

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





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

## 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
- It may be described as low risk (progresses slowly) or high risk (progresses quickly)
- Patients with an MDS might need blood transfusions
- In rare cases, MDS can progress to a form of leukemia

### Symptoms

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

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)

## Your diagnosis

With a 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.

Here are some possible tests you may undergo:

Name of test	Description
<b>Medical history and physical exam</b>	The doctor will review past illnesses, injuries, and symptoms, examining your lungs, heart, and other organs.
<b>Complete blood count (CBC)</b>	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.
<b>Bone marrow aspiration and biopsy</b>	These two tests look at bone marrow cells for anything unusual in the chromosomes or genes. They are usually done at the same time.
<b>Cytogenetic testing (karyotyping)</b>	This test looks at blood or bone marrow samples to see chromosome changes specific to MDS.
<b>Molecular testing (gene sequencing)</b>	This test looks at blood or bone marrow cells to identify specific changes to the DNA (genes) related to MDS.

## MDS subtypes

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

## Treatment for MDS

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

You may experience mild to severe side effects during treatment, depending on your age, overall health, and treatment plan. If so, let your doctor know.

Side effects can affect people in different ways. Most side effects improve or go away after treatment ends. New drugs and therapies can help control most side effects.

**Clinical trials are research studies that aim to improve the care and treatment of people living with cancer.**

**For some people with a blood cancer, a clinical trial may be the best treatment choice. Talk to your healthcare team for more information.**

## Types of treatment

Common MDS treatments include:

### Watch and wait or active surveillance

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

### Supportive care

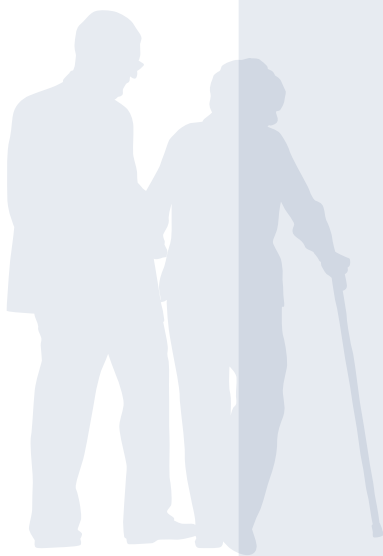
Supportive care aims to relieve the symptoms of MDS and the side effects of treatment. Supportive care can include antibiotics, infection management, and:

- Blood transfusions
  - **Potential side effects:** fever, skin rash or hives, chills, nausea, pain at the site of transfusion, shortness of breath, drop in blood pressure, back pain, dark or red urine
- Blood cell growth factor therapy, which helps your body make more blood cells
  - **Potential side effects:** headache, fever, diarrhea, skin rash, weakness, dizziness, and bone, joint or muscle pain, rarely heart attack or stroke
- Iron chelation, a process that removes excess iron from your body
  - **Potential side effects:** vomiting and nausea, dizziness, diarrhea, rash, red urine, muscle cramps, and changes to vision and hearing

### Drug therapy

Drug therapy can include:

- Low- or high-intensity chemotherapy kills cancer cells. Azacitidine, a type of chemotherapy drug, is commonly used for MDS. It is given under the skin.
  - **Potential side effects:** nausea, vomiting, loss of appetite, diarrhea, constipation, brain fog (chemo-brain), fatigue, shortness of breath, temporary hair loss, mouth sores, rashes, and neuropathy
- Immunomodulating drugs help your immune system respond to the cancer. They are often used to treat low-risk MDS.
  - **Potential side effects:** low blood cell counts, muscle cramps, fatigue and drowsiness, constipation, neuropathy (nerve damage), and the risk of a blood clot
- Novel agents identify and attack specific cancer cells without harming normal cells. This is known as targeted therapy. A common drug used is luspatercept.
  - **Potential side effects:** increase in blood pressure, blood clots, allergic reactions, back pain, weakness in the arms and legs, loss of bowel or bladder control
- Immunosuppressants reduce immune system activity. Anti-thymocyte globulin and alemtuzumab are two immunosuppressants used (rarely) for MDS.
  - **Potential side effects:** allergic reactions that can lead to low blood pressure and breathing problems



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### A stem cell transplant

A stem cell transplant 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 treatment that offers a possible cure for MDS.

- **Potential side effects:** low blood cell counts (white, red, and platelets), infection, bleeding, anemia, graft-versus-host disease (GvHD), veno-occlusive disease (VOD), and issues with the digestive system, skin and hair, pain, kidney, lung, heart, eyes, or central nervous system
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It is very important to watch out for signs of infection with MDS. Keep a good thermometer on hand. If you develop a fever, call your doctor or go to emergency.

### Treatment for low-risk vs. high-risk MDS

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

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

### 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 age and overall health
- 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



## Long-term or late effects of treatment

Medical follow-up is important during and after treatment for MDS. You may need blood tests, bone marrow tests, or imaging tests to determine if you need further treatment. Your medical team will provide a care plan listing 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 brain fog.

**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, secondary cancers, fertility issues, thyroid problems, trouble concentrating, and chronic fatigue.



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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