This is a navigation tool designed for patients with MDS, their care partners, and the multidisciplinary team to:

- Provide patients and care partners with valuable education to use throughout their care journey
- Equip the care team with a tool to assist in maneuvering patient conversations
- Highlight key milestones and evidence-based considerations of the MDS care journey

"= Key Terms found on the back side of this resource.
KEY TERMS
- **Allo-SCT** is the process of destroying cells in the bone marrow using [chemotherapy or radiation] and replacing them with healthy, blood-forming cells from another person through a transfusion or a slow infusion of blood through a vein.
- **Cytogenetic testing** is the examination of whole chromosomes in individual cells under a microscope to look for any abnormal differences.
- **Genomic testing** is the detailed examination of the complete set of genes or genetic information to look for any genetic changes.
- **Palliative care** is given to patients at any stage of a serious illness and along with curative treatment to provide symptom relief and psychosocial support, which aims to improve quality of life (QOL) for both patients and care partners.
- **Hospice care** focuses on symptom management and QOL care for people with an anticipated life expectancy of 6 months or less.

**REFERENCES**

Along my journey with MDS:
- My care team could change throughout my journey depending on my treatment plan.
- My treatment outcomes may include a period of remission (no detectable disease), relapse (disease recurrence), or I may become a long-term survivor.

**Patient Takeaway:**
- Prolonged disease-free survival has been reported in ~30% to 50% of patients receiving allo-SCT®, a potential curative treatment option for MDS.

**Navigator Role:**
- Coordinate follow-ups and support multidisciplinary coordination of care.
- Ensure appropriate disease monitoring is performed.
- Educate on late and long-term side effects, signs & symptoms of recurrence and/or disease progression, and when to report to the care team.
- Incorporate QOL goals into survivorship care plans.

My journey with MDS may transform into AML:
- AML is a form of blood cancer that can arise from MDS.
- Active treatment may not always be an option. In this case, I should begin to consider what is most important to me as I approach the last stages of my life.

**Patient Takeaways:**
- Ask my care team about my risk for AML and what I need to know.
- Ask my care team about symptom management and hospice care.

**Navigator Role:**
- Provide resources, education, and any needed support.
- Discuss goals of care and advance care planning.
- Facilitate appropriate referrals to supportive services (eg, advocacy groups, financial navigation, hospice care, psychosocial support, etc).

**REFERENCES**

This educational material is not intended to provide medical advice, diagnosis, or treatment. Patients should always seek the advice and guidance of a physician or other qualified healthcare provider with any questions regarding a medical condition or treatment and before undertaking a new healthcare regimen.
Navigating Myelodysplastic Syndromes (MDS)
The Basics of MDS and Helpful Information Guiding Your Journey

What are MDS?¹,²
- MDS are a diverse group of bone marrow disorders, where the body no longer makes enough blood cells in the bone marrow
- MDS are considered a form of blood cancer and are associated with a risk for disease transformation to a form of blood cancer called acute myeloid leukemia (AML)

How common are MDS?¹
- MDS occur in 3-4 people per 100,000 in the United States
- MDS are more common in men and in people aged 60 years or older

What typically leads to detection of MDS?¹
- MDS are often suspected by presence of a cytopenia on a routine blood test
  - Presence of a cytopenia means that you have a lower-than-normal number of blood cells

What signs and symptoms are common with MDS?³
- Signs and symptoms of MDS are typically related to cytopenias and include:
  - Fatigue
  - Easy bruising and/or bleeding
  - Increased risk of infections

What do patients with MDS typically experience?²
- Patients with MDS experience:
  - Ineffective regulation of the blood cell production process
  - Variable cytopenias
  - Risk of disease transformation to AML

What factors are considered for risk status?³
- Risk status takes into account several factors, including:
  - Number or degree of cytopenias
  - Cytogenetic profile
  - Percentage of bone marrow blasts (% Blasts)
- There are several different scoring systems used to establish the risk status of patients with MDS

Why is knowing my risk status important?¹
- Risk status is important because it may impact the treatment and management of my MDS, as well as my risk for disease transformation to AML
  - Risk status may also determine my eligibility for clinical trials

What factors may contribute to making a treatment decision?¹
- Several factors contribute to treatment decisions, including, but not limited to, my:
  - Risk status
  - Need for blood transfusions
  - Cytopenias (frequency and severity)
  - Age
  - Candidacy for allogeneic stem cell transplant
  - Other health conditions (type and severity)
  - Quality of life
  - Life milestones

What is the relevance of AML?¹
- MDS have a risk of transforming to AML, another form of blood cancer

Risk for transformation should be considered at the time of diagnosis with MDS, as MDS disease characteristics ultimately impact risk for transformation to AML.

This resource was developed in collaboration with Gilead Sciences, Inc.
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Potential members of my care team
- Financial navigators
- Financial counselors
- Nurses
- Nurse navigators
- Pharmacists
- Nurse practitioners and/or physician assistants
- Dieticians
- Spiritual care providers
- Social workers
- Patient navigators
- Palliative care and/or hospice care providers
- Physicians (hematologists and oncologists)
- Rehabilitation (physical and occupational therapy)

Support and/or advocacy groups4-10
- The MDS Foundation: www.mds-foundation.org
- The MDS Alliance: www.mds-alliance.org
- Leukemia & Lymphoma Society: www.lls.org
- The Aplastic Anemia and MDS International Foundation: www.aamds.org
- American Cancer Society (ACS): www.cancer.org
- Patient Advocate Foundation: www.patientadvocate.org
- PAN Foundation: www.panfoundation.org

Resources11-15
- Be the Match: www.bethematch.org
- National Bone Marrow Transplant Link: www.nbmtlink.org
- Cleaning for a Reason – Home Cleaning: www.cleaningforareason.org
- Blood & Marrow Transplant Information Network: www.bmtinfonet.org
- ACS Road to Recovery – Transportation for Treatment: www.cancer.org/support-programs-and-services/road-to-recovery.html

Choosing a treatment with my healthcare provider
► Ask your healthcare provider:
  - What are the treatment options available to me?
  - What do you consider to be the best treatment for me, and why?

My MDS Treatment Plan
► The treatment my healthcare provider and I have decided is best for me is:

Key questions to ask my care team:
- What signs and/or symptoms should I immediately report to my care team?
- What signs and/or symptoms should alert me to call 911 and/or go to the emergency room?
- Is my treatment taken by mouth or does it require an infusion?
- How often will I need my treatment?
- What are the side effects of my treatment and what should I expect?
- What possible late- and/or long-term effects might I experience from treatment?
- How often will I need to follow up with my healthcare provider?
- When should I see improvements in my symptoms?
- Will I need a caregiver to receive this treatment?
- How much will my treatment cost?
- What financial resources are available?
- How does my diagnosis of MDS impact me?
- How often will I need blood work/lab tests?
- Will I be able to continue work and complete activities of daily living?
- What will my quality of life be?
- How will this impact my family?
- What services are available to help with coordinating my care (for example, assistance for transportation needs)?
- What additional patient/caregiver support is available?

My Care Team Contact Information:

References

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