

# NAVIGATING MYELODYSPLASTIC SYNDROMES (MDS)

## The Journey Informed: A Patient-Focused Roadmap to Managing MDS

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.

BEGIN

1

### Leading up to my diagnosis with MDS<sup>1</sup>:

Several tests should have been performed to help determine my **risk status** (eg, low- or high-risk), including:

- Bone marrow aspiration, biopsy, and **cytogenetic testing** ☰
- **Genomic testing** ☰

#### Patient Takeaways:

- I should receive education on my **risk status**, which helps to determine my treatment options
- **Risk status** also informs my risk for transformation to acute myeloid leukemia (AML)

#### Navigator Role:

- Provide diagnosis-specific education and resources (including risk status, disease outlook, etc)
- Encourage shared decision-making

2

### Throughout my care journey with MDS<sup>1-3</sup>:

- I will need periodic **laboratory testing** (*blood draws*) to check my blood levels and assess for any needs I may have (including **blood transfusions** and/or other supportive care measures)
- I may receive medication for **treatment**. I may be a candidate for **allogeneic stem cell transplantation (allo-SCT)** ☰, and/or I may be eligible for a clinical trial
- I should report any **needs** or **barriers to care** to my healthcare team throughout my entire journey

#### Patient Takeaways:

- I should ask my care team if there is an open **clinical trial** nearby
- Goals of my **treatment** are to control the natural progression of my MDS or to improve my quality of life by restoring my blood counts to normal levels and minimizing my need for transfusions

#### Navigator Role:

- Provide treatment-specific education and resources
- Regularly assess for any needs or barriers to care
- Support multidisciplinary coordination of care
- Facilitate appropriate referrals to supportive services (eg, advocacy groups, financial navigation, **palliative care** ☰, patient navigation, psychosocial support)

3

### As management of my MDS<sup>2,3</sup>:

- I may need more than one course of treatment due to nonresponse, disease progression, or other reasons
- I will have frequent **follow-up appointments** to assess for any needs I may have, my response to treatment, and my prognosis based on results from my **lab tests**

#### Patient Takeaways:

- Frequency of **lab tests**, **blood transfusions**, and **follow-ups** with healthcare providers may be highly dependent on factors specific to me (eg, age, overall health status, etc)

#### Navigator Role:

- Educate on important side effects to check for and when to report to the care team
- Regularly assess for side effects and any needs or barriers to care
- Promote side effect management measures to minimize impacts

## 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<sup>4</sup>
- **Cytogenetic testing** is the examination of whole chromosomes in individual cells under a microscope to look for any abnormal differences<sup>5</sup>
- **Genomic testing** is the detailed examination of the complete set of genes or genetic information to look for any genetic changes<sup>5</sup>
- **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<sup>6</sup>
- **Hospice care** focuses on symptom management and QOL care for people with an anticipated life expectancy of 6 months or less<sup>7</sup>

### Along my journey with MDS<sup>1,3</sup>:

- 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**<sup>4</sup>, a potential curative treatment option for MDS<sup>1</sup>

#### 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

For more information, scan here using the camera of your mobile device/cell phone:



## REFERENCES

1. Garcia-Manero G, Chien KS, Montalban-Bravo G. Myelodysplastic syndromes: 2021 update on diagnosis, risk stratification and management. *Am J Hematol*. 2020;95(11):1399-1420.
2. Fenaux P, Platzbecker U, Ades L. How we manage adults with myelodysplastic syndrome. *Br J Haematol*. 2020;189(6):1016-1027. 3. Platzbecker U, Kubasch AS, Homer-Bouthiette C, Prebet T. Current challenges and unmet medical needs in myelodysplastic syndromes. *Leukemia*. 2021;35(8):2182-2198. 4. Allogeneic stem cell transplantation. Leukemia & Lymphoma Society. <https://www.lls.org/treatment/types-treatment/stem-cell-transplantation/allogeneic-stem-cell-transplantation>. Accessed Oct. 24, 2023. 5. Cytogenetics and genomics. UW Medicine Laboratory Medicine & Pathology. <https://dlmp.uw.edu/patient-care/cytogenetics#:~:text=Cytogenetics%20refers%20to%20the%20microscopic,specimens%2C%20and%20on%20fixed%20specimens>. Accessed Oct. 24, 2023. 6. What is palliative care? Center to Advance Palliative Care. <https://getpalliativecare.org/whatis/>. Accessed Oct. 24, 2023. 7. What is hospice? Hospice Foundation of America. <https://hospicefoundation.org/Hospice-Care/Hospice-Services>. Accessed Oct. 24, 2023.

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.

### My journey with MDS may transform into AML<sup>2</sup>:

- **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**<sup>6</sup>

#### 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**<sup>6</sup>, psychosocial support, etc)

## Lead Advisors

Jiajoyce Conway, DNP, CRNP, AOCNP  
Ginna Granroth, PA-C, MS, ACLS

## Contributing Advisors

Jennifer Bires, MSW, LICSW, OSW-C  
Tracey Iraca  
Paige Kim, PA-C  
Sandra Kurtin, PhD, ANP-C, AOCN  
Clara Lambert, CPH, BBA, OPN-CG  
Tiffany Santiago, CHES, BCPA

**AONN** Academy of Oncology  
Nurse & Patient Navigators

This resource was developed in collaboration with Gilead Sciences, Inc.

# Navigating Myelodysplastic Syndromes (MDS)

## The Basics of MDS and Helpful Information Guiding Your Journey

### What are MDS?<sup>1,2</sup>

- ▶ 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?<sup>1</sup>

- ▶ 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?<sup>1</sup>

- ▶ 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?<sup>3</sup>

- ▶ 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?<sup>2</sup>

- ▶ 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?<sup>3</sup>

- ▶ 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

*Talk to your healthcare provider about the scoring system used to determine your risk status, as well as the different factors accounted for.*

This resource was developed in collaboration with Gilead Sciences, Inc.

### Why is knowing my risk status important?<sup>1</sup>

- ▶ 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?<sup>1</sup>

- ▶ 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?<sup>1</sup>

- ▶ 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.*



The endorsement mark certifies that the information presented in educational seminars, publications, or other resources is reliable and credible.

# Navigating Myelodysplastic Syndromes (MDS)

## The Basics of MDS and Helpful Information Guiding Your Journey

### 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 groups<sup>4-10</sup>

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

### Resources<sup>11-15</sup>

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

Resources may include referrals to independent third-party nonprofit patient assistance programs. These programs are not operated or controlled by Gilead, and Gilead does not endorse any program or third-party organization.

### References

1. Garcia-Manero G, Chien KS, Montalban-Bravo G. Myelodysplastic syndromes: 2021 update on diagnosis, risk stratification and management. *Am J Hematol*. 2020;95(11):1399-1420. 2. Fenaux P, Platzbecker U, Ades L. How we manage adults with myelodysplastic syndrome. *Br J Haematol*. 2020;189(6):1016-1027. doi:10.1111/bjh.16206. 3. Platzbecker U, Kubasch AS, Homer-Bouthiette C, Prebet T. Current challenges and unmet medical needs in myelodysplastic syndromes. *Leukemia*. 2021;35(8):2182-2198. 4. The MDS Foundation. [www.mds-foundation.org](http://www.mds-foundation.org). Accessed August 3, 2023. 5. The MDS Alliance. [www.mds-alliance.org](http://www.mds-alliance.org). Accessed August 3, 2023. 6. Leukemia & Lymphoma Society. [www.lls.org](http://www.lls.org). Accessed August 3, 2023. 7. The Aplastic Anemia and MDS International Foundation. [www.aamds.org](http://www.aamds.org). Accessed August 3, 2023. 8. American Cancer Society. [www.cancer.org](http://www.cancer.org). Accessed August 3, 2023. 9. Patient Advocate Foundation. [www.patientadvocate.org](http://www.patientadvocate.org). Accessed August 3, 2023. 10. PAN Foundation. [www.panfoundation.org](http://www.panfoundation.org). Accessed October 24, 2023. 11. Be the Match. [www.bethematch.org](http://www.bethematch.org). Accessed August 3, 2023. 12. National Bone Marrow Transplant Link. [www.nbmtlink.org](http://www.nbmtlink.org). Accessed August 3, 2023. 13. Blood & Marrow Transplant Information Network. [www.bmtinfonet.org](http://www.bmtinfonet.org). Accessed August 3, 2023. 14. Cleaning for a Reason. [www.cleaningforareason.org](http://www.cleaningforareason.org). Accessed August 3, 2023. 15. Road to Recovery. American Cancer Society. [www.cancer.org/support-programs-and-services/road-to-recovery.html](http://www.cancer.org/support-programs-and-services/road-to-recovery.html). Accessed August 3, 2023.

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.

This resource was developed in collaboration with Gilead Sciences, Inc.

### 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:

---

---

---