

Myelodysplastic
syndromes
MDS

WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with a myelodysplastic syndrome (MDS). What does it mean and how will it affect you?

This fact sheet will help you:

Learn about myelodysplastic syndromes and how they are diagnosed

Get an overview of treatment options

Understand what happens next



What are myelodysplastic syndromes?

Myelodysplastic syndromes are a group of cancers of the blood and bone marrow. With an MDS, your bone marrow – the soft, spongy material inside your bones – does not produce enough healthy blood cells.

When you have an MDS, stem cells in your blood go through a genetic mutation: the cells are damaged and become abnormal. This causes you to have too many immature bone marrow cells, known as blast cells. They don't work the same way as healthy, mature blood cells.

About MDS


- There are several different MDS types and subtypes.
- Some MDS can be caused by cancer treatments (for example, radiation).
- MDS can progress very slowly or very quickly.
- They may be described as low risk or high risk.
- A person with MDS might need blood transfusions.
- In rare cases, MDS can progress to a form of leukemia.

Signs and symptoms

MDS can develop slowly. Some people have no signs or symptoms, and the disease is uncovered during a routine blood test. It shows that you have an abnormally low level of one or more types of blood cells (red blood cells, white blood cells, or platelets).

You may experience:

- Fatigue, dizziness, weakness, shortness of breath or chest discomfort, and pale skin
 - When you have a lower level of red blood cells (anemia)
- Frequent or severe infections
 - When you have a lower level of white blood cells (neutropenia)
- Easy bruising and bleeding
 - When you have a lower level of platelets (thrombocytopenia)



A person with MDS has too many immature bone marrow cells, known as blast cells.

In a healthy person, blast cells make up less than 5% of the bone marrow. In someone with MDS, blast cells make up anywhere from 5% to 19% of the bone marrow.



After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how MDS will likely progress and how you may respond to treatment.

Name of test	Description
Medical history and physical exam	The doctor reviews past illnesses, injuries, and symptoms. They examine your lungs, heart, and other organs.
Complete blood count (CBC)	This test measures the number of red blood cells, white blood cells, and platelets in the blood. With MDS, one or more of these numbers will be low.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual in your chromosomes or genes. They are usually done at the same time.
Cytogenetic testing (karyotyping)	This test looks at your blood or bone marrow samples to see any changes in chromosomes that are specific to MDS.
Molecular testing (gene sequencing)	This test looks at your blood or bone marrow cells to identify specific changes to the DNA (genes) that are related to MDS.

MDS subtypes

Identifying the subtype and risk level of your disease is an important step in planning your treatment. There are a few different subtypes of MDS. Your MDS subtype is determined by a combination of how your blood and bone marrow look under the microscope, as well as what chromosome and gene changes are found. Your doctor will also use a clinical prediction tool to determine your MDS risk level.

MDS treatment

MDS is a disease that is manageable with treatment, although not everyone needs treatment right away. Treatment is usually focused on relieving symptoms, improving blood counts, and preventing progression. Treatments can be used alone or together.

Types of treatment

Watch and wait or active surveillance

Watch and wait (active surveillance) involves monitoring your blood cell counts. It delays treatment until the disease progresses.

Supportive care

Supportive care aims to relieve the symptoms of MDS and the side effects of treatment. This can include:

- Blood transfusions
- Iron chelation, a process that removes excess iron from your body
- Blood cell growth factor therapy to stimulate the making of more blood cells
- Infection management

Drug therapy

Drug therapy can include:

- Low or high-intensity chemotherapy is used to kill cancer cells.
 - One of the common chemotherapies for MDS is called azacitidine. It is given under the skin as an outpatient. It is a low-intensity chemotherapy.
- Lenalidomide is used for people with specific chromosome mutations.
 - This is an immune system modifying drug taken in pill format.
- Luspatercept is sometimes used for people who need frequent blood transfusions.
 - This can decrease how many blood transfusions are needed for dealing with a specific type of MDS.

Allogeneic stem cell transplantation

Allogeneic stem cell transplantation transfers a healthy person's (donor) stem cells to your body to slow the growth of the disease. This can be a high-risk procedure, and many people cannot safely have a stem cell transplant. It is the only option for a possible cure for people with MDS.

If you are **low risk**, your cancer is more likely to progress slowly, and can often be stable for many years. You will likely undergo a period of active surveillance.

If you are **high risk**, your cancer tends to progress quickly and there is a higher risk of developing acute myeloid leukemia (AML). You will likely undergo chemotherapy treatments, or other therapies.

Ask your medical team about **clinical trials**. These are research studies where people voluntarily receive a new treatment. New treatments are being developed in clinical trials for MDS, including immunotherapies that boost the immune system and drugs that target specific mutations.

Factors that affect treatment

Discuss your treatment options with your doctor to make sure you understand the benefits and risks of each approach. Your treatment plan is based on:

- Your MDS subtype and risk level
- Your blood cell counts and need for blood transfusions
- The percentage of blast cells in your bone marrow
- The type and number of chromosome and gene changes you have

Treatment side effects

When you begin your treatment for MDS, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan. Most side effects disappear once your treatment ends. New drugs and therapies can help control side effects, such as nausea. Speak to your doctor if you are having side effects.

Chemotherapy-related side effects

You may experience the following side effects from chemotherapy:

- Diarrhea or constipation
- Nausea
- Rashes
- Increased risk for infections
- Changes to your blood counts

It is very important to watch out for signs of infection with MDS, as your immune system can be low. Keep a good thermometer on hand. If you develop a fever, call your doctor or go to the emergency room.

Long-term or late effects of treatment

Medical follow-up is important after treatment for MDS. You may need blood tests, bone marrow tests, or molecular tests to determine if you need further treatment. Your medical team should provide you with a care plan listing the frequency of follow-up visits and the tests you will have at those visits.

- **Long-term side effects** are common and can last for months or years after treatment ends. Examples include chronic fatigue and problems concentrating (chemo brain).
- **Late effects** are medical problems that do not show up until years after treatment ends. See your doctor to get follow-up care for possible early detection of heart disease and secondary cancers.

Living with an MDS can be overwhelming. Seek medical help if you are feeling “down” or “blue” or don’t want to do anything – and your mood does not improve over time. These could be signs of depression, an illness that should be treated even when you’re undergoing treatment for an MDS. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.



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