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Treating Myelodysplastic Syndromes (MDS)

If you've been diagnosed with a myelodysplastic syndrome (MDS), your treatment team will discuss your options with you. It's important to weigh the benefits of each treatment option against the possible risks and side effects.

Which treatments are used for MDS?

The main types of treatment for MDS are:

- [Supportive Therapy for Myelodysplastic Syndromes \(MDS\)](#)
- [Medicines for Myelodysplastic Syndromes \(MDS\)](#)
- [Stem Cell Transplant for Myelodysplastic Syndrome \(MDS\)](#)

Common treatment approaches

Treatment is based on the type of MDS, MDS risk group and other factors, as well as your age and overall health. Often more than one type of treatment is used. Doctors plan each person's treatment individually to give them the best chance of treating the tumor while limiting the side effects as much as possible.

- [General Approach to Treatment of Myelodysplastic Syndromes \(MDS\)](#)

Who treats MDS?

Based on your treatment options, you may have different types of doctors on your treatment team. These doctors could include:

- A **hematologist**: a doctor who treats disorders of the blood
- A **medical oncologist**: a doctor who treats cancer with medicines

Many other specialists might be part of your treatment team as well, including physician assistants (PAs), nurse practitioners (NPs), nurses, nutrition specialists, social workers, and other health professionals.

- [Health Professionals Who Are Part of a Cancer Care Team](#)

Making treatment decisions

It's important to discuss all treatment options, including their goals and possible side effects, with your doctors to help make the decision that best fits your needs. You may feel that you need to make a decision quickly, but it's important to give yourself time to absorb the information you have learned. Ask your cancer care team questions.

If time permits, it is often a good idea to seek a second opinion. A second opinion can give you more information and help you feel more confident about the treatment plan you choose.

- [Questions to Ask Your Doctor About Myelodysplastic Syndromes \(MDS\)](#)
- [Seeking a Second Opinion](#)

Thinking about taking part in a clinical trial

Clinical trials are carefully controlled research studies that are done to get a closer look at promising new treatments or procedures. Clinical trials are one way to get state-of-the-art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the best way for doctors to learn better methods to treat cancer.

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.

- [Clinical Trials](#)

Considering complementary and alternative methods

You may hear about alternative or complementary methods to relieve symptoms or treat your cancer that your doctors haven't mentioned. These methods can include vitamins,

herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

Complementary methods are treatments that are used **along with** your regular medical care. **Alternative** treatments are used **instead of** standard medical treatment. Although some of these methods might be helpful in relieving symptoms or helping you feel better, many have not been proven to work. Some might even be harmful.

Be sure to talk to your cancer care team about any method you are thinking about using. They can help you learn what is known (or not known) about the method, which can help you make an informed decision.

- [Complementary and Integrative Medicine](#)

Help getting through cancer treatment

People with cancer need support and information, no matter what stage of illness they may be in. Knowing all of your options and finding the resources you need will help you make informed decisions about your care.

Whether you are thinking about treatment, getting treatment, or not being treated at all, you can still get supportive care to help with pain or other symptoms. Communicating with your cancer care team is important so you understand your diagnosis, what treatment is recommended, and ways to maintain or improve your quality of life.

Different types of programs and support services may be helpful, and they can be an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help.

The American Cancer Society also has programs and services - including rides to treatment, lodging, and more - to help you get through treatment. Call our Cancer Knowledge Hub at 1-800-227-2345 and speak with one of our caring, trained cancer helpline specialists. Or, if you prefer, you can use our chat feature on cancer.org to connect with one of our specialists.

- [Palliative Care](#)
- [Programs & Services](#)

Choosing to stop treatment or choosing no treatment at all

For some people, when treatments have been tried and are no longer controlling the

cancer, it could be time to weigh the benefits and risks of continuing to try new treatments. Whether or not you continue treatment, there are still things you can do to help maintain or improve your quality of life.

Some people, especially if the cancer is advanced, might not want to be treated at all. There are many reasons you might decide not to get cancer treatment, but it's important to talk to your doctors as you make that decision. Remember that even if you choose not to treat the cancer, you can still get supportive care to help with pain or other symptoms.

- [If Cancer Treatments Stop Working](#)

The treatment information given here is not official policy of the American Cancer Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor. Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask your cancer care team any questions you may have about your treatment options.

Supportive Therapy for Myelodysplastic Syndromes (MDS)

Supportive therapies help treat (or prevent) the symptoms or complications of myelodysplastic syndromes (MDS), as opposed to treating the MDS directly. Supportive therapy might be used alone, especially for people with lower-risk MDS, or it might be used along with other treatments.

The main goal of this type of treatment is to improve a person's comfort and quality of life, regardless of how advanced the MDS might be. You might also hear supportive care referred to as **palliative care**, symptom management, or **comfort care**.

- [Treating low red blood cell counts \(anemia\)](#)
- [Treating low platelet counts](#)
- [Treating low white blood cell counts](#)
- [More information about palliative care](#)

For example, shortages of blood cells (red blood cells, platelets, or white blood cells) cause most of the symptoms and complications in people with MDS, so one of the main goals is to prevent or treat the problems caused by low blood cell counts.

Treating low red blood cell counts (anemia)

Having too few red blood cells (anemia) is the most common type of blood cell shortage in people with MDS. Anemia can cause severe fatigue and other symptoms.

Red blood cell transfusions

People with MDS and anemia that's causing symptoms might be helped by **red blood cell transfusions**. While some people might be concerned about getting an infection (such as hepatitis or HIV) from a blood transfusion, this risk is extremely low, and the benefits of getting the transfused cells greatly outweigh this risk.

Treating iron build up from blood transfusions

One problem with getting a lot of blood transfusions over time is that it can cause excess iron to build up in the liver, heart, and other organs, affecting how they function. This usually is seen only in people who get many transfusions over a period of years. People at risk for iron overload are often advised to avoid taking iron supplements.

Growth factors are hormone-like substances that help bone marrow make new blood cells. These substances occur naturally in the body, but they can also be manmade in large amounts.

Growth factors are given usually by subcutaneous (under the skin) injection. Your health care team can give the injections, or you or your family members might be able to learn to give them at home.

- **Epoetin alfa (EpoGen and [other brand names](#)²)** is a manmade version of the growth factor erythropoietin, which helps the bone marrow make new red blood cells. It can help lower the number of [red blood cell transfusions](#)³ some people need.
- **Darbepoetin alfa (Aranesp)** is a long-acting form of epoetin. It works in the same way but can be given less often.

Other medicines that raise red blood cell counts in different ways might also be helpful for some people.

- **Luspatercept (Reblozyl)** is a **red blood cell maturation agent**. This drug affects TGF- proteins in the bone marrow, which normally help control how quickly new cells in the bone marrow mature into functioning red blood cells. By acting on specific TGF- proteins, luspatercept helps the bone marrow make more mature red blood cells. This drug is injected under the skin, typically once every 3 weeks.
- **Imetelstat (Rytelo)** is a **telomerase inhibitor**. It can be used to help raise red blood cell counts in people with MDS whose anemia isn't being helped by the growth factors above. Imetelstat is given as an infusion into a vein (IV), typically once every 4 weeks.
- **Lenalidomide (Revlimid)** is an **immunomodulating drug (IMiD)**. It can often lower the need for blood transfusions in people with MDS, especially if the MDS cells are missing a part of chromosome 5 (del[5q]). To learn more about this drug, see [Medicines to Treat Myelodysplastic Syndromes](#).

Treating low platelet counts

People with MDS who have low platelet counts might bleed or bruise easily.

Platelet transfusions

works in the same way but can be given less often.

Antibiotics and vaccines

Typically, known or suspected bacterial infections are treated with **antibiotics**. But usually, antibiotics aren't given to help prevent infections in people with low white blood cell counts.

Because people with MDS are often at higher risk of infections, it's important to stay up to date with vaccines to help prevent them. To learn more, see [Vaccinations and Flu Shots for People with Cancer](#)⁷.

For more information about infections and how to lower your risk, see [Infections in People With Cancer](#)⁸.

More information about palliative care

To learn more about how palliative care can be used to help control or reduce symptoms caused by cancer, see [Palliative Care](#)⁹.

To learn about some of the side effects of cancer or treatment and how to manage them, see [Managing Cancer-related Side Effects](#)¹⁰.

Hyperlinks

1. </cancer/managing-cancer/treatment-types/blood-transfusion-and-donation.html>
2. www.cancer.org/cancer/managing-cancer/treatment-types/biosimilar-drugs.html
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Medicines for Myelodysplastic

(sometimes enough so that blood transfusions aren't needed), improve quality of life, lower the chance of the MDS progressing to [acute myeloid leukemia \(AML\)](#)¹, and even help a person live longer.

Azacitidine is usually injected under the skin (subcutaneously).

Decitabine can be injected under the skin (subcutaneously) or into a vein (IV).

A newer form of this drug, known as **Inqovi**, combines **decitabine with cedazuridine**, which helps stop the decitabine from being broken down in the digestive system. This lets the patient take the drug by mouth as a tablet.

Side effects of hypomethylating agents

Hypomethylating agents can have some of the same **side effects** as standard chemo drugs (see below), but these are usually milder.

A major side effect of these drugs is usually an early drop in blood cell counts, which tends to get better as the drug begins to work. Other side effects can include:

- Fever
- Nausea/vomiting
- Diarrhea or constipation
- Fatigue and weakness

Standard chemo drugs for more intense treatment

Standard chemo drugs are not used often for people with [lower-risk forms of MDS](#)². But higher-risk MDS is more likely to progress to [acute myeloid leukemia \(AML\)](#)³, so some people with these types of MDS may get the same chemo treatment as people with AML.

The chemo drug most often used for MDS is **cytarabine (ara-C)**. It can be given by

- **Idarubicin**
- **Daunorubicin**

Other chemo drugs might be used as well.

People with MDS who get higher-dose chemo are more likely to go into remission, but they also tend to have more severe, even life-threatening side effects, so this treatment is typically given in the hospital.

Side effects of chemo

Chemo drugs can cause many [side effects](#)⁵. These depend on the type and dose of the drugs given and how long they are taken. Common side effects include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Diarrhea or constipation

People with MDS often already have low blood counts, which can become even worse before they get better.

- Low white blood cell counts lead to an increased risk of serious infections.
- Low platelet counts (thrombocytopenia) can lead to problems with easy bruising and serious bleeding.
- Low red blood cell counts (anemia) can lead to fatigue and shortness of breath. In people with heart problems, severe anemia can lead to a heart attack.

If a person's blood cell counts get too low, they may need [supportive therapy](#)⁶ (including transfusions, growth factors, or other medicines) to help prevent or treat serious side effects.

Most side effects from chemo will go away after treatment is finished. Your health care team can often suggest ways to lessen side effects. For example, drugs can be given to help prevent or reduce nausea and vomiting.

Chemo drugs can also affect other organs. For example:

- Idarubicin and daunorubicin can damage the heart, so they are often not given to people who already have heart problems.
- Cytarabine can affect the brain and cause balance problems, sleepiness, and confusion. This is more common with higher doses.

If serious side effects occur, the chemo treatments may have to be reduced or stopped, at least for a while. It's important to carefully monitor and adjust drug doses, because some side effects can be permanent.

Immune therapy

Some medicines can help treat MDS by affecting the body's immune system.

Immunomodulating drugs (IMiDs)

Lenalidomide (Revlimid) belongs to a class of drugs known as immunomodulating drugs (IMiDs). It seems to work well in [lower-risk MDS](#)⁷, often eliminating the need for blood transfusions, at least for a time.

This drug seems to work best when the MDS cells are missing a part of chromosome 5. But it can also help some people with MDS who do not have this abnormal chromosome.

Side effects of lenalidomide can include:

- Low blood cell counts (most often the white blood cells and platelets)
- Diarrhea or constipation
- Fatigue and

Anti-thymocyte globulin (ATG) is an antibody against a type of white blood cell called a **T cell**. For some people with MDS, T cells interfere with normal blood cell production, so giving ATG can be helpful.

ATG is given by infusion through a vein. It must be given in the hospital because it can sometimes cause severe allergic reactions leading to low blood pressure and problems breathing.

Cyclosporine is another drug that can suppress the immune system. It can be used along with ATG to help some people with MDS. Side effects of cyclosporine can include loss of appetite and kidney damage.

Targeted therapy drugs

IDH1 inhibitor

In some people with MDS, the cancer cells have a change (mutation) in the *IDH1* gene, which normally helps cells make the IDH1 protein. Mutations in this gene can lead to an abnormal IDH1 protein, which can stop MDS cells from maturing the way they normally would.

Ivosidenib (Tibsovo) is an IDH1 inhibitor. It blocks the abnormal IDH1 protein, which helps the MDS cells mature into more normal cells. This drug can be used in people with advanced, previously treated MDS, if the MDS cells are found to have an *IDH1* mutation. Your doctor can test your MDS cells for this mutation. This drug is taken once a day, by mouth.

Possible side effects of ivosidenib

Common side effects can include fatigue, nausea, vomiting, belly pain or swelling, diarrhea, loss of appetite, cough, low red blood cell counts (anemia), rash, and changes on lab tests showing the drug is affecting the liver.

Less common but more serious side effects can include changes in heart rhythm, pneumonia, and jaundice (yellowing of the eyes and skin).

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1. www.cancer.org/cancer/types/acute-myeloid-leukemia.html
2. www.cancer.org/cancer/types/myelodysplastic-syndrome/about/mds-types.html
3. www.cancer.org/cancer/types/acute-myeloid-leukemia.html
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Stem Cell Transplant for Myelodysplastic Syndrome (MDS)

A stem cell transplant (SCT), also known as a bone marrow transplant (BMT), might be an option to treat some people with myelodysplastic syndromes (MDS), especially people with [higher-risk MDS](#)¹.

- [Types of stem cell transplants](#)
- [When is a stem cell transplant used to treat MDS?](#)
- [Side effects of stem cell transplants](#)
- [More information about stem cell transplant](#)

In this treatment, a person first gets high-dose [chemotherapy](#)² and/or total body irradiation to kill the cells in the bone marrow (including the abnormal bone marrow cells). Then they get new blood-forming stem cells to help rebuild the bone marrow.

Types of stem cell transplants

The main types of stem cell transplants differ in the source of the blood stem cells used (who they come from).

In an **autologous (AUTO) SCT**, the person has **some of their own stem cells** removed before treating the bone marrow, and then gets them back after treatment. While this type of transplant tends to cause fewer side effects, it's not as effective in treating MDS, so it's rarely used.

When is a stem cell transplant used to treat MDS?

Allogeneic SCTs are most often done in people with higher-risk MDS, as they offer the best chance to put the MDS into long-term remission. They might also be an option in people for whom other treatments are no longer working.

Allogeneic SCTs can have serious, even life-threatening, side effects, so they are most often done in people who are younger and in relatively good health. There is no strict age cutoff, but in general, the younger and healthier a person is, the more likely they can tolerate the intense treatment.

Non-myeloablative transplant (mini-transplant): Many people who are older or who have other health issues might not be able to tolerate a standard allogeneic SCT using high doses of chemo. Some people may still be able to get a non-myeloablative transplant (also known as a mini-transplant or reduced-intensity transplant).

For this treatment, a person gets lower doses of chemo and radiation that don't destroy the cells in their bone marrow completely. They then get the allogeneic (donor) stem cells. These cells enter the body and establish a new immune system, which sees the MDS cells as foreign and attacks them.

A non-myeloablative transplant can still sometimes work, while having less severe side effects. In fact, a person can often get the transplant as an outpatient.

Side effects of stem cell transplants

The [side effects from a SCT³](#) are similar to the side effects expected from chemotherapy and radiation, although they might be more severe because of the higher doses used.

One of the most serious side effects is **low blood cell counts**, which can lead to risks of serious infections and bleeding. Because of this, people getting a SCT typically need to stay in the hospital until their blood cell counts have recovered.

Another possible serious side effect from allogeneic transplants is **graft-versus-host disease (GVHD)**. This occurs when the new immune cells (from the donor) see the

patient's tissues as foreign and attack them. GVHD can affect any part of the body and can be life-threatening.

While allogeneic SCT offers the best chance to cure some people with MDS, not everyone who gets a transplant is cured, and some people may die from complications of this treatment. Because of this, doctors often don't recommend stem cell transplants for lower-risk MDS, as long as other treatments are still likely to be helpful.

More information about stem cell transplant

To learn more about stem cell transplants, including how they are done and their potential side effects, see [Stem Cell Transplant for Cancer](#)⁴.

For more general information about side effects and how to manage them, see [Managing Cancer-related Side Effects](#)⁵.

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General Approach to Treatment of Myelodysplastic Syndromes (MDS)

The treatment options for people with myelodysplastic syndromes (MDS) depend on a number of factors, such as:

- The [type of MDS](#)¹ a person has
- The [prognostic score \(risk group\)](#)² of the MDS
- What symptoms a person is having (if any)

A person's age, overall health, and preferences

Treating lower-risk MDS

Lower-risk MDS is less likely to progress to [acute myeloid leukemia \(AML\)](#)⁴ or to cause

- Other targeted medicines, if the MDS cells have certain gene or chromosome changes

More intense treatments, like those used to treat acute myeloid leukemia (AML) (such as high-dose chemo, possibly with a [stem cell transplant](#)), are usually reserved for people with higher-risk MDS. However, they might be an option for some people with lower-risk MDS, especially those who are younger, in good health, and who want to try to put the MDS into long-term remission. Even then, many doctors would advise that treatment be done as part of a [clinical trial](#)

While these treatments are less likely to result in long-term remissions on their own than a SCT, they might help keep the MDS in check until a SCT can be done.

Regardless of which approach is used, people can also get [supportive therapies](#) to help prevent or relieve symptoms from the MDS. Supportive care is important no matter what other treatments a person is getting.

Careful general medical care and measures to prevent and treat infections are also very important.

For people who can't have (or don't want) a stem cell transplant

When a stem cell transplant isn't a good option, [other treatments](#) can still be helpful in people with higher-risk MDS. Treatment can still help prevent or relieve symptoms, improve a person's quality of life, and possibly help them live longer as well.

Most people who aren't candidates for a SCT most likely wouldn't be able to tolerate high-dose chemotherapy either, so this isn't used often.

Examples of treatments that might be used include:

- Lower-intensity chemo with a hypomethylating agent (azacitidine or decitabine)
- Targeted therapy or other drugs, if the MDS cells have certain gene or chromosome changes
- [Supportive care](#) as needed, with treatments such as blood transfusions, growth factors, or other medicines

Careful general medical care and measures to prevent and treat infections are also very

Whichever treatment plan you choose, supportive care is still important to help with symptoms.

Many new medicines to treat MDS are also being studied in [clinical trials](#)⁹. Because the best options to treat MDS aren't always clear, and because MDS often becomes harder to treat over time, taking part in a clinical trial might be a good option at some point. Talk to your health care team to learn more about clinical trials that might be right for you.

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