer Support Helpline**<sup>®</sup>—Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am–9 pm ET.

**Open to Options**<sup>®</sup>—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**<sup>®</sup>—Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

[www.CancerSupportCommunity.org/FranklySpeakingAboutCancer](http://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](http://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. Connect with other AML patients by joining the Living with AML online discussion board. Sign up at [www.MyLifeLine.org](http://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](http://www.CancerSupportCommunity.org/become-advocate).

**Cancer Experience Registry**<sup>®</sup>—Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:**



This book is available to download and print yourself at [www.CancerSupportCommunity.org/AML](http://www.CancerSupportCommunity.org/AML). For print copies of this booklet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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.

© May 2020. Cancer Support Community. All rights reserved. Photography by Ed Cunicelli.