

Please note: If you are completing this survey on behalf of an MDS patient, the survey answers should express the facts and opinions of the MDS patient, not yours as the caregiver.

*** Required Information.**

If for any reason you need to leave the survey, be sure to click the "Save & continue later" link available at the bottom of each page.

*** 1. The person completing this survey is:** (Select one option)

- A patient diagnosed with Myelodysplastic Syndrome (MDS) Go to Question No. 2
- A caregiver assisting a patient diagnosed with MDS Go to Question No. 2
- Neither Stop, you have finished the survey

If Did Not Answer Then Go to Question No. 2

*** 2. What is your age?**

*** 3. Are you male or female?** (Select one option)

- Male
- Female

*** 4. What is the highest level of education you have completed?** (Select one option)

- High school
- Some college
- College degree
- Other (please specify) _____

*** 5. In what state do you currently live?**

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada

- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming

*** 6. Aside from MDS, what other medical problems do you have? (Select all that apply)**

- Heart disease or other heart problems
- Kidney disease
- Lung disease
- Liver abnormalities
- Stroke or problems with blood vessels

- Blood clots
- Mental health problem
- None
- Other (please specify) _____

*** 7. In what year were you diagnosed with MDS?**

*** 8. Who first diagnosed you with MDS? (Select one option)**

- General or primary care doctor
- Hematologist/Oncologist
- Other (please specify) _____

*** 9. How was MDS first described to you? (Select all that apply.)**

- Anemia (low red blood cell count)
- Blood disorder
- Bone marrow disorder
- Cancer
- Hematologic malignancy
- Leukemia
- Syndrome
- Thrombocytopenia (low platelet count)
- Neutropenia (low white blood cell count)
- Other (please specify) _____

*** 10. Did your doctor ever talk with you about prognosis or about how long you could expect to live with MDS? (Select one option)**

- Yes

No

*** 11. Prior to learning that you had MDS, were you ever diagnosed with any of the following:**

-low white blood cell count

-low platelet count

-anemia

(Select one option)

Yes

Go to Question No. 12

No

Go to Question No. 13

Don't know

Go to Question No. 13

If Did Not Answer Then Go to Question No. 12

*** 12. What year was the low white blood cell count, low platelet count, or anemia first detected?**

*** 13. Do you have anemia caused by MDS?** (Select one option)

Yes

No

*** 14. What is your IPSS (International Prognostic Scoring System) risk?** (Select one option)

Low (0)

INT-1 (0.5 - 1.0)

INT-2 (1.5 - 2.0)

High (2.5 or higher)

Don't know

*** 15. Have you ever had a bone marrow biopsy?** (Select one option)

Yes

Go to Question No. 16

No

Go to Question No. 20

If Did Not Answer Then Go to Question No. 16

*** 16. How many bone marrow biopsies have you undergone in your lifetime?**

*** 17. Did your bone marrow biopsy ever reveal abnormal genes or chromosomes?** (Select one option)

- Yes
- No
- Don't know

*** 18. What percentage of abnormal cells (blasts) did your most recent bone marrow biopsy reveal?**

(Select one option)

- Less than 5%
- 5% - 9%
- 10% - 19%
- 20% or higher
- Don't know

*** 19. What was the highest percentage of abnormal cells (blasts) a bone marrow biopsy has ever shown?**

(Select one option)

- Less than 5%
- 5% - 9%
- 10% - 19%
- 20% or higher
- Don't know

*** 20. Do you currently have a low platelet count (thrombocytopenia) due to your MDS or your treatment for MDS?** (Select one option)

- Yes
- No
- Don't know

*** 21. Do you currently have a low white blood cell count (neutropenia) due to your MDS or your treatment for MDS?** (Select one option)

- Yes
- No
- Don't know

*** 22. In general, would you say that your health is:** (Select one option)

- Excellent
- Very good
- Good
- Fair
- Poor

*** 23. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?**

*** 24. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?**

*** 25. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?**

*** 26. What are your main goals for your MDS treatment?**

[Please select up to 3 treatment goals.]

- Relieve my fatigue
- Relieve my anemia caused by MDS
- Stop or slow the progression of my MDS
- Increase my life expectancy
- Return to my normal daily activities
- Improve my bone marrow
- Relieve my thrombocytopenia (low platelet count)
- Improve my overall quality of life
- Other (please specify) _____

*** 27. What do you feel are the main goals of the doctor who provides your primary MDS treatment?**

[Please select up to 3 treatment goals.]

- Relieve my fatigue
- Relieve my anemia caused by MDS
- Stop or slow the progression of my MDS
- Increase my life expectancy
- Return to my normal daily activities
- Improve my bone marrow
- Relieve my thrombocytopenia (low platelet count)
- Improve my overall quality of life
- My doctor and I did not discuss treatment goals
- Other (please specify) _____

*** 28. When discussing treatment for MDS with your main doctor, which of the following people ever came to your appointments or talked to the doctor on their own: (select all that apply)**

- Husband or wife
- Son(s) or daughter(s)
- Brother(s) or sister(s)
- Grandchildren
- Friend(s)
- Parent(s)
- No one came with me

*** 29. I chose my current MDS treatment because I wanted to do what was right for: (select all that apply)**

- Myself
- Husband or wife
- Son(s) or daughter(s)
- Brother(s) or sister(s)
- Grandchildren
- Friend(s)
- Parent(s)

Which of these treatments have you received in the last 3 months for your MDS? Which have you ever received?

30. Please check all that apply:		
	Last 3 months	Ever
(a) Blood transfusions	<input type="checkbox"/>	<input type="checkbox"/>
(b) G-CSF (Neupogen [®] , Granocyte [®] , Neulasta [®])	<input type="checkbox"/>	<input type="checkbox"/>
(c) Aranesp [®] (darbepoetin alfa)	<input type="checkbox"/>	<input type="checkbox"/>
(d) Iron chelation	<input type="checkbox"/>	<input type="checkbox"/>
(e) Nplate [™] (romiplostim)	<input type="checkbox"/>	<input type="checkbox"/>
(f) Procrit [®] (epoetin alfa)	<input type="checkbox"/>	<input type="checkbox"/>
(g) Doctor visits with no drug treatment	<input type="checkbox"/>	<input type="checkbox"/>

*** 31. Are you currently receiving blood transfusions?** (Select one option)

Yes

Go to Question No. 32

No

Go to Question No. 38

If Did Not Answer Then Go to Question No. 32

*** 32. How long have you been receiving blood transfusions?** (Select one option)

Less than 3 months

3-6 months

6-12 months

1-2 years

2-3 years

More than 3 years

*** 33. About how often do you receive blood transfusions?** (Select one option)

Once a week

Twice a month

Once a month

Once every 8 weeks

Other (please specify) _____

*** 34. From when you leave your house until you return home, about how many hours does it take to get a blood transfusion?**

For each transfusion, what are your out-of-pocket costs for:

35. Enter the cost below (Enter 0 if none)

*** (a) Copay**

*** (b) Gas**

*** (c) Parking**

*** (d) Meals**

*** (e) Other**

36. Please indicate how much you agree with the following statement.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
*(a) Blood transfusions are a burden to my family and those who help care for me. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
* (a) I would undergo a drug treatment that temporarily made me feel worse, if it would enable me to stop or reduce my blood transfusions. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Which of these treatments have you received in the last 3 months for your MDS? Which have you ever received?

38. Please check all that apply:		
	Last 3 months	Ever
(a) ATG (antithymocyte globulin)	<input type="checkbox"/>	<input type="checkbox"/>
(b) Revlimid [®] (lenalidomide)	<input type="checkbox"/>	<input type="checkbox"/>
(c) Vidaza [®] (azacitidine)	<input type="checkbox"/>	<input type="checkbox"/>
(d) Dacogen [®] (decitabine)	<input type="checkbox"/>	<input type="checkbox"/>
(e) Stem cell or bone marrow transplant (Allotransplant)	<input type="checkbox"/>	<input type="checkbox"/>
(f) Clinical trial for MDS	<input type="checkbox"/>	<input type="checkbox"/>

*** 39. On average, how many hours a month does it take to receive all your current treatment(s) for MDS, including doctor visits and blood or platelet transfusions? (Enter 0 if none)**

On average, what are your monthly out-of-pocket costs (excluding insurance premiums) for all of your treatment(s) for MDS, including doctor visits and blood or platelet transfusions?

40. Enter the cost below (Enter 0 if none)

*** (a) Copay**

*** (b) Gas**

*** (c) Parking**

*** (d) Meals**

*** (e) Other**

41. Please indicate how much you agree with the following statement.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
* (a) Even if I didn't respond	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

right away, I would continue with a drug treatment that would ultimately delay the progression of my MDS. (Select one option)					
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42. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
*(a) Even if I didn't respond right away, I would continue with a drug treatment that would ultimately increase my chances of survival. (Select one option)	○	○	○	○	○

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43. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
* (a) My most current treatment is helping me get better by slowing down the disease. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

44. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
* (a) I prefer my most current therapy because it treats my MDS, not just the symptoms. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

45. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

*(a) My most current MDS treatment gives me a more positive outlook on the future. (Select one option)					
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

46. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
*(a) My most current treatment has a chance of curing my MDS. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
*(a) My most current MDS treatment will increase	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

my chances of survival. (Select one option)					
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48. Please indicate how much you agree with the following statement.					
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
*(a) Overall, my most current MDS therapy is meeting my treatment goals. (Select one option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*** 49. The chance that my current treatment will prolong my survival is:** (Select one option)

- Less than 10%
- 10% - 50%
- 51% - 75%
- 76% or higher
- Not sure

*** 50. The chance that my current treatment will cure me is:** (Select one option)

- Less than 10%

- 10% – 50%
- 51% – 75%
- 76% or higher
- Not sure

*** 51. What are the main sources where you currently get most of your information about MDS and its treatment?**

[Please select up to 3 options.]

- Your doctor(s)
- A nurse
- Aplastic Anemia & MDS International Foundation
- Marrowforums.org
- Pharmaceutical company literature
- Other patients
- Other sources (please specify) _____

*** 52. In what form do you currently get most of that information?**

[Please select up to 3 options.]

- Printed materials (booklets, newsletters)
- Web sites
- Webinars or webcasts
- Speaking with a patient educator
- Conversation with your doctor
- Conversation with a nurse
- In-person conferences or meetings
- In-person support groups
- Online chats or forums
- Talking with other patients
- Other (please specify) _____

*** 53. How would you prefer to get that information?**

[Please select up to 3 options.]

- Printed materials (booklets, newsletters)
- Web sites
- Webinars or webcasts
- Speaking with a patient educator
- Conversation with your doctor
- Conversation with a nurse
- In-person conferences or meetings
- In-person support groups
- Online chats or forums
- Talking with other patients
- Other (please specify) _____

*** 54. What topics are of greatest interest or would best meet your needs?**

[Please select up to 3 options.]

- Basic information about MDS
- Treatment options
- Effects of drugs/treatments
- Living well with MDS
- Financial/insurance issues
- Clinical trials
- Latest research
- Other (please specify) _____

*** 55. Other than medical treatments, what types of services or programs would be most valuable to you?**

[Please select up to 2 options.]

- Education about MDS and its treatment
- Counseling and emotional support

- Financial assistance with medical bills
- Information for family members and caregivers
- Wellness programs, like nutrition and exercise
- Talking with other patients
- Other (please specify) _____

By clicking the "Submit" button, you give us permission to use your answers in presentations and publications by AA&MDSIF, physicians, and pharmaceutical companies.

Problem with the survey? Call 1-800-747-2820 ext. 100.
