Effective Practices for Achieving and Maintaining Better Outcomes for Patients with Acute Myeloid Leukemia

INTRODUCTION

This effective practice guide has been prepared to highlight opportunities and strategies for cancer programs and practices to improve quality of care and outcomes for patients with acute myeloid leukemia who do not receive a transplant. This guide draws from multiple sources including academic literature, clinical guidelines, and interviews with experts in the field of acute myeloid leukemia.

Acute myeloid leukemia is an aggressive form of leukemia and occurs primarily in people who are 65 years or older.[1] The National Cancer Institute estimates that from 2015 to 2019, there were 4.1 new cases of acute myeloid leukemia per 100,000 individuals. Generally, in the same period, the 5-year relative survival rate was 30.5%. The median age of patients at diagnosis is 68, with most diagnosed between the ages of 65 to 74 years (26.0%), 75 to 84 years (22.9%), and 55 to 64 years (16.8%).[2]

Selection of therapies is based on individual characteristics, such as age, performance status, and the presence of (or lack thereof) comorbidities as well as disease characteristics. The preferred treatment for many adult patients with acute myeloid leukemia is induction therapy followed by hematopoietic cell transplant. As many patients do not receive a transplant, alternative approaches are needed to maintain remission and extend survival. For example, continued therapy with oral azacitidine may be an option for patients who have received intensive induction therapy. Regardless of treatment course, cancer care team members should consider the following strategies to help patients with acute myeloid leukemia achieve and maintain better outcomes.

Expert Insights

"For many people newly diagnosed with acute myeloid leukemia, transplant is considered the only potentially curative route. [Because] acute myeloid leukemia is a disease of the elderly, some patients may not be candidates based on comorbidities and other factors. Also, when you work with diverse populations, the number of people not receiving a transplant goes up even further based on needing intensive social support, inability to move away from home to a transplant center, inability to find a donor, etc. So, what happens is many of these patients are treated with nontransplant therapies, whether they were not candidates or otherwise could not get a transplant due to social determinants of health or other factors."

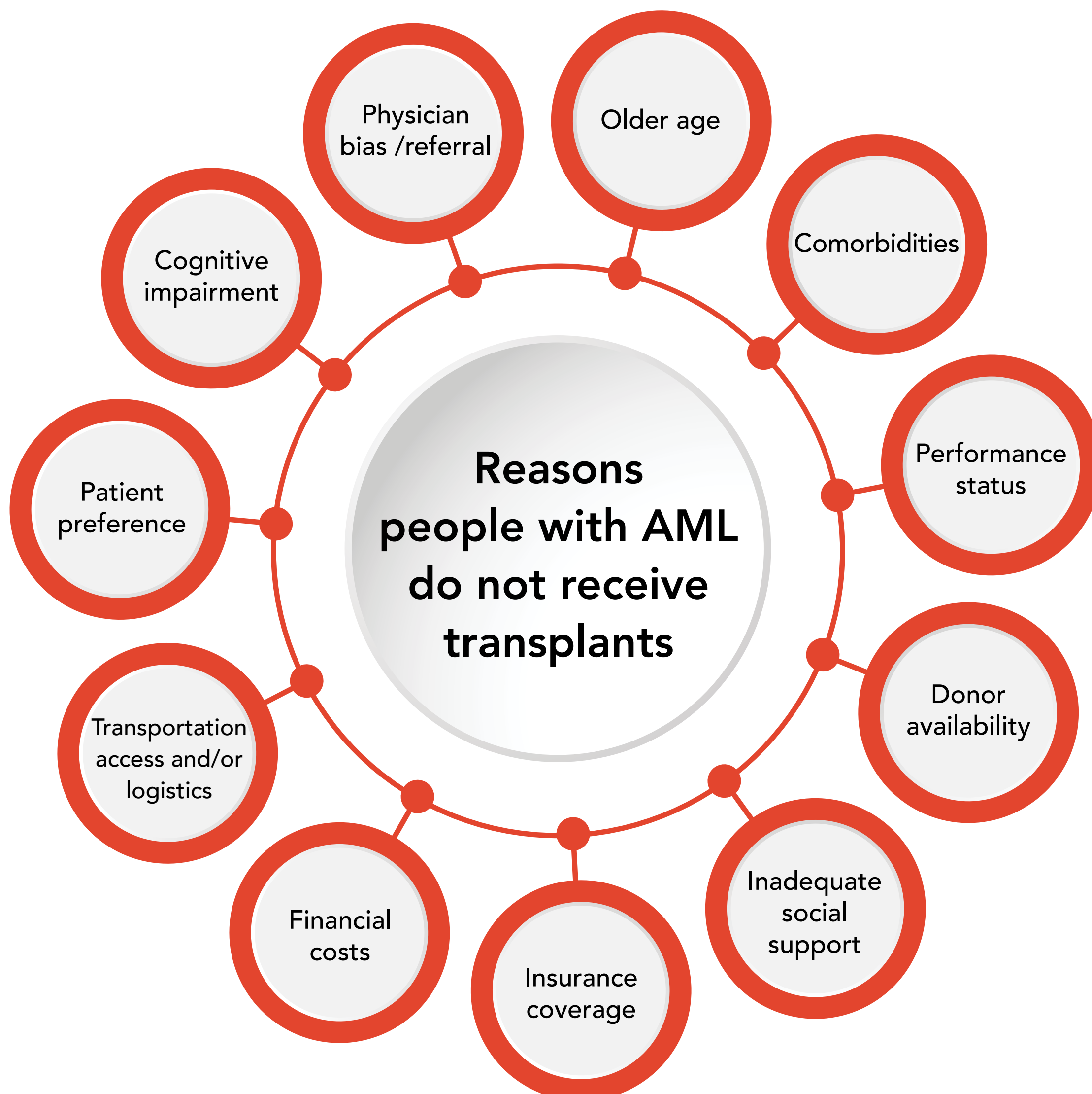
— Keri Maher, DO
Medical Oncologist and Director of the Acute Leukemia program
VCU Health System
VCU Massey Cancer Center

Expert Insights

"A large proportion of my practice is acute myeloid leukemia. The average age and onset of acute myeloid leukemia is 68 to 69 years and rising. In that age group, most people do not get a transplant. It is not necessarily because we do not think they should, but they may have organ impairment issues that make a transplant too risky or the patient decides not to get the transplant because of all that's involved—such as finances, caregiver support, geography/ability to move for 3 months to get a transplant. All these reasons conspire to make it such that although an allogeneic transplant is usually the only meaningful chance at long-term remission, most of my patients do not actually go on to get one. So, I'm managing many of my patients with nontransplant therapies."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

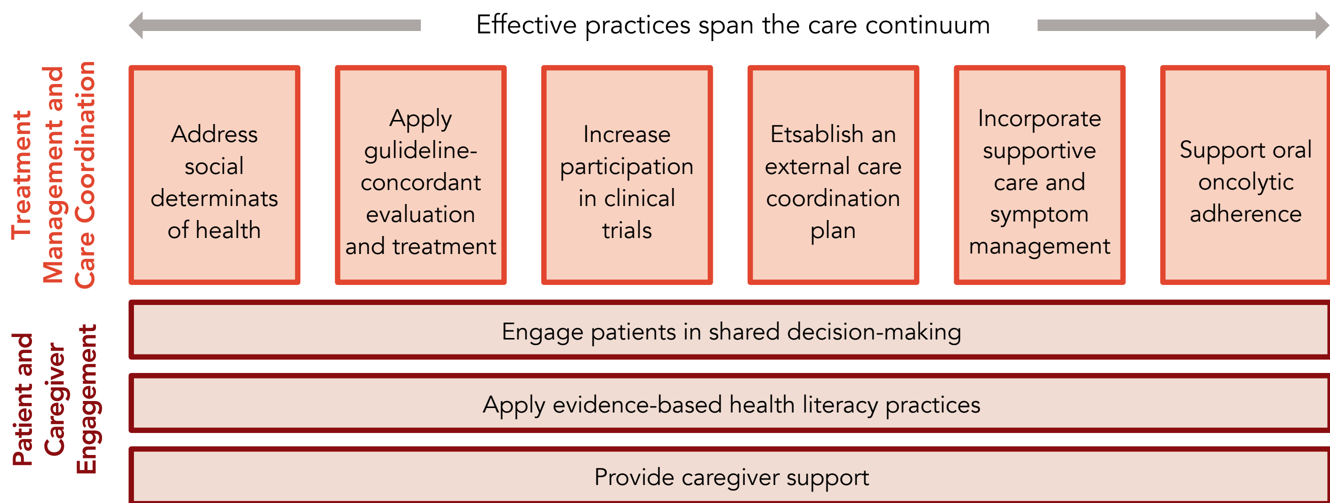
Figure 1. Factors That Contribute to Patients Not Receiving a Transplant[3]



EFFECTIVE PRACTICES

The following effective practices provide expert-driven, actionable recommendations for cancer programs and practices to incorporate into the evaluation, treatment, and management of patients with acute myeloid leukemia. These 9 effective practices, supported by practical tips, expert insights, and helpful resources, are equally important and may be utilized or referenced in any sequence.

Figure 2. Effective Practices in Optimizing Care for People with Acute Myeloid Leukemia



ADDRESS SOCIAL DETERMINANTS OF HEALTH

Practical Tips

Social determinants of health may account for many of the reasons why people with acute myeloid leukemia do not receive a transplant, such as access to health care, financial hardship, transportation challenges, housing insecurity, access to language services, and insufficient social support. Socioeconomically disadvantaged family and community members of patients may not be able to provide the caregiving support required to receive a transplant. Social determinants of health also contribute to disparities or inequities, such as access to affordable health insurance or to stem cell transplant and have been shown to impact survival outcomes for patients with acute myeloid leukemia.[4,5]

Screening for social needs can help cancer programs and providers better understand how social determinants of health impact the communities they serve and identify and mitigate barriers to care.

Experts recommend the following:

- Screen for social determinants at the patient's first visit to identify barriers and needs that would inform transplant evaluation, treatment planning, and referrals to team members who can address barriers, such as nurse navigators, social workers, and financial advocates.

- Connect patients with a nurse navigator to serve as the main liaison for the care team, conduct screening for social determinants, proactively address barriers, make referrals, and follow up with patients regarding symptoms and adherence.

- Work with a financial advocate to screen patients for risk of financial hardship at the beginning of treatment and at treatment milestones. Use this screening to identify appropriate interventions, such as manufacturer co-pay assistance and foundation financial assistance.

- Include nurse navigators, social workers, and financial advocates in multidisciplinary cancer conferences to identify and address specific barriers to care.

Expert Insights

"We know that patients who are ineligible for transplant may be so because of social determinants in and of themselves…[It is important to understand that] there are 3 categories of barriers that patients face when accessing care. I like to think of them as patient-based barriers, institutional-based barriers, and social-based barriers."

— Keri Maher, DO
Medical Oncologist and Director of the Acute Leukemia program
VCU Health System
VCU Massey Cancer Center

"Financial toxicity and transportation challenges are always our biggest barriers to care, especially for patients seen daily at the infusion center. Our navigators are our first line of defense for figuring out barriers and how to overcome them, including referring to the supportive services we offer. We have a financial navigation team that can identify interventions, such as accessing free drugs or working with [insurance providers] to make sure patients are paying the least out-of-pocket expenses as possible. We also have a social worker, who can help with transportation costs, taxi services, and Medicaid buses. We have counseling services for psychosocial support. Our navigators also connect patients with outside community cancer support services. So, our navigators are crucial to identifying what those barriers are and connecting them with these services."

— Brandy Morgan, BSN, RN, BMT-CN
Cellular Therapy Quality Navigator
Bon Secours, St Francis Health System

"We focus our energies on tailoring therapies to the patient's physical health, as well as the molecular characteristics of the leukemia, but no one's really paid attention to the third piece in that Venn diagram, which is the social determinants of health, both individual as well as the neighborhood, which represents the continuum of their experiences—their access to food, access to healthy spaces to stay fit and active, transportation, access to clinical care when needed. Our collective work, together with real-world data, suggests that incorporating validated measures of social determinants of health into clinical care is likely to contribute significantly to narrowing disparities in leukemia survival."[6]

— Irum Khan, MD
Associate Professor of Hematology/Oncology
Robert H. Lurie Comprehensive Cancer Center at Northwestern Medicine

"We are focused on shifting our culture at the team level to talk about where the patient's care is going to take place and the circumstances that impact their care up front in each conversation about the patient. We are incorporating this into our inpatient residents' notes templates in the electronic health record."

— Katie Russell, ARNP
Advanced Registered Nurse Practitioner
Fred Hutch Cancer Center

Helpful Resources

- **Structural Racism is a Mediator of Disparities in Acute Myeloid Leukemia Outcomes**
  Article in *Blood* that investigates structural racism as a mediator of survival disparities.

- **Strategies to Addressing Disparities in Patients with AML**
  Video podcast from ACCC discussing strategies to address social determinants of health that impact people with acute myeloid leukemia.

- **Practice Improvement and Social Determinants of Health**
  Resources from the Agency for Healthcare Research and Quality (AHRQ) to help health systems and providers assess social risks and needs, as well as tools to address them.

- **Financial Advocacy Services Guidelines**
  ACCC's evidence-based, consensus-driven guidelines for cancer programs and practices delivering financial advocacy services.

- **Financial Advocacy Playbook**
  A comprehensive toolkit from ACCC that provides practical tools and tips for oncology financial advocates and organizations looking to expand financial advocacy services.

- **Social Drivers of Health (SDOH) Resource Library**
  A comprehensive resource bank from ACCC of nationally available publications, tools, videos, and other relevant assets to help multidisciplinary cancer care teams identify and address social drivers of health and provide equitable care for patients.

- **Geriatric Oncology Resource Library**
  Curated resources and tools from ACCC for cancer programs looking to enhance their care for older adults with cancer.

APPLY GUIDELINE-CONCORDANT EVALUATION AND TREATMENT

Practical Tips

Oncology clinicians face the challenge of staying up to date on rapidly advancing diagnostic, treatment, and management recommendations for acute myeloid leukemia. Allogeneic transplant remains the best strategy for long-term remission for people with acute myeloid leukemia, but the barriers to transplant are high. Without a transplant, it is critical for cancer care teams to consider strategies that help keep the patient in remission as long as possible.

Treatment selection should incorporate up-to-date, expert-driven guidance and account for both disease-specific and patient-specific characteristics and risk factors.[7] To promote guideline-concordant personalized care, experts recommend the following for the multidisciplinary team:

- Learn about the importance and application of complete risk stratification in acute myeloid leukemia utilizing both molecular (polymerase chain reaction [PCR], next generation sequencing [NGS]) and cytogenetic (Fluorescence in situ hybridization [FISH], conventional karyotype) techniques.[8]

- Review updated guidelines from the National Comprehensive Cancer Network (NCCN) and American Society of Hematology (ASH) to guide evaluation and treatment and develop treatment algorithms. For example:

  - Evaluate all patients for transplant candidacy, ideally at or in collaboration with a specialist at a transplant center.

  - Define guideline-concordant treatment algorithms that tailor treatment options based on the patient's risk stratification.

  - Consider at least a one-time consult with an acute myeloid leukemia expert to review diagnostic workup, treatment options, and available clinical trials.

- For patients who are in remission but cannot or choose not to receive a transplant, learn about maintenance therapy as an option to extend remission and prolong survival.

- Consider performing a comprehensive geriatric assessment for patients 65 years and older who receive chemotherapy per the *Practical Assessment and Management of Vulnerabilities in Older Patients Receiving Chemotherapy: ASCO Guideline for Geriatric Oncology* to inform shared decision-making, treatment planning, and reduce age-related bias.

- Establish a process to assess fitness for intensive induction chemotherapy to ensure guideline-concordant treatment. Consider incorporating Ferrara criteria, which is used in clinical trials, and offers guidance on how to operationalize a fitness assessment.

- Discuss acute myeloid leukemia cases during hematology-specific multidisciplinary cancer conferences and molecular tumor boards.

- Assess program's expertise and capabilities to evaluate and deliver guideline-concordant molecular testing and treatment options.

- Identify and build relationships with cancer programs regionally for collaboration to address gaps in care, including hematopathologists and those with expertise in treating acute myeloid leukemia, molecular testing infrastructure, clinical trials, and comprehensive geriatric assessment.

Expert Insights

"We learned acute myeloid leukemia is an incredibly heterogeneous disease genetically. We now have different targeted treatments. However, we must know if those targets are there, and we have to recharacterize them every time a patient has a relapse or progression or some additional line of therapy that is being given. In community settings, we recognize that there is an opportunity for additional uptake of molecular profiling to be able to use this important information to guide treatment or help with shared decision-making with the patient."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

"Even just for the initial visit, think about referring to an expert who specializes in leukemia. Sometimes we need to make a decision pretty quickly, and molecular tests can usually be performed quickly at a center that has existing expertise and infrastructure. Getting these tests is guideline recommended and can help determine a patient's risk category."

— Melissa Kah Poh Loh, MBBCh, BAO, FACCC
Geriatric Hematologist and Oncologist
University of Rochester Medical Center
Wilmot Cancer Institute

"Acute myeloid leukemia is an uncommon disease. Community physicians do an outstanding job taking care of these patients. It's not something they necessarily see every day. With emerging treatments and new diagnostics, there's a lot of complexity in the management of these patients, it's important for community physicians to have individuals with specialized expertise with this disease that they can contact and rely on to communicate, bounce questions off, or refer patients to when needed."

— Geoffrey Uy, MD
Bone Marrow Transplant Specialist and Medical Oncologist
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

Helpful Resources

- **NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Acute Myeloid Leukemia**
- **NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Supportive Care**
- **ASH 2020 Guidelines for Treating Newly Diagnosed AML in Older Adults**
  Clinical practice guidelines for clinicians treating acute myeloid leukemia in older adults.
- **2021 Update on MRD in acute myeloid leukemia: a consensus document from the European LeukemiaNet MRD Working Party**
  Consensus-based recommendations for measurable residual disease (MRD) assessment in acute myeloid leukemia.
- **Diagnosis and management of AML in adults: 2022 recommendations from an international expert panel on behalf of the ELN**
  Updated recommendations from the European LeukemiaNet.
- **Practical Application of Geriatric Assessment: A How-To Guide for the Multidisciplinary Care Team**
  ACCC's guide on how to use comprehensive geriatric assessments to inform treatment decision-making, predict morbidity and mortality, guide supportive care interventions, improve patient and caregiver satisfaction, reduce treatment-related toxicity, and improve quality of life.
- **Acute Myeloid Leukemia and Myelodysplastic Syndromes in Older Adults**
  Journal of Clinical Oncology article reviewing evidence in the treatment of older adults with acute myeloid leukemia, including the role of individualized patient assessment.
- **Clarifying the Role of Maintenance Therapy**
  Video podcast from ACCC that discusses how to identify patients who are candidates for maintenance therapy and strategies to address barriers related to access and adverse event management.

ENGAGE PATIENTS IN SHARED DECISION-MAKING

Practical Tips

The sudden onset of acute myeloid leukemia in patients and the complexities of the disease and treatment options result in unique challenges to decision-making. Establishing goals of care is a key step of shared decision-making and should not be a one-time conversation. The conversation should be revisited throughout the course of treatment for a patient with acute myeloid leukemia. This includes during diagnosis, and at key treatment phases such as induction, evaluation for transplant, consolidation, maintenance, and disease relapse or progression.

The goals of care conversation should focus on learning about who the patient is as a person, how they make decisions, and their values and priorities, so providers can then discuss treatment options in a way that aligns with the patients' goals, preferences, and how they make decisions.

Experts recommend that care team members:

- Document patient values, goals, preferences, and priorities in their health record.
- Assess how patients want to participate in treatment decisions and who from among their support system they would like to include in decision making.
- Use an evidence-based decision framework to structure decision-making conversations with patients and caregivers, such as the Choice-Options-Decision model.[9]
- Incorporate discussion of the patient's goals of care and any preferences or values that would influence care planning recommendations into multidisciplinary cancer conferences.
- Involve nurses, who are often best positioned to identify patient preferences and detect distress, in the shared decision-making process.

Expert Insights

"I like to start shared decision-making conversations from the very beginning at diagnosis. You let the patient know that you see them as a human, their whole self, not just the disease. It's also important to keep these conversations going throughout treatment because their goals and preferences can change over time. Different goals are managed in different ways. You never know about a change in goals without asking. At the end of the day, that's what we're here for – to help patients live the best life they can – as defined by them."

— Keri Maher, DO
Medical Oncologist and Director of the Acute Leukemia program
VCU Health System
VCU Massey Cancer Center

"I use the comprehensive geriatric assessment and the preferences and values of the patient to help me know what is important to them, and then we will make a treatment decision together with the patients and caregiver(s)."

— Melissa Kah Poh Loh, MBBCh, BAO, FACCC
Geriatric Hematologist and Oncologist
University of Rochester Medical Center
Wilmot Cancer Institute

"Patients say, 'Oh, I'm doing well, I'm feeling better. I'm in remission, why do I need to keep taking this treatment?' You have to explain that if we stop, the leukemia will come roaring back within probably just a couple of months, maybe even a few weeks. This treatment just keeps the pressure on it to keep it at bay, so that you can live longer and live better. And then together, we have to balance the [adverse] effects of the treatment vs hurting the leukemia and keeping it suppressed."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

Helpful Resources

- **Critical Conversation Strategies for Patients with AML**
  Video podcast from ACCC that highlights strategies for engaging people patients with acute myeloid leukemia in critical conversations.
- **Shared Decision-Making in Acute Myeloid Leukemia**
  Seminars in Oncology Nursing article highlighting unique considerations for engaging patients with acute myeloid leukemia in shared decision-making and strategies for implementation.
- **Talking About Acute Myeloid Leukemia**
  A guide from Cancer Support Community that helps patients talk about their goals and treatment options with their care team.
- **Personalizing Care for Patients of All Backgrounds**
  A suite of resources from ACCC including videos, a resource library, and an infographic exploring best practices in personalizing care.
- **Shared Decision-Making: Practical Implementation for the Oncology Team**
  A guide from ACCC highlighting effective practices in building engagement with patients, with a special focus on shared decision-making in the context of metastatic disease, geriatric oncology, and limited health literacy.
- **SHARE Approach**
  A 5-step process clinicians can use to support shared decision-making. As part of SHARE, the ARHQ offers a training curriculum, decision aids, posters, and more to support implementation of shared decision-making into practice.
- **Broadening the Dialogue with Your Oncology Team About AML**
  This video from HealthTree highlights the importance of shared decision-making from the perspective of both the patient and the provider.

INCREASE PARTICIPATION IN CLINICAL TRIALS

Practical Tips

With increasing numbers of acute myeloid leukemia clinical trials being designed for older adults, participation in a clinical trial may be the best treatment option for patients. This is particularly true for acute myeloid leukemia because despite advances in treatment options, outcomes for patients who do not receive transplant remain poor. To increase enrollment of patients into trials, experts recommend that programs and practices:

- Offer clinical trials at all stages of diagnosis and treatment. Providers should refrain from considering clinical trials as a last resort.

- Communication and coordination are key between treating oncologist, clinical trial principal investigator (academic oncologist) and clinical research coordinator to ensure trial timepoints are being met, adherence to protocol, safety in community, and effective care. Consider leveraging telemedicine to help with communication and co-management of care.

- If your program or practice does not have clinical trials for people with acute myeloid leukemia, utilize an academic or leukemia center as a collaborative partner.

- Develop or join a local consortium, where there is dedicated time for academic and community providers to formally meet and discuss available trials.

- Engage directly with patients with acute myeloid leukemia and their caregivers to increase research awareness and incorporate their experiences and perspectives into the research process.

Expert Insights

"People tend to think an older, frailer patient is not eligible for a clinical trial, but we have many trials in our region that are specifically designed for people who are older."

— Keri Maher, DO
Medical Oncologist and Director of the Acute Leukemia program
VCU Health System
VCU Massey Cancer Center

"We send community physicians periodic emails updating them on available trials. We also have a yearly American Society of Hematology update that we invite community oncologists to join and include our clinical trials too."

— Melissa Kah Poh Loh, MBBCh, BAO, FACCC
Geriatric Hematologist and Oncologist
University of Rochester Medical Center
Wilmot Cancer Institute

Helpful Resources

- **ACCC Community Oncology Research Institute (ACORI)**
A network that helps community oncology programs access tools, knowledge-sharing, effective practices, and peer mentorships.

- **Clinical Research Terms Glossary**
An ACORI resource that provides definitions of words and terms related to clinical research in clear language to help improve patient education and shared decision-making discussions.

- **Leukemia & Lymphoma Society (LLS) Clinical Trial Support Center**
Provides patients and caregivers with access to clinical trial nurse navigators to identify clinical trial options.

- **HealthTree Clinical Trials**
An online resource that lists acute myeloid leukemia clinical trials. HealthTree also has a patient experience team that can help patients find and enroll in a trial.

- **Clinicaltrials.gov**
A searchable database of current clinical studies.

ESTABLISH AN EXTERNAL CARE COORDINATION PLAN

Practical Tips

Several factors come into play when considering where a patient with acute myeloid leukemia should be treated, including level of acute myeloid leukemia expertise, treatment capabilities (eg, transplant, induction therapy), and the patient's ability to travel.

External care coordination between programs with advanced capabilities to treat acute myeloid leukemia and community oncologists can help ensure the patient has access to up-to-date treatments and clinical trials while having some degree of care close to home. Below are some circumstances where referral from a community program to an academic or leukemia center should be considered[10]:

- Patient preference
- Patients treated with curative intent
- Possibility for future allogeneic hematopoietic cell transplantation
- Clinical trial availability
- Limited experience with selected therapy/therapies
- Supportive care therapies not available or readily accessible
- Therapy-related acute myeloid leukemia or acute myeloid leukemia with myelodysplasia-related changes
- Relapsed/refractory acute myeloid leukemia.

Additional recommendations include the following:

- Academic centers and other specialized leukemia programs should build relationships with local and regional community physicians and share information on their services; this should include how to refer for timely evaluation of patients with diagnosed or suspected acute myeloid leukemia. Consider conducting regular education or symposia on both clinical and operational topics related to acute myeloid leukemia.
- Share direct contact information, such as direct office and mobile numbers, between referring physicians and acute myeloid leukemia experts.
- For referring programs and providers, establish a process with a nearby leukemia-treating center to transfer acutely ill patients presenting with acute myeloid leukemia.[11]
- Consider using telehealth to coordinate joint meetings between the community oncologist, the acute myeloid leukemia expert, and the patient and caregiver(s).
- Acute myeloid leukemia experts and community oncologists should establish an external care coordination plan that is documented in the patient's medical record(s), included in discharge plans, and shared with the patient and their caregiver(s) (see Appendices A and B for examples).

Expert Insights

"We collaborate a lot with community centers around the management of patients with acute myeloid leukemia, particularly if patients live far away from our center or prefer to be treated locally. How coordination looks in practice really depends on the site and their comfort level in treating patients with acute myeloid leukemia. It ranges from us providing our evaluation of the patient and the regimen we recommend and then the community site takes on the rest, vs we may give the chemotherapy at our site and then have some of the supportive follow-up care happen locally…Through care coordination and telehealth, we can deliver high quality care to patients in their community, and that's tremendous for patients and their caregivers not spending 3-4 hours a day in the car seeing their provider."

— Geoffrey Uy, MD
Bone Marrow Transplant Specialist and Medical Oncologist
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

"We get referrals from primary care physicians and from other community oncologists who do not have the capability to treat acute myeloid leukemia. While the pandemic temporarily slowed outreach efforts, we recognize the importance of reaching out to small community practices to say we are close by and can help take care of patients with acute myeloid leukemia."

— Brandy Morgan, BSN, RN, BMT-CN
Cellular Therapy Quality Navigator
Bon Secours, St Francis Health System

"When developing a co-management plan with a community oncologist, I see the patient in person or via telehealth monthly for the first 2 to 3 months. If they are in remission and doing OK, I space visits out further. There are people I still see every 3 months that are 3 years into remission, but they still see their community oncologists once a month. The oncologists reach out if they have questions and I am in the background supporting."

— Melissa Kah Poh Loh, MBBCh, BAO, FACCC
Geriatric Hematologist and Oncologist
University of Rochester Medical Center
Wilmot Cancer Institute

Helpful Resources

- **Co-management Strategies for Acute Myeloid Leukemia Patients in the Community Setting**
  A *Frontiers in Oncology* article that reviews strategies for managing acute myeloid leukemia in the community setting, including circumstances where referral and co-management should be considered.

- **Optimizing Management of Acute Leukemia in Community Centers and When to Refer**
  An American Society of Hematology (ASH) education program to help review the management acute leukemia in the community setting and understanding barriers to treatment outside of academic centers.

- **AML Care Coordination in the Community Setting**
  A video podcast from ACCC that discusses strategies for co-managing patients with acute myeloid leukemia in the community setting.

- **Clinical Sustainability Assessment Tool**
  A dynamic tool that helps clinical practices evaluate their capacity across 7 domains, including organizational readiness, engaged staff, and workflow integration.

- **AML Specialist Directory**
  HealthTree offers a searchable directory to find acute myeloid leukemia specialists in the United States.

SPOTLIGHT: QUALITY IMPROVEMENT TO OPTIMIZE EXTERNAL CARE COORDINATION

A cohort of 4 ACCC cancer program members were selected to participate in a quality improvement initiative to optimize care for patients with acute myeloid leukemia: I*vinson Community Hospital* in Laramie, Wyoming, *University of Colorado Anschutz Medical Center* in Aurora, Colorado, *Rocky Mountain Cancer Centers* in Englewood, Colorado, and *Fred Hutchinson Cancer Center* in Seattle, Washington. The goal of the program was to help patients with acute myeloid leukemia who do not receive a transplant achieve and maintain first remission and improve quality of care, specifically related to:

- Improving care coordination internally and/or between community and academic/leukemia centers, and
- Managing adverse treatment events, including maintenance therapy.

Program participants identified an opportunity for this diverse group of practices to create tools on how to transition a patient with acute myeloid leukemia between academic and community sites. The cohort decided to work together to create tools to empower care team members to improve care planning and coordination. Each site tailored the tools to align with their internal workflows and external partners.

The following resources were developed and implemented during the quality improvement program. These tools provide a list of considerations to include in external care coordination checklists for use between programs with advanced capabilities to treat acute myeloid leukemia and community oncologists.

Checklist: External Care Coordination at Diagnosis
This tool (see Appendix A) can be adapted for any cancer program, and includes:

- Care partner direct contact information
- Workup prior to arrival at leukemia treatment center
- Cardiac screenings
- Vascular access
- Intensive therapy eligibility
- Clinical trial availability
- Provider resources
- Patient resources.

Checklist: Post-Induction External Care Coordination for Patients on Maintenance Therapy
This tool (see Appendix B) can be adapted for any cancer program, and includes:

- Care partner direct contact information
- Summary of discharge instructions
- External care coordination process
- Patient circumstances
- Treatment needed and parameters
- Anticipatory guidance for bone marrow biopsies
- Supportive care parameters
- Adverse event management plan
- Provider resources
- Patient resources.

INCORPORATE SUPPORTIVE CARE AND SYMPTOM MANAGEMENT

Practical Tips

Supportive care for acute myeloid leukemia addresses the symptoms caused by the disease and its treatment. It is critical for care teams to both proactively prevent common symptoms and have symptom management strategies in place so treatments can continue to keep the disease at bay. Patients and caregivers must also understand what to look for and what actions to take. Experts recommend the following:

- Identify which supportive care services are feasible for local care providers to manage closer to the patient's home. Partner with a program that has capacity to supplement any gaps in services (eg, ability to access blood products for frequent transfusions).
- Establish standard orders for supportive care medications as part of treatment plans for acute myeloid leukemia regimens (eg, infectious disease prophylaxis for high or low intensity treatment, nausea and vomiting prophylaxis for oral azacitidine).
- Develop pathways for early and prompt evaluation and management of patients in the event of severe neutropenia and fevers or potentially life-threatening infections.
- Create a clear game plan for what happens if a patient goes to the emergency department or to urgent care, and how that is communicated to the patient's care team, including consultation of the acute myeloid leukemia expert before deciding to pause treatment.
- Consult acute myeloid leukemia experts to manage dose modifications and adverse events during post-remission treatment, including consolidation therapy and maintenance therapy.
- Integrate palliative care services early for patients with acute myeloid leukemia. If there is not an outpatient palliative care practice, oncology programs and practices can integrate palliative care clinicians, such as nurse practitioners or physician associates, or consider connecting patients with a clinician via telehealth.
- Utilize pharmacy and nursing staff to engage patients in education about their treatment, including medication instructions, potential adverse effects, how to manage at home, what to watch for, and a game plan for how to report concerning symptoms as well as when/how to seek medical attention.
- Proactively reach out to patients, particularly during the first cycle of a new regimen, to assess symptoms and identify any necessary interventions.

Expert Insights

"For patients with acute myeloid leukemia, we have done a conclusive trial showing the benefits of integrated palliative care, including substantial improvements in quality of life, psychological distress, and end of life care. It should be considered a new standard of care for this population. Integrating palliative care clinicians reduces the need for people to go to the emergency room or be hospitalized, and it helps patients, families, and the practice—everyone wins."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

"Patients with acute myeloid leukemia often run into infections in the first 1 to 2 months of treatment, and when they are admitted to the hospital, treatment is stopped. When a patient's white blood cells are low or they are anemic, a physician may also pause treatment because they are concerned the blood cell numbers will get worse. For other kinds of cancer, we typically do pause treatment when blood cell numbers are low, but in this case, it is the leukemia that is causing those numbers to be low. If you stop treatment, those numbers will likely not improve so sometimes we push through and still treat. We would transfuse the patient to get them through the first 2 cycles because that is the most important to get them to remission. If blood counts are low once the patient is in remission, it is likely due to the treatment which is why it is helpful to have an expert in the background who can collaborate via video or phone call to support treatment decisions."

— Melissa Kah Poh Loh, MBBCh, BAO, FACCC
Geriatric Hematologist and Oncologist
University of Rochester Medical Center
Wilmot Cancer Institute

"When the physician is putting in the goals of care and treatment plan, we as pharmacists are looking at appropriate dosing and any drug-to-drug interactions, or if there needs to be alternative agents for psychiatric or cardiology medications. Additionally, we will assess to make sure patients have the appropriate supportive care medications available to them up-front to address management of nausea/vomiting as well as infectious disease risks, such as prophylactic antiviral, antifungal, or antibacterial medications."

"We have a standard process in place for any patient who is new to treatment, whether oral or intravenous. Within 24 to 48 hours of that treatment, they get a follow-up phone call from the nurse in clinic to check-in, remind patients we are here to help, and how to reach us if a situation arises. Repetitive follow up is tough to do if you are not resourced appropriately, but you can start with the beginning of patients' treatment and work from there."

— Drew Mace, PharmD
Manager of Pharmacy Services
Penn Medicine Lancaster General Health
Ann B. Barshinger Cancer Institute

"Especially for acute myeloid leukemia, really put some focus on your psychosocial supportive services. We are not a big hospital, but if you can just get the right person in that role, you have the ability to make such an impact on patients and the care delivery that you give as a community hospital. I know it is hard, putting new bodies in positions. But maybe it is utilized in another service line and it is a matter of how to incorporate that into our oncology line as well."

— Brandy Morgan, BSN, RN, BMT-CN
Cellular Therapy Quality Navigator
Bon Secours, St Francis Health System

Helpful Resources

- **CCN Supportive Care Guidelines**
  Clinical practice guidelines for clinicians to incorporate supportive care across cancer type, including guidelines for antiemesis, growth factors, palliative care, and prevention and treatment of infections.

- **Antiemetics: ASCO Guideline Update 2020**
  Clinical practice guidelines with recommendations on the use of antiemetics during cancer treatment.

- **Clarifying the Role of Maintenance Therapy**
  Video podcast from ACCC that discusses how to identify patients who are candidates for maintenance therapy and strategies to address barriers related to access and adverse event management.

SUPPORT ORAL ONCOLYTIC ADHERENCE

Practical Tips

The use of oral drugs to treat cancer continues to grow exponentially. For acute myeloid leukemia, there are a number of oral agents that may be taken alone or in conjunction with intravenous chemotherapies. Although oral drugs offer benefits, such as reducing clinic visits, patients are still faced with similar adverse effects to intravenous chemotherapies as well as potentially more out-of-pocket expenses. To support adherence to oral agents, experts recommend the following:

- Ensure patients receive oral oncolytic education using evidence-based health literacy practices.
- Assess social determinants of health and financial toxicity that could impact adherence or access to medication.
- Document, whether in the EHR or other tracking mechanism, which patients are on an oral agent.
- Establish a consistent process to assess patients on oral therapies at each visit for potential toxicities and barriers to taking medications at home.
- Create a smart phrase in the EHR to trigger documentation of conversations with patients about toxicities, adherence, and financial barriers.

Expert Insights

"Standardizing follow up for patients on oral therapies to identify if they have challenges, such as a phone call 24 to 48 hours after refilling a medication, is helpful. You can also assess refill data to see if they are adherent. Because when you sit in front a physician, we all are inclined to say we are taking all of our medications. But it could be a totally different story."

— Brandy Morgan, BSN, RN, BMT-CN
Cellular Therapy Quality Navigator
Bon Secours, St Francis Health System

"Oral therapies are growing exponentially, so we have to learn how to manage those as well as we do with intravenous therapies. Since everything goes through our financial navigation team to help patients with insurance benefits and financial assistance, we work with them to get a list of which patients are on oral therapies. Once patients start on their drug, we create a smart phrase in the EHR that helps track if the physician or nurse practitioner has addressed all of the important elements, like assessing for toxicities each time, confirming medication adherence, and assessing for financial barriers to refilling prescriptions."

— Lara Widener
Oncology Quality Manager
Bon Secours, St Francis Health System

Helpful Resources

- **Oral Anticancer Medication Learning Library**
  Learning library from the Oncology Nursing Society (ONS) offering resources for nurses and other providers to be able to support patients who take oral agents.

- **Steps to Success: Implementing Oral Oncolytics**
  White paper from ACCC offering effective practices, peer-to-peer insight, tools, and resources to help support the implementation and adherence to oral oncolytics.

- **Oral Chemotherapy Education (OCE)**
  OCE is a resource established by NCODA with partners (including ACCC) for patients and healthcare professionals to help communicate vital information about oral chemotherapy medicines.

APPLY EVIDENCE-BASED HEALTH LITERACY PRACTICES

Practical Tips

Acute myeloid leukemia is a complicated disease. Further, treatment options are based on a variety of different factors, but could include combination therapies, emerging therapies, and clinical trials. For providers, this means there is a lot of complex information to convey to patients and caregivers. For patients, this means potential information overload or receiving very general information, but neither option supports patients nor their loved ones in informed decision-making.

The importance of delivering multimodal communications that are health literate and culturally and linguistically appropriate has been well documented. When communicating with patients with acute myeloid leukemia, experts recommend:

- Know that all patients can experience difficulty understanding complex information in a health crisis; apply health literacy practices universally to every patient, every time.

- Provide acute myeloid leukemia-specific, patient-centered education resources in a variety of formats to account for varied learning styles and preferences of patient and caregiver(s).

- Break down medical jargon into simple terms.

- Ask open-ended questions.

- Engage patients in the teach-back method[12].

- Use interpretation services (not a family member) and provide resources in multiple languages.

Expert Insights

"The term 'remission' can be confusing for patients and caregivers. I emphasize that remission doesn't necessarily mean a cure, but it can be a step toward a cure. But once a person is in remission, if we stop treatment, at that point almost everybody with this disease will have a relapse where the disease comes back and then it is more difficult to treat. So remission is the first step. Once we get there, we give post-remission therapy, to basically deepen and prolong the remission, or maybe to increase the chance of cure if that is something that is on the table for a particular patient."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

Helpful Resources

- **Frankly Speaking About Cancer: Acute Myeloid Leukemia**
  A Cancer Support Community resource for patients and caregivers that provides an overview of AML diagnosis, treatment, comping strategies, and helpful resources.

- **HealthTree University: Acute Myeloid Leukemia**
  A series of educational videos for patients and caregivers, including topics on diagnostic testing, preparing for treatment, clinical trials, financial toxicity, and palliative care.

- **AHRQ Health Literacy Universal Precautions Toolkit**
  This toolkit, while developed for primary care, can help all programs and practices support patients at all health literacy levels, reduce miscommunication between providers and patients, and create a program that is easier to navigate.

- **Let's Be Clear: Communicating to Improve the Cancer Patient Experience**
  A set of tools, resources, and an assessment to help cancer programs put health literacy principles into action.

- **National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care**
  A set of action steps to support health care organizations with implementing culturally and linguistically appropriate services.

PROVIDE CAREGIVER SUPPORT

Practical Tips

Family members, friends, and others often help with many activities outside of clinical touchpoints—whether it is providing or arranging transportation to appointments, making meals, helping with medication management, navigating insurance—the list can go on. Caregivers often step into this role with no training but must be recognized as a critical part of the care team. To prevent burnout and negative impacts on caregivers' quality of life, the National Cancer Institute recommends the following for providers and practices:

- Assess caregiver burden utilizing a validated screening tool.
- Recognize the informal caregivers' roles, responsibilities, and challenges.
- Provide information about treatment plans, goals, anticipated complications or adverse effects, and likely outcomes.
- Provide guidance for how to respond to changes in patients' physical and emotional health over the disease trajectory.
- Support in coping with the stress of their role (for which they are most often unprepared and untrained).
- Provide detailed education about medical and nursing tasks they are expected to perform, such as giving injections, providing wound care, and managing adverse effects.[13]

Expert Insights

"Most larger cancer centers have caregiver support groups where you can go and meet with a group of other caregivers who are facing similar issues. It is sometimes helpful for caregivers just to hear what other people are going through, to normalize what it feels like for them. To know, they are not alone, and that others have had or are currently having similar experiences. For programs that do not have caregiver support groups, patient organizations like Leukemia and Lymphoma Society (LLS) offer virtual options."

— Thomas LeBlanc, MD MA, MHS, FAAHPM, FASCO
Medical Oncologist, Palliative Care Physician,
and Chief Patient Experience and Safety Officer
Duke Cancer Network, Duke Cancer Institute

Helpful Resources

- **Informal Caregivers in Cancer: Roles, Burden, and Support (PDQ®)–Health Professional Version**
  Information, interventions, and tools on how to support caregivers from the National Cancer Institute.
- **HealthTree Coach Program**
  This program offers one-on-one peer mentorship and support for people impacted by acute myeloid leukemia.
- **HealthTree AML Caregivers Chapter**
  HealthTree offers tailored, virtual events specific to caregivers of patients with acute myeloid leukemia.
- **LLS Family Support Groups**
  Regional support groups for patients with blood cancers and their families that provide support and education.
- **LLS Caregiver Support**
  Strategies and resources for caregivers of people with blood cancers.

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In partnership with:

Supporters:

To access additional resources on acute myeloid leukemia, please visit **accc-cancer.org/effective-practices-AML**.

The Association of Cancer Care Centers (ACCC) provides education and advocacy for the cancer care community. For more information, visit **accc-cancer.org**.

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APPENDIX A:

ACUTE MYELOID LEUKEMIA: EXTERNAL CARE COORDINATION CHECKLIST AT DIAGNOSIS

The goal of this checklist is to support treatment selection and delivery for patients with acute myeloid leukemia based on clinical guidelines, disease characteristics, and patient preferences and goals to ensure optimal care and outcomes.

External care coordination between programs with advanced capabilities to treat acute myeloid leukemia and community oncologists can help ensure the patient has access to up-to-date treatments and clinical trials while having some degree of care close to home.

Checklist for External Care Coordination at Diagnosis:

☑ **Care Partner Direct Contact Information:**

- Community point(s) of contact
- Leukemia expert point(s) of contact

☑ **Work Up Prior to Arrival at Leukemia Treatment Center:**

- Age and overall health
- Patient goals and preferences
  - This should include advance directives, medical power of attorney (POA), and physician orders for life-sustaining treatment (POLST)
- Social determinants and psychosocial assessment (by social worker), including:
  - Barriers to treatment
  - Caregiver support
  - Concerns about cost of care
  - Transportation barriers
  - Payment concerns
- Transfer between community center/hospital and academic/leukemia center
  - Distance from academic/leukemia center to patient's home
  - Initial transfer process
  - Transportation options/logistics
  - Eligibility for patient to transfer home
- If patient has rapidly proliferating disease and requires a prompt hospital-to-hospital transfer:
  - CBC with differential, renal and hepatic panel, uric acid, LDH, DIC screen (PT, PTT, fibrinogen)
- If patient is stable, also include:
  - Morphology
  - Flow cytometry
  - Cytogenetics
  - AML FISH

- Molecular: FLT3 (ITD/TKD), NPM1, CEBPA bzip, NPM1, depending on your center IDH1/2, p53m
- Myeloid NGS panel
- HLA type for all patients to inform transplant eligibility
- Coags, PT, PTT, fibrinogen to initial labs
- Hepatitis panel and HIV testing

☑ Cardiac Screenings

- Echocardiogram
- Electrocardiogram (EKG)

☑ Vascular Access

- Ports are not recommended for patients with acute myeloid leukemia

☑ Intensive Therapy Eligibility

- Ferrara Risk stratifications (this includes pulmonary function tests, but if no history of pulmonary disease can be adjusted to exclude if necessary)
- Treatment-Related Mortality (TRM) Calculator

☑ Clinical Trial Availability

- Introduce clinical trials as a standard of care to patient
  - Most common: new diagnosis, transplant or with relapse refractory disease
  - Less common: Maintenance therapy and measurable residual disease (MRD) studies
  - Natural history or repository studies

☑ Resources for Physicians:

- American Society of Hematology (ASH) Pocket Guides
  - HCT Co-morbidity Index
  - Acute Leukemia Initial Diagnostic Work-Up
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Acute Myeloid Leukemia

☑ Resources for Patients:

- Leukemia & Lymphoma Society
- HealthTree Foundation for Acute Myeloid Leukemia
- Cancer Support Community

APPENDIX B:

ACUTE MYELOID LEUKEMIA: POST-INDUCTION EXTERNAL CARE COORDINATION CHECKLIST FOR PATIENTS ON MAINTENANCE THERAPY

The goal of this checklist is to optimize care coordination and outcomes for patients with acute myeloid leukemia who are being discharged from an academic/leukemia center and transferring to a community-based outpatient facility for ongoing treatment (eg, maintenance therapy) and monitoring.

Checklist for Post-Induction External Care Coordination for Maintenance Therapy:

☑ **Care Partner Direct Contact Information:**

- Community point(s) of contact
- Leukemia expert point(s) of contact

☑ **Summary of Discharge Instructions**

☑ **External Care Coordination Process**

- To what extent will the leukemia expert stay involved in patient's care
- If/when will follow-ups with leukemia expert will be needed
- Process for communication
- Social work/navigator coordination
- Considerations for transfer back if there are complications
- Provider-to-provider discussion of care coordination plan

☑ **Patient Circumstances**

- Patient goals and preferences
- Proximity to care:
    - Distance to community outpatient center
    - Distance to hospital
- Social determinants and psychosocial assessment (by social worker), including:
    - Caregiver support
    - Concerns about cost of care
    - Transportation barriers

☑ **Treatments Needed and Parameters**

- Can your center provide high intensity consolidation therapy?
- Are you able to give HMA +/- Venetoclax? (eg can you provide frequent transfusion support if needed, including platelets? Can you obtain an end-of-cycle-1 bone marrow and receive results back within a few days, to inform the timing of cycle 2 initiation?)
- Plan for managing dose modifications or pauses in treatment (when to consult leukemia expert)
- Recommendations for repeat testing
- For oral oncolytic treatments, who is obtaining and where will refills happen

☑ **Summary of Discharge Instructions**

☑ **Supportive Care Parameters**

- Ability to provide transfusion support with irradiated blood products
- Ability to provide same-day transfusions
- How frequent transfusion support
- Infectious disease prophylaxis
- Nausea and vomiting prophylaxis for oral azacitidine
- Survivorship and palliative care services

☑ **Adverse Event Management Plan for Maintenance Therapy**

- Plan for monitoring
- Communication plan between providers if patient goes to emergency department or urgent care
- Plan for rapidly identifying and initiating treatment for neutropenic fever
- Patient/caregiver education

☑ **Resources for Providers:**

- American Society of Hematology (ASH) Pocket Guides
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Acute Myeloid Leukemia
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Supportive Care

☑ **Resources for Patients:**

- Leukemia & Lymphoma Society
- HealthTree Foundation for Acute Myeloid Leukemia
- Cancer Support Community