



Simply complete this form and return it to the MDS Foundation via mail or fax.

The MDS Foundation, 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515  
FAX: 1-609-298-0590

## Myelodysplastic Syndromes Nursing Practice and Treatment Survey

Sponsored by the MDS Foundation, Inc.

**Overview and Objectives:** The MDS Foundation recognizes that data on many aspects of MDS worldwide is limited in existence. Individual physical investigators have developed databases to track MDS within their individual sites or working groups, however that information is not located within one easily accessible database.

The MDS Foundation has attempted to design a nursing survey that we hope will assist in describing some of the issues related to MDS worldwide as well as treatments being utilized in this disease. While we recognize that this information is, in most instances, based on subjective criteria it can assist in identifying education and research opportunities in the near future.

The results of this survey will be shared with the nursing advisory board and with each of MDS Centers of Excellence and used by the MDS Foundation to assess new educational and research opportunities. Thank you in advance for your consideration in completing this form.

1. Please indicate the country in which you practice:

2. Is your practice based at:  An academic hospital  A community-based hospital  A private practice

3. Please describe your role in caring for patients with MDS: (Check all that apply)

- Primary contact  Medical history  Physical examination  Vital signs  
 Medication dispensing  Education  Other \_\_\_\_\_

4. How many MDS patients do you treat/care for in your practice or institution each month?

- None, 1 to 10  11 to 25  26 to 50  > 50

5. In the past five years did the number of patients you see for MDS increase, decrease, or remain the same? (Check one.)

- Increased  Decreased  Remained the same

6. If you believe the number of patients you see has increased please tell us why you feel this increase has occurred?

(Specify your response below.)

7. How often do you see each of your MDS patients?

- Monthly  Every 3-6 months  Annually  Only with clinical indication of disease progression  
 Never, they are referred  Clinical conditions dictates frequency of visits

8. Do you educate your patients that MDS is a cancer?  Yes  No

9. If patients are referred to you how are they classified by the referring physician? (Check all that apply.)

- Not categorized  International Prognostic Scoring System (IPSS)  French-American-British (FAB)  
 World Health Organization (WHO)  Other (specify)

10. Is the classification of MDS readily available to you as a nurse in the patient chart/record?  Yes  No

11. Do you feel you understand the prognostic significance of the IPSS scoring system?  Yes  No

12. Do your MDS patients have cytogenetics performed with every bone marrow exam?  Yes  No

13. Do you believe that cytogenetic results have an impact on the prognosis and management of patients with MDS?  Yes  No

14. What percentage of your MDS patients belong in the following IPSS risk categories?

(Enter percents, so that the total % number is 100%.)

\_\_\_\_\_ % Low      \_\_\_\_\_ % Intermediate-1      \_\_\_\_\_ % Intermediate-2      \_\_\_\_\_ % High      \_\_\_\_\_ Unknown

15. What percent of your MDS patients are transfusion-dependent?

16. Do you monitor ferritin levels in your transfusion-dependent patients?  Yes  No

17. How is the decision made to begin chelation therapy in RBC transfusion-dependent patients?

- Ferritin level >1,000  Ferritin level >2,000  Ferritin level of \_\_\_\_\_  
 Number of RBC transfusions: How many, on average?  
 Other criteria (specify)

18. Has the availability of Deferasirox (Exjade®) increased the number of transfusion-dependent patients that are on chelation therapy?

- Yes  No

19. What types of supportive care are used in your practice? (Check all that apply.)

- Transfusions only (RBC, platelet)  Growth factors (epo, G/GM-CSF)  
 Antibiotics  Vitamins  
 Other (specify)

20. When using EPO how is the decision made that a patient is non-responsive to EPO?

- No Hgb response after 6 weeks of therapy  No Hgb response after 12 weeks of therapy  
 Patient remains transfusion dependent  Other (specify)

**21. Does your center use any of the following agents to treat your MDS patients?**

- Azacitidine     Decitabine     Lenalidomide     Low dose Ara-c     ATG (antithymocyte globulin)

**22. If your center is using the agents in question 21, how comfortable are you, as the nurse, with managing the side effects?**

*(Place an "X" on the scale of 1 to 10, with 1 being very uncomfortable and 10 being very comfortable)*

**EXAMPLE:**

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

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Azacitidine

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

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Decitabine

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

---

Lenalidomide

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

---

Low dose Ara-c

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

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ATG

(antithymocyte globulin)

(very uncomfortable) (very comfortable)

1      2      3      4      5      6      7      8      9      10

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**23. Do you use any tracking methods/tools to monitor your MDS patient?**     Yes     No

If yes, please describe your tool:

**24. List MDS education resources you use with your MDS patients/families** *(booklets, web sites)*

**25. Does your clinical practice site offer participation in a clinical trial as an option for treatment?**     Yes     No

**26. Would you be interested in educational programs designed for nurses to increase your understanding of MDS/treatment options?**     Yes     No

- If you answered yes, would you prefer a:
- Live program     Internet available program
- Written program     CD Rom/DVD based program

**If you have answered yes to question 26, please provide your contact information below:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

E-mail: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_



If you would like additional information, please contact us at:

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