



FRANKLY SPEAKING ABOUT CANCER

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



MYELOUDYSPLASTIC SYNDROMES



What is MDS?

Myelodysplastic syndromes (MDS) are a group of rare blood cancers that affect the bone marrow. They occur when stem cells (immature cells) in the bone marrow do not age or develop in a normal way. When this occurs, the bone marrow does not work correctly because it is not able to make enough healthy blood cells. This causes the blood cell counts in the body to become low. MDS often affects red blood cells, but it can affect white blood cells or platelets too. Over time, the body makes fewer and fewer blood cells. As this occurs, symptoms can become worse and potentially life-threatening.

Some people develop MDS following treatment for another cancer. When MDS is caused by cancer treatment or other medical treatment, it is considered “secondary MDS.” MDS without a known cause is called primary or *de novo* MDS. Around 80% of people with MDS have primary MDS.

WHAT ARE THE SUBTYPES OF MDS?

There are 6 main subtypes of MDS. The subtype affects the symptoms you may have, how the disease should be treated, and how well treatment might work. The subtypes are:

- MDS with single lineage dysplasia (MDS-SLD)
- MDS with multilineage dysplasia (MDS-MLD)
- MDS with ring sideroblasts (MDS-RS) – includes MDS-RS-SLD and MDS-RS-MLD
- MDS with excess blasts (MDS-EB) – includes MDS-EB1 and MDS-EB2
- MDS with isolated del (5q)
- MDS, unclassifiable (MDS-U)

TALKING ABOUT MDS

You may hear many words used to talk about MDS. Some key ones to know are:

- **Blood Cancer:** Cancer that begins in blood-forming tissue, such as bone marrow, or in the cells of the immune system.
- **Blasts:** Immature blood cells that, in some types of MDS, pile up in the bone marrow. This leaves little room for healthy cells.
- **Dysplasia or Dysplastic Cells:** These words are used to describe cells that look abnormal under the microscope. The bone marrow of someone with MDS will show signs of dysplasia.
- **Anemia:** A low number of red blood cells.
- **Bone Marrow:** The soft, spongy material in the middle of many large bones. Blood cells are made in the bone marrow.
- **Biomarkers:** Can be proteins, genes, or gene mutations. They can be a sign that something is not functioning properly in the body. They are usually measured in the blood, tissue, or bodily fluid.

Diagnosis & Staging

RISK FACTORS

The cause of MDS is mostly unknown, but there are some known risk factors. Risk factors are things that can increase the chance of developing a disease. Certain cancer risk factors can be changed. Others, like a person’s age or family history, cannot be changed. Having one or even many risk factors does not mean that a person will get the disease.



Risk factors for MDS include:

- **Age:** Most people are over 65 when they develop MDS, though it can affect younger people too.
- **Biological sex:** People who were born male are more likely to get MDS.
- **Smoking:** People who smoke cigarettes are more likely to develop MDS.
- **Rare bone marrow conditions:** People with certain rare diseases are more likely to develop MDS. These include Fanconi anemia and Familial aplastic anemia, for example.
- **Previous cancer treatment:** MDS occasionally occurs because of prior cancer treatment. It can show up years after chemotherapy or radiation. However, most people who are treated for cancer do not develop MDS.

For more information on MDS risk factors, visit www.CancerSupportCommunity.org/MDS.

SYMPTOMS & SIGNS TO START TREATMENT

Not everyone with MDS has signs or symptoms at the time of diagnosis. Those who do may notice the following:

- Fatigue
- Weakness
- Fever
- Shortness of breath
- Bone pain
- Easy bruising or bleeding
- Frequent infections
- Paleness

MDS DIAGNOSIS

MDS can be difficult to diagnose. Some people with MDS do not have any symptoms. The symptoms that may appear can be like those of other diseases. For this reason, diagnosis may involve ruling out other diseases. Your doctor will also need to determine the subtype of MDS before starting treatment. Different lab tests will be needed for a complete diagnosis, and some may need to be repeated. The following tests may be used to diagnose MDS and to determine the subtype:

- **Complete blood count (CBC):** This shows the number of red blood cells, white blood cells, and platelets. The first sign of MDS may show up in low blood counts, found through blood tests. Your doctor may order a CBC because you have symptoms or as part of a routine check-up.
- **Blood smear:** This test provides a closer look at the blood cells under a microscope.
- **Bone marrow aspiration and biopsy:** Your doctor will insert a needle into your hipbone to get a sample of liquid and tissue from the bone marrow. The removal of liquid is an aspiration. The removal of tissue is a biopsy. These 2 tests are usually done at the same time.

Bone marrow samples are sent to a lab for analysis. The following approaches may be used:

- **Flow cytometry:** This test shows whether blood cells in the bone marrow are maturing in a normal way. It also gives an approximate count of the immature blood cells. It can also provide information on cell characteristics, such as markers on cells.
- **Cytogenetic testing or chromosome analysis karyotyping:** This test looks at the cells of the bone marrow.



Specifically, doctors look at the chromosomes inside the cells to see if anything looks abnormal. Each person's cells have 23 pairs of chromosomes. It is common to see certain genetic changes in the cells affected by MDS. Some cells may be missing chromosome pairs or have rearranged chromosomes.

- Fluorescence in situ hybridization (FISH): This lab test looks at differences in chromosomes or other genetic changes that are common in people with MDS. The results come back faster than results of some other tests.
- Immunophenotyping: This test looks at the markers on cells. It can be used to see which markers are present on the cells and the portion of cells that have them.
- Molecular tests: These tests look for mutations in the genes or proteins of the bone marrow cell. Sometimes these are done as part of a larger procedure called a “myeloid next generation sequencing panel” or “myeloid NGS test”. This procedure looks for mutations in 50 or more genes that are commonly found with MDS.

STAGING

The goal of staging is to learn the subtype and the risk score of the disease. MDS is harder to understand than some cancers, so staging or classifying MDS is done differently from most cancers. To stage MDS, your doctor will look at:

- The percentage of immature blood cells (blasts)
- The blood counts that are affected – red blood cells (hemoglobin), white blood cells, and platelets

- The abnormal cells – how many and what they look like
- Changes to the chromosomes or genes within the cells

A final diagnosis will answer 3 questions:

1. Is this primary or secondary MDS?

Primary MDS has no known cause.

Secondary MDS is an outcome of prior cancer treatment.

2. What is the World Health Organization (WHO) subtype?

The subtype is based on whether red or white blood cells, or platelets, are affected. MDS can affect one, two, or all blood cell counts. The subtype also describes percentage of blood cells that are affected and how they are affected, and whether certain chromosome changes are detected.

The subtypes are:

- MDS with single lineage dysplasia (MDS-SLD) – This is a less common, more mild form of MDS. Some people with this subtype do not need treatment.
- MDS with multilineage dysplasia (MDS-MLD) – This is the most common subtype of MDS. It may develop into acute myeloid leukemia (AML).
- MDS with ring sideroblasts (MDS-RS) – This subtype includes MDS-RS-SLD and MDS-RS-MLD. It is less common and less likely to turn into AML.
- MDS with excess blasts (MDS-EB) – This subtype includes MDS-EB1 and MDS-EB2. It is a more common subtype. Around 1 in 4 people with MDS have this subtype. It is also more likely to turn into AML.



- MDS with isolated del(5q) – This subtype is more common in older women and has better outcomes. It is less likely to turn into AML.
- MDS, unclassifiable (MDS-U) – This very rare subtype describes MDS that does not fit the definition of any of the other subtypes.

3. What is the risk score?

The Revised International Prognostic Scoring System (IPSS-R) is the system used to assign a risk score. The score describes how serious or advanced the disease is. There are 5 ratings ranging from very low to very high. A lower score has a better outlook. A higher score means that the MDS is more advanced and will be harder to treat. A higher score also means that the MDS is more likely to turn into acute myeloid leukemia, a serious blood cancer.

Choosing Your Treatment Team

Cancer treatments can be complicated and change all the time with new discoveries. You want a health care team you can trust to take the best care of you. You also want a doctor and team that you can communicate with well. Your team may include many people, such as:

- **Medical oncologist/hematologist:** Look for a doctor who specializes in blood cancers.
- **Advanced Practice Providers (Nurse Practitioners and Physician assistants)**
- **Oncology nurses, nurse navigator/advocate, or nurse coordinators:** A person who helps patients through the care system, from diagnosis through treatment and recovery.



- **Social worker:** Can help you and your family find resources to cope with cancer, cope with treatment, and pay for care.
- **Oncology pharmacist:** A pharmacist who has expert training and knowledge about cancer treatments. This person can help you learn more about what to expect from your treatment and any side effects to look out for.

GETTING A 'SECOND OPINION'

If your doctor treats all cancers, ask about how many MDS patients they treat each year and if they stay current on the newest MDS treatments. Consider getting treatment or a second opinion at a major cancer center or university hospital. Talking with a second doctor can help you better understand your disease and how to treat it.

They may reassure you that the first treatment recommended is best. Let your doctor know if you want a second opinion. It is your choice to continue with the first or second doctor.

Treatment Planning

Your doctor will recommend treatment options based on the stage and subtype of your MDS, whether certain biomarkers



are present, and your overall health. Your doctor may also ask about your treatment preferences. This is called treatment planning.

You may make choices at the start of treatment and again along the way. Your treatment plan should be designed specifically for your cancer.

As you plan your treatment, 2 things you will want to consider are:

1. What is the goal of each treatment?

This may be a cure, or it may be treatment to help you live longer with a good quality of life.

2. What are the side effects of each treatment?

Ask how side effects may affect your quality of life. Find out what you and your health care team can do to help you manage them.

BIOMARKER TESTING

Many genes and changes to genes can play a role in MDS. Doctors often test for these biomarkers as a standard part of MDS staging. The results inform treatment even though there may not be a drug to target the biomarkers that are found.

OPEN TO OPTIONS® If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. **Call 888-793-9355** to schedule an appointment or to find a Cancer Support Community near you.



TIPS FOR TREATMENT PLANNING

- Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, bring a recorder or use a cell phone to record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.
- Talk to your health care team or financial navigator about ways to manage treatment costs before you start treatment.
- If your health care team has recommended watchful waiting, talk with them about what this means. Ask about next steps and treatment options.
- If you don't feel your health care team is addressing your concerns, consider getting a second opinion.
- Write down your questions before each doctor's visit. Keep a journal to track your side effects and results over time.
- Learn the words that doctors use to talk about MDS. This can help you better understand your test results and treatment options.



Treatment Options

MDS varies from person to person. The timing and type of treatment depends on both the subtype and the IPSS-R risk score. Your lifestyle and overall health may influence your treatment choices as well. The goals of treatment are to keep the disease from progressing or turning into leukemia, maintain or improve blood counts, and help you feel better. Your treatment options may include:

ACTIVE SURVEILLANCE

In some cases, you may not need to start treatment right away. Instead, active surveillance (also called “watchful waiting”) may be the safest approach for your care. With watchful waiting, you see a doctor regularly but don’t begin treatment until needed. Studies have shown that when there is no indication to start treatment, watchful waiting allows the patient to continue their lifestyle without causing their disease to progress more rapidly. Studies do not show any benefit to starting treatment before there is a need. Watchful waiting delays treatment-related side effects, while still allowing your treatment to begin when needed.

CHEMOTHERAPY

Chemotherapy uses drugs to destroy cancer cells. It is a systemic (whole body) treatment. This means it can destroy cancer cells almost anywhere in your body. It may be given by IV (through a vein), in pill form (by mouth), as an injection (a shot), applied directly on the skin into the area around the tumor, or placed directly into the tumor site. Most often, chemotherapy is given in an outpatient clinic. You will have a regular schedule of treatments for a set period of time.

Chemotherapy is most effective against fast growing cells, like cancer. But some healthy, normal cells may also be damaged by this treatment. The side effects will vary depending on the drug(s) you take, the dose of your drugs, and how often you get treatments. Be sure to talk with your health care team about any side-effects you may have.

STEM CELL TRANSPLANT OR BONE MARROW TRANSPLANT

A stem cell transplant (SCT) is an infusion of blood-forming cells (stem cells). It is not a surgery. The procedure has two parts. First, you will receive high doses of chemotherapy. This destroys blood cells. Next, stem cells are introduced into the bloodstream to replace blood cells. Bone marrow transplant is one kind of SCT. Sometimes patients serve as their own donors (autologous stem cell transplant). Other times, patients get stem cells from donors (allogeneic stem cell transplant).

When your risk score is high, your doctor may recommend SCT. This is the only possible cure for MDS, but it is not always effective. Before you go through SCT, there are many things to consider. Learn the risks and benefits of SCT if it is recommended for you. Learn what to expect from the procedure and how to prepare for it. You’ll also want to know what to expect for recovery and beyond. Ask if your transplant will be done in the hospital or as an outpatient.

To learn more about SCT, please visit www.CancerSupportCommunity.org/Stem-Cell-Transplant.

IMMUNOTHERAPY

In rare cases, immunotherapy may be used to treat MDS. Immunotherapy uses the body’s natural defenses (the immune system) to find, attack, and kill cancer cells.



One type of immunotherapy, monoclonal antibodies, may be used in combination with chemotherapy. Some immunotherapy treatments are available only through clinical trials.

To learn more, visit www.CancerSupportCommunity.org/Immunotherapy.

www.CancerSupportCommunity.org/Immunotherapy.

PALLIATIVE CARE

People with MDS often experience ongoing symptoms that lead to discomfort. Ask to see a doctor or other medical professional who specializes in palliative care. This person can provide care to help improve your quality of life.

SUPPORTIVE CARE

Many people with MDS receive supportive care. These treatments are designed to boost blood counts and reduce symptoms. They do not treat the cancer. They can take considerable time and interfere with everyday life.

Supportive care may involve:

- **Blood transfusions:** This can help boost blood counts and reduce symptoms. People with MDS sometimes get transfusions as often as every week or 2 weeks. A transfusion can take up to several hours. You may feel better soon after a transfusion.
- **Antibiotics to treat infections:** Low blood counts can lead to frequent infections.
- **Growth factors:** These drugs are used to increase the number of mature blood cells. Different drugs boost different types of blood cells.

- **Chelating agents:** These drugs are used to reduce iron build-up that can be caused by having many transfusions.

CLINICAL TRIALS

Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments. At leading cancer centers, clinical trials provide new treatments for many types of cancer, including MDS. To learn more, check with your health care team about clinical trials that may be an option for you.

To learn more, visit www.CancerSupportCommunity.org/Clinical-Trials.

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Managing Side Effects

It helps to learn more about the side effects of treatment before you begin so you will know what to expect. When you know more, you can work with your health care team to manage your quality of life during and after treatment. There are many medications available to address side effects from cancer treatment.



KEY THINGS TO KNOW ABOUT CLINICAL TRIALS

- Clinical trials for MDS are done to test new treatments, new combinations of treatments, or different ways of doing stem cell transplant.
- A doctor experienced in treating MDS should be able to recommend specific trials.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Not every doctor offers the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health care plan and your copay cover “standard” treatment costs. Be sure to ask what costs you may incur.

Everyone reacts differently to treatment and experiences side effects differently. After you start treatment, keep track of how you feel. It is important to let your health care team know if you have any side effects.

Your doctor may discuss options such as lowering the dose of your treatment if these side effects persist and are not easy to manage. You may also experience treatment side effects well after your treatment has ended. It is important to talk to your doctor about the long-term effects of treatment as part of your post-treatment plan.

The following are common side effects of MDS and its treatment:

DEPRESSION AND ANXIETY

It is normal to feel alone, angry, anxious, or despair. Depression and anxiety can make it difficult to cope with symptoms and treatment. It can also affect your well-being. Tell your health care team if you are feeling depressed or anxious. They can help you get treated for these conditions, which can make a big difference in your daily life.

FATIGUE

Fatigue is a feeling of tiredness that doesn't go away. Some people also have muscle weakness or difficulty concentrating. It may be caused by the cancer, by treatment, or other health problems. Fatigue in MDS patients can be the result of having too few red blood cells. If you have cancer-related fatigue, your doctor will try to find and treat what is causing it.

BLEEDING

Platelets are blood cells that help control bleeding. Sometimes cancer treatment lowers the number of platelets in your body (thrombocytopenia). When this happens, bleeding can occur from any part of your body. Some drugs, including aspirin or some herbal supplements, can increase your risk of bleeding. Tell your doctor about any non-prescription medications you take. Let your health care team know right away if you notice any bleeding from your nose, around your gums, or during bowel movements.

BRUISING

Low platelet counts can also cause bruising. You may notice tiny red dots on your skin (petechiae).



Bruising may occur even if you haven't injured yourself. Let your health care team know if you notice any bruises on any part of your body, especially if you haven't injured yourself.

PAIN OR DISCOMFORT

Treatment for cancer can cause pain and discomfort. If you begin experiencing new pain or severe pain, it is important that you tell your doctor immediately. You are the expert in your cancer experience, so your health care team will look to you to provide information regarding your pain. Your doctor may ask questions about how often you have pain and how much the pain hurts. Using a Pain Rating Scale will help your doctor better understand the pain you have and provide an appropriate course of treatment.

By talking about pain, you begin the process of controlling it. Recording details in your planner can also be helpful. Do not ignore the pain. Track your pain, using a scale of 0–10 to rate it, then report it back to your health care team. Your doctor can help you manage the pain with prescription or non-prescription drugs, surgery, or nerve blocks.

Cost of Care

The treatment for MDS and follow-up appointments can be costly. Treatment often involves many blood tests and transfusions. Same-day hospital visits may be long and frequent. You may find that taking care of your health takes a lot of time. The costs associated with transportation, missed time at work, childcare, and more may become burdensome and overwhelming.

QUESTIONS TO ASK YOUR HEALTH CARE TEAM:

What type of MDS do I have?

What stage is my MDS, or what “risk group” am I in?

What type of treatment do you recommend?

How often and where will the treatment take place? Will I have to stay overnight in the hospital for any part of the treatment?

What are the goals of my treatment?

What are the possible side effects of treatment?

Will I need someone to take care of me at any point during this treatment?

Do you recommend a clinical trial?

How will my cancer affect my quality of life?

What will my treatment cost and how much will my insurance cover?



Many families facing cancer say that financial worries about cancer costs are a big source of stress, and they don't know where to turn. There are resources that can help.

Visit www.CancerSupportCommunity.org/Cost for more information on managing health care costs.

Coping with MDS

Cancer stirs up many feelings. It affects people who have it, their families, and loved ones. It is normal to feel sad, worried, shocked, stressed, or even panicked. The feelings may be mild or more serious. Remember that cancer can affect anyone. No one deserves cancer. And everyone with cancer deserves good care.

10 Tips for Living Well with MDS

1. Take one step at a time and make one decision at a time.
2. Find a treatment team you trust.
3. Use a notebook to keep track of your diagnosis, symptoms, answers to questions, and next steps.
4. Accept help when it is offered.
5. Reach out to other people with MDS.
6. Seek support from a patient advocate.
7. Learn to relax and find a new perspective.
8. Find ways to feel in charge of your life.
9. Focus on nutrition and exercise.
10. Remember that hope is possible.

Caregivers

Caregivers help or arrange help for people who are ill or disabled. This can take different forms. It might involve physical care or emotional support.

Some caregivers assist with money matters, insurance, household chores, rides, or making appointments. Caregivers may or may not live with the person. Caring for someone who has cancer is not easy. People who do so need support and help from their family, friends, and health care team.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time.

Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit www.CancerSupportCommunity.org/Caregivers.



GENERAL CANCER INFORMATION, SURVIVORSHIP, AND SUPPORT

Cancer Support Community · 1-888-793-9355 · www.CancerSupportCommunity.org

American Cancer Society · 800-227-2345 · www.Cancer.org

CancerCare · 800-813-4673 · www.CancerCare.org

Cancer.net · 888-651-3038 · www.Cancer.net

National Cancer Institute (NCI) · 800-422-6237 · www.Cancer.gov

NCI Clinical Trial Information · 800-422-6237 · www.Cancer.gov/ClinicalTrials

Patient Advocate Foundation · 1-800-532-5274 · www.PatientAdvocate.org

CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-9pm ET and Sat-Sun 9am-5pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

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This booklet is available to download and print yourself at www.CancerSupportCommunity.org/MDS. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

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