EPEP | Myelodysplastic Syndromes (MDS)

Healthcare Provider Checklist

Patient Empowerment Network

Support Patient Understanding of the Diagnosis

- [ ] Explain what MDS is: a group of bone marrow disorders affecting blood cell production and how it differs from other blood cancers or anemias
- [ ] Clarify the subtype and risk category (e.g., low-risk vs. high-risk) using IPSS/IPSS-R or IPSS-M
- [ ] Review diagnostic tests: bone marrow biopsy, cytogenetics, molecular profiling
- [ ] Use visual aids or analogies to explain complex concepts

Source

Discuss Prognosis and Monitoring

- [ ] Outline what prognostic score and risk category means for disease progression and AML transformation
- [ ] Discuss potential progression from low-risk to high-risk MDS, when applicable
- [ ] Set expectations for regular follow-up: lab work, bone marrow exams, symptom tracking & frequency of transfusions
- [ ] Introduce measurable residual disease (MRD) and its relevance, if applicable
- [ ] Discuss how age and comorbidities may influence prognosis and treatment choices
- [ ] Explain the role of genetic mutations (e.g., TP53, SF3B1) in treatment selection and responses to therapy
- [ ]
  - Address delays and access issues with this too

Source

Explore Treatment Options

- Review treatment goals: symptom relief, disease control, potential cure, prolonging life
- Explain side effects, timelines, and expected outcomes
- Consider treatment regimens based on local resource availability
- Discuss frontline and second-line therapies based on mutation status
  - Supportive care (transfusions, growth factors)
  - Hypomethylating agents (azacitidine, decitabine)
  - Immunomodulatory drugs
  - Clinical trials or early referral for stem cell transplant (if eligible, for high-risk patients)

Source

Support Patient Education and Emotional Well-Being

- Provide take-home educational resources for trusted sources like American Cancer Society, the MDS Foundation, the Aplastic Anemia & MDS International Foundation, Blood Cancer United (*formerly* the Leukemia & Lymphoma Society). Offer resources in multiple languages
- Encourage open dialogue and questions to build trust. Address any cultural or faith-based concerns
- Offer referrals for psychosocial support, counseling, or peer groups
- Discuss how to communicate the diagnosis with loved ones

Source

Address Lifestyle and Supportive Care Needs

- [ ] Assess patient's support system and caregiving needs. Include family or trusted advisors in decision-making.
- [ ] Discuss work, travel, and daily activity adjustments.
- [ ] Review fatigue management, infection prevention, and nutrition.
- [ ] Schedule follow-ups, using telehealth when possible, and provide contact info for urgent concerns.
- [ ] Plan for transportation and transfusion logistics.
- [ ] Coordinate with academic centers for specialized input.
- [ ] Connect patients with financial counselors or advocacy organizations for support.

Reviewed by Dr. Irum Khan

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