Myelodysplastic Syndromes

What is bone marrow?
Bone marrow is the soft, spongy tissue found in the center of large bones that stores immature cells called stem cells. Typically, stem cells mature into white blood cells, red blood cells, and platelets. White blood cells fight infections, red blood cells carry oxygen throughout the body, and platelets help blood clot.

What are myelodysplastic syndromes?
Myelodysplastic syndromes (MDS) are a group of blood and bone marrow disorders. MDS is considered a type of cancer. With MDS, stem cells do not mature correctly. The number of blasts and dysplastic cells increases, and the number of healthy, mature cells decreases. This means that there are fewer healthy red blood cells, white blood cells, and platelets.

Because of the decrease in healthy cells, people with MDS may experience anemia, neutropenia, and thrombocytopenia. In addition, dysplastic white blood cells and platelets may not work right, and chromosomes in the dysplastic bone marrow cells may be abnormal. Sometimes, a person’s blood counts are normal, but the blood and bone marrow cells are abnormal.

What are subtypes and classifications?
MDS is classified into several different subtypes, depending on blood cell counts, the percentage of blasts in the bone marrow, and the risk that it will turn into acute myeloid leukemia (AML). MDS is also classified as either primary or secondary MDS and may be given a disease staging called an IPSS-R score. These classifications help doctors plan treatment and predict a patient’s prognosis, which is the chance of recovery. Find more information at www.cancer.net/mds.

How are myelodysplastic syndromes treated?
The goal of treatment ranges from trying to achieve a remission to improving blood counts back to healthy levels. Treatment options and recommendations depend on several factors. These factors include the subtype and IPSS-R score, the risk of developing AML, possible side effects, and the patient’s preferences, age, and overall health. Treatment options include low-intensity therapies, chemotherapy, and bone marrow transplantation. Immunotherapy is sometimes an option for some patients.

When making treatment decisions, people may also consider a clinical trial. Clinical trials are an option to consider for treatment and care for all stages of cancer. Talk with your doctor about all treatment options. The side effects of MDS treatment can often be prevented or managed with the help of your health care team. This is called supportive care or palliative care, and it is an important part of the overall treatment plan.

How can I cope with a myelodysplastic syndrome?
Absorbing the news of an MDS diagnosis and communicating with your health care team are key parts of the coping process. Seeking support, organizing your health information, getting your questions answered, and participating in the decision-making process are other steps. Talk with your health care team about any concerns. Understanding your emotions and those of people close to you can be helpful in managing the diagnosis, treatment, and healing process.

ASCO ANSWERS is a collection of oncologist-approved patient education materials developed by the American Society of Clinical Oncology (ASCO) for people with cancer and their caregivers.
Questions to ask the health care team
Regular communication is important in making informed decisions about your health care. It can be helpful to bring someone along to your appointments to take notes. Consider asking your health care team the following questions:

- What subtype of MDS do I have?
- What risk group am I in? What does this mean?
- Can you explain my pathology report (laboratory test results) to me?
- What is my prognosis?
- What are my treatment options?
- What clinical trials are available for me? Where are they located, and how do I find out more about them?
- What treatment plan do you recommend? Why?
- What is the goal of each treatment? Is it to eliminate the MDS, manage my symptoms, or both?
- Who will be part of my health care team, and what does each member do?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- Will this treatment affect my ability to become pregnant or have children?
- Could this treatment affect my sex life? If so, how and for how long?
- What are the possible side effects of this treatment, both in the short term and the long term?
- If I’m worried about managing the costs of cancer care, who can help me?
- What support services are available to me? To my family?
- Whom should I call with questions or problems?

Find more questions to ask the health care team at www.cancer.net/mds. For a digital list of questions, download Cancer.Net’s free mobile app at www.cancer.net/app.

WORDS TO KNOW

Acute myeloid leukemia: A cancer of the blood in which blasts increase and grow out of control

Anemia: A low level of red blood cells

Blasts: Immature cells

Bone marrow transplantation: A treatment that injects stem cells to create new, healthy blood cells; also called stem cell transplantation

Chromosome: A long strands of genes

Dysplastic cells: Abnormally developed cells

Hematopoiesis: The production of white blood cells, red blood cells, and platelets

Immunotherapy: A treatment that boosts the body’s natural defenses to fight MDS, also called biologic therapy

Neutropenia: A low level of white blood cells

Remission: When MDS cannot be detected in the body and there are no symptoms

Thrombocytopenia: A low level of platelets

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