

# If You Have Myelodysplastic Syndrome (MDS)

If you or someone you know has just been diagnosed with **myelodysplastic syndrome (MDS)**, this short guide can help. Find information on myelodysplastic syndrome here.

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## What are myelodysplastic syndromes?

Cancer can start any place in the body. Myelodysplastic syndromes , or **MDS** for short, are cancers that start in the **bone marrow**, the soft inner part of some bones where new blood cells are made. In MDS, some cells in the bone marrow don't grow like they should, so there aren't enough of some types of blood cells. This makes it hard for the body to work the way it should.

Some people with MDS go on to get [leukemia](#)<sup>1</sup>, a cancer of the bone marrow in which blood cells start to grow out of control.

## Normal blood cells

To understand MDS, it helps to know about all the types of blood cells.

- **Red blood cells (RBCs)** carry oxygen from the lungs to all other parts of the body.

People without enough RBCs (called *anemia*) often feel tired or weak.

- **White blood cells (WBCs)** help the body fight infections. There are many types of white blood cells.
- **Platelets** are parts that break off from some bone marrow cells. Platelets help stop bleeding by plugging holes in blood vessels.

## Different types of MDS

In MDS, some bone marrow cells have problems making new blood cells. This can leave you with too few normal blood cells. There are [several types of MDS](#)<sup>2</sup>, which are based on how the blood and bone marrow cells have been changed. Some types of MDS are more likely to turn into leukemia later on. Ask your doctor to tell you the exact kind of MDS you have.

## Questions to ask the doctor

- Why do you think I have MDS?
- Is there a chance I don't have MDS?
- Would you please write down the kind of MDS you think I might have?
- What will happen next?

## How does the doctor know I have MDS?

MDS is sometimes found by blood tests done for some other reason. Even when there are [symptoms](#)<sup>3</sup>, they may be very general, such as feeling tired or weak, losing weight without trying to, having a fever, getting black and blue marks or bleeding easily, having pale skin, or getting sick a lot.

## Tests that may be done

The doctor will ask you questions about your health and do a physical and exam. If signs are pointing to MDS, more tests will be done. Here are some of the [tests you may need](#)<sup>4</sup>:

**Blood cell counts:** This blood test is often the first test done. Most people with MDS have too few RBCs. They might also have too few WBCs or platelets.

**Other blood tests:** Other blood tests might be done to look for other causes of low blood counts, such as low levels of vitamin B12 and folate.

**Bone marrow aspiration and biopsy** (ASP-er-AY-shun and BY-op-see): For these tests, a doctor uses thin, hollow needles to remove a little bit of bone marrow, most of the time from the hip bone. The area around the bone is numbed, and you may be given a drug to make you sleep during the test. The samples are sent to a lab to see how many early (immature) cells (called *blasts*) are in the bone marrow. Other lab tests might be done on the bone marrow cells as well, such as looking for certain gene changes. These tests can help tell which type of MDS you have.

### Questions to ask the doctor

- What tests will I need?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

### How serious is my MDS?

MDS is a disease of the bone marrow. Unlike most other cancers, it is not staged by looking at the how much cancer is in the body. In MDS other factors like your age, blood counts, how the bone marrow looks, and changes in the bone marrow cells are used to give the MDS a score, which can help tell how likely it is to grow or be helped by treatment. Ask your doctor [how your MDS will be scored](#)<sup>5</sup> and what that means for you.

### Questions to ask the doctor

- Does anything about my cells change the treatment? Or make my case better or worse?
- Are there other doctors I need to see?
- How many people with MDS have you treated?
- What type of MDS do I have?
- Based on the type of MDS, how long do you think I'll live?
- What will happen next?

## What kind of treatment will I need?

MDS is a group of diseases. The treatment plan that is best for you will depend on the type of MDS you have, your age and general health, and other factors. Some people with MDS might not need to be treated right away, but can just be watched closely instead. If you do need treatment, the main treatments are:

- Chemotherapy
- Immune treatments
- Growth factors
- Supportive therapy
- Stem cell transplant

## Chemo

Chemo is the short word for chemotherapy – the use of drugs to fight cancer. Chemo can be taken as a pill or put into a vein. The drugs go into the blood and reach most places in the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. For MDS, there are a few [types of chemo drugs and ways to take them](#)<sup>6</sup>. Ask your doctor which chemo drugs you will get, how you will take them, and how often you will take them.

## *Side effects of chemo*

Chemo can have many side effects, like:

- Hair loss
- Mouth sores
- Not feeling like eating
- Diarrhea
- Feeling sick to your stomach and throwing up
- More risk of infections
- Getting black and blue marks and bleeding easily
- Tiredness

But these problems tend to go away after treatment ends. There are ways to treat most

chemo side effects. Talk to your cancer care team so they can help.

## **Immune treatments**

These treatments either boost or hold back your immune system. A few types of immune treatments can be used to treat MDS. These drugs may be given into a vein, as a shot, or taken as pills. Ask your doctor which drugs you will get and what to expect.

### ***Side effects of immune treatments***

These drugs can cause many side effects. Some of the drugs can make you feel weak or tired or can cause diarrhea, low blood counts, and blood clots. Most of these problems go away after treatment ends.

There are ways to treat many of the side effects caused by these drugs. If you have side effects, talk to your cancer care team so they can help

## **Growth factors**

Having too few blood cells causes most of the symptoms in MDS. Growth factors speed up the process of making blood cells in the bone marrow. The body makes growth factors, but they can also be made in a lab. Growth factors can be given (most of the time as injections under the skin) to help make more blood cells. [Different growth factors can be used<sup>7</sup>](#), depending on the case. Ask your doctor which kind of growth factor you may get and what to expect.

## **Supportive treatment**

For many people with MDS, the main goal of treatment is to prevent problems from low blood cell counts. Sometimes you may need blood transfusions or other drugs to help manage your symptoms. Ask your doctor what kind of [supportive treatment<sup>8</sup>](#) to expect with your type of MDS.

## **Stem cell transplant**

A stem cell transplant (SCT) is the only treatment that can cure MDS. SCT lets doctors use very high doses of chemo to kill cells in the bone marrow. The high doses of these drugs destroy the bone marrow, which keeps new blood cells from being made. Although the drugs destroy the bone marrow, stem cells given after the chemo can bring back the bone marrow. For people with MDS, these new stem cells come from someone else who donates some of their stem cells. There are [different kinds of SCT<sup>9</sup>](#),

each of which can have bad side effects. Ask your doctor which type you will have and what to expect.

## Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

Clinical trials are one way to get the newest cancer treatments. They are the best way for doctors to find better ways to treat cancer. Still, they're not right for everyone. And it's up to you whether to take part in a clinical trial.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)<sup>10</sup> to learn more.

## What about other treatments I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be [vitamins, herbs, special diets, and other things](#)<sup>11</sup>. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

## Questions to ask the doctor

- What treatment do you think is best for me?
- What's the goal of this treatment? How is it likely to help?
- Will I need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Should we think about a stem cell transplant? If so, when?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?

- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

## What will happen after treatment?

If you have MDS you may go through a series of treatments with rests in between. Sometimes you may stop treatment for a while in favor of supportive care that treats other problems you have. Even if you have stopped your treatment, it's still very important to see your cancer doctor. Be sure to go to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and may do blood tests and other tests to see if the MDS is getting worse.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

### For connecting and sharing during a cancer journey

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

## Hyperlinks

1. [www.cancer.org/cancer/types/leukemia.html](http://www.cancer.org/cancer/types/leukemia.html)
2. [www.cancer.org/cancer/types/myelodysplastic-syndrome/about/mds-types.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/about/mds-types.html)
3. [www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-staging/signs-symptoms.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-staging/signs-symptoms.html)
4. [www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-staging/how-diagnosed.html)
5. [www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/detection-diagnosis-)

- [staging/staging.html](#)
6. [www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/chemotherapy.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/chemotherapy.html)
  7. [www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/growth-factors.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/growth-factors.html)
  8. [www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/supportive-therapy.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/supportive-therapy.html)
  9. [www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/stem-cell-transplant.html](http://www.cancer.org/cancer/types/myelodysplastic-syndrome/treating/stem-cell-transplant.html)
  10. [www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html](http://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html)
  11. [www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine.html](http://www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine.html)
  12. [www.cancer.org](http://www.cancer.org)

## Words to know

**Biopsy** (BY-op-see): taking out a small piece of tissue to see if there are cancer cells in it.

**Bone marrow:** The soft, spongy tissue in the middle of certain bones of the body. This is where new blood cells are made.

**Bone marrow aspiration and biopsy** (ASP-er-AY-shun and BY-op-see): A procedure in which a thin, hollow needle is put into the center of a bone, usually the hip bone, to take out a small amount of bone marrow so that it can be looked at under a microscope.

**Platelets** (PLATE-lets): Parts of blood cells that help stop bleeding by plugging up holes in blood vessels after an injury.

**Red blood cells (RBCs):** Blood cells that carry oxygen from the lungs to all other tissues of the body and take carbon dioxide back to the lungs to be removed. People with MDS often do not have enough RBCs in their blood.

**Stem cell transplant:** A treatment that replaces blood-forming stem cells in the bone marrow with new stem cells that come from the bone marrow of a donor.

**White blood cells (WBCs):** Blood cells that help defend the body against infections. There are many types of white blood cells.



## How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org)<sup>12</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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## Written by

The American Cancer Society medical and editorial content team  
(<https://www.cancer.org/cancer/acs-medical-content-and-news-staff.html>)

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