Myelodysplastic syndromes (MDS) are a group of diseases of the bone marrow and blood that affect approximately 19,000 people in the United States. Read below for information about the causes, symptoms, diagnosis, and treatment of MDS.

This “Patient Education” tear sheet was produced in collaboration with the Aplastic Anemia & MDS International Foundation (AA&MDSIF).

What Is MDS?
With MDS, your blood-forming stem cells are defective and fail to make enough healthy blood cells. People with MDS can lack the right amount of red blood cells, white blood cells, and platelets (the small cells that help blood to clot). MDS occurs because the bone marrow cells do not develop into mature blood cells. Instead, these blood cells stay within the bone marrow in an immature state.

How Is MDS Diagnosed?
MDS is a complex disease, so diagnosing it is a complex process. To reach a diagnosis, your doctor will take a detailed medical history, take samples of your blood and bone marrow, and examine those samples.

All people with MDS have two things in common:
• They have a low blood cell count for at least one blood cell type. (This is called cytopenia.)
• Their bone marrow and blood contain blood cells with an abnormal shape, size, or look.

What Causes MDS?
Most of the time, doctors do not know the exact cause of MDS, but certain lifestyle factors are linked to MDS. For instance, you are more likely to develop MDS if you have:
• Been a smoker
• Been heavily exposed to certain chemicals, such as benzene
• Had chemotherapy or radiation treatments

MDS cannot be passed down through the genes from parent to child, nor can it be passed through germs from person to person.

What Are the Symptoms of MDS?
The symptoms and the course of MDS may vary greatly from person to person, depending on which blood cells are affected and how low the blood counts have fallen. For instance, if your MDS is in its early stages and your blood counts are not too low yet, you may have only mild symptoms. As your blood counts decrease, you will have more symptoms.

Review the Symptom Checklist (on the back of this page) and share with your doctor.

How Is MDS Treated?
The main goal of MDS treatment is to increase the number of healthy cells in your blood (blood count). When your blood counts go up, you are less likely to need blood from a donor (transfusion), your quality of life becomes better, and your symptoms are not as bad.

Your doctor will look at several issues to find the best treatment plan for you. These include your symptoms, your age, the subtype of MDS you have, your disease risk score, other conditions or diseases you have, and if someone is willing and able to donate matching bone marrow to you (preferably a family member).

There are six general approaches used in the treatment of MDS:
• Wait and watch (or “watchful waiting”) is an approach your doctor might suggest if your blood counts aren’t too low and your symptoms aren’t too bad.
• Supportive care helps you manage the symptoms of your MDS. Its goals are to increase blood counts, treat infections, and treat iron overload. Treatments typically include blood transfusions and antibiotics and may include growth factors or iron chelation for some patients.
• Immunosuppressive therapy can lower your body’s immune response.
• Medicines approved specifically to treat MDS stop abnormal cells from growing and stimulate the growth of healthy bone marrow cells.
• Chemotherapy treats MDS by using drugs that kill abnormal cells.
• Bone marrow/stem cell transplantation replaces your unhealthy blood-forming stem cells with healthy ones from a donor.

Clinical trials are also an option, and participating in a clinical trial investigating new MDS treatments allows access to treatments that may work before they become standard treatments. Discuss the possible risks and benefits of entering a clinical trial with your doctor.
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