

# The MDS Guide: Information for Patients and Caregivers



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## A six-word narrative about living with blood cancer from patients in our LLS Community

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Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at  
[www.LLS.org/Community](http://www.LLS.org/Community)

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find:

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

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## INTRODUCTION

Myelodysplastic syndromes (MDS) are a group of blood cancers that start in the bone marrow. In patients with MDS, the bone marrow does not make enough healthy blood cells.

Although MDS can occur at any age, most people are older than age 60 when diagnosed.

- An average of 15,099 new cases of MDS were diagnosed in the United States each year from 2013 to 2017.
- An estimated 58,471 people in the United States are living with or in remission from MDS.

Today, there are many treatments to help people who have MDS. But much work remains to be done. Researchers continue to study and develop new treatments in clinical trials for patients with MDS.

New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

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**Feedback.** Visit [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback) to make suggestions about the content of this book.

## PART 1 MYELODYSPLASTIC SYNDROMES

### Overview of This Section

- Myelodysplastic syndromes (MDS) are a group of cancers of the blood and bone marrow.
- Blood cells begin as stem cells, which are made in the bone marrow. Bone marrow is the spongy tissue found in the center of most bones. Stem cells normally develop into healthy red blood cells, white blood cells or platelets, and then leave the bone marrow and enter the bloodstream.

- MDS starts with a mutation (change) in the DNA of a single stem cell in the bone marrow.
- MDS is diagnosed with blood and bone marrow tests.
- There are many subtypes of MDS. Knowing your MDS subtype helps doctors determine your treatment options.

## About Bone Marrow, Blood and Blood Cells

The general descriptions below may help you understand the information in the rest of this Guide.

**Bone marrow** is the spongy center inside bones where blood cells are made.

**Blood cells** begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After the cells have matured in the bone marrow, the red blood cells, white blood cells and platelets enter the bloodstream.

**Red blood cells** carry oxygen around the body. When the number of red blood cells is below normal, a condition called **anemia** usually develops. Anemia may make you feel tired or short of breath. It may make your skin look pale.

**White blood cells** fight infection in the body. There are two major types of white blood cells: lymphocytes and germ-eating cells.

- Lymphocytes are infection-fighting cells. The three main types are:
  - B cells
  - T cells
  - NK cells
- Germ-eating cells kill and ingest bacteria and viruses. The two types are:
  - Neutrophils
  - Monocytes

**Platelets** help stop bleeding by clotting (clumping together) at the site of an injury. **Thrombocytopenia** is a condition in which there is a lower-than-normal number of platelets in the blood. It may cause unexplained bruising and bleeding.

**Plasma** is the liquid part of the blood, not including the blood cells. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

## Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. They may be a little different from lab to lab and for children and teens.

### Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

### Hematocrit (the part of the blood made up of red blood cells)

- Men: 42% to 50%
- Women: 36% to 45%

### Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

### Platelet count (PLAT C)

- 150,000 to 450,000 platelets per microliter of blood

### White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

### Differential (also called diff)

- Shows the part of the blood made up of different types of white blood cells
- Counts the types of white blood cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
  - Normal adult white blood cell count: neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood

## About MDS

MDS are a group of blood cancers that start in the bone marrow. A person can get MDS at any age, but most people diagnosed with MDS are older adults.

**Causes and Risk Factors of MDS.** MDS starts with a change to a single stem cell in the bone marrow. This means:

- A normal stem cell mutates (changes)
- Mutated cells multiply into many cells (MDS cells)

While doctors do not know what causes most cases of MDS, certain factors may increase the risk of developing MDS. Having a risk factor does not mean that a person will develop the disease. Some people with several risk factors for MDS never develop it, while other people with no known risk factors do. There is no way to prevent MDS, and you cannot catch MDS from someone else.

Risk factors associated with MDS include:

- Age. The risk of developing MDS increases with age.
- Sex. Males are more likely than females to develop MDS.
- Prior cancer treatments. Some types of chemotherapy and radiation therapy may increase a person's risk of developing MDS. This is called "secondary MDS" or "treatment-related MDS."
- Genetic disorders. Certain genetic conditions present at birth seem to increase the risk of developing MDS. These include: Fanconi anemia, Shwachman syndrome, Diamond-Blackfan Anemia (DBA) syndrome and Down syndrome.

There are two types of MDS: primary (no cause can be identified) and secondary (treatment-related and less common). Most people diagnosed with MDS have primary MDS.

## Signs and Symptoms

Healthy people often have a sign or symptom when they get an illness or a disease.

A **sign** is a change in the body that the doctor sees in an exam or a test result. A **symptom** is a change in the body that the patient can see or feel.

Signs and symptoms of MDS may include:

- Tiredness
- Dizziness
- Shortness of breath
- Headaches
- Pale skin
- Frequent infections
- Fever
- Bruising easily
- Frequent and/or severe bleeding

Many of the signs and symptoms of MDS are also signs and symptoms of other illnesses. Most people with these signs and symptoms do not have MDS.

# Diagnosis

It is important for patients to receive the correct diagnosis. People with MDS are diagnosed with blood and bone marrow tests.

**Here are some questions you may want to ask your healthcare team.** See pages 34-39 for a full list of questions.

1. What kind of testing will be done to diagnose my disease and to monitor my treatment?
2. How long does it take to get the results?
3. How will I find out the results?
4. How often will testing be needed?
5. Where will the testing be done?

**Blood Cell Count.** A test called a **complete blood count (CBC)** is used to count the number of red blood cells, white blood cells and platelets in a sample of blood. Most patients with MDS have low blood cell counts, called “cytopenias.” Most often they have too few red blood cells. They may also have low white blood cell counts and/or low platelet counts.

**Peripheral Blood Smear.** In this test, a single drop of blood is spread on a glass slide, dried and then stained with a special dye. The sample is viewed under a microscope to examine the number, size, shape and appearance of the blood cells. In MDS, some blood cells have an abnormal shape or size, called “dysplasia.” A peripheral blood smear also checks for blast (immature) cells in the blood. Blast cells should not be found in the blood; they are normally found in the bone marrow. In some cases of MDS, blast cells are found in the blood.

**Bone Marrow Tests.** Bone marrow aspiration and bone marrow biopsy are different tests in which two small samples of bone marrow (liquid and bone) are removed from the top part of the back of the hip bone using special needles. The samples are then sent to the lab for examination. Bone marrow tests are done to confirm the diagnosis of MDS and to help make treatment decisions.

**Visit [www.LLS.org/3D](http://www.LLS.org/3D) and click on “Bone Marrow Biopsy and Aspiration” to view an interactive 3D image which will help you visualize and better understand the bone marrow aspiration and biopsy procedures.**

## How Are the Blood and Bone Marrow Tests Done?

**Blood Test** — Blood is taken from the patient's arm with a needle. The blood is collected in tubes and sent to a lab.

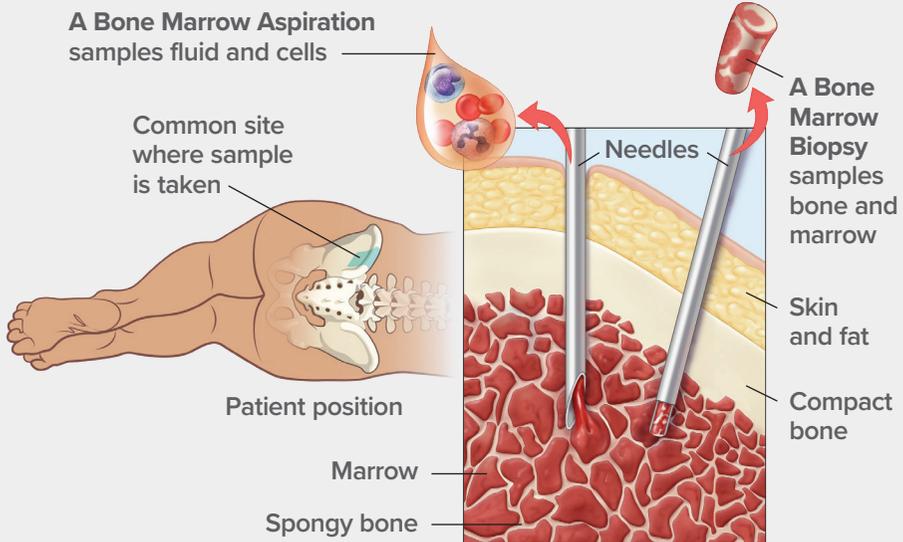
**Bone Marrow Aspiration** — The removal of a sample of fluid with cells from the bone marrow.

**Bone Marrow Biopsy** — A very small amount of bone filled with marrow cells is taken from the body.

Both bone marrow tests are done with special needles. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to take the sample of cells. Some patients are given a drug that makes them sleep during this procedure. The sample of cells is usually taken from the back of the patient's hip bone.

Blood and marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and biopsy are almost always done at the same visit.

### Bone Marrow Aspiration and Biopsy



**Left:** The place on the back of the patient's hip bone where a bone marrow aspiration or biopsy is done. **Right:** Where the needle (on the left) goes into bone marrow to collect a liquid sample for aspiration and the other needle (on the right) to collect the bone for a bone biopsy. The needles are different sizes for each of these tests.

**Cytogenetic Analysis (Karyotyping).** This test uses a microscope to examine the chromosomes inside cells. Chromosomes are the part of a cell that contains genetic information. Normal human cells contain 46 chromosomes. The chromosomes are a certain size, shape and structure. In some cases of MDS, the chromosomes of the MDS cells have abnormal changes. The results of the cytogenetic analysis help your doctor identify your MDS subtype and plan your treatment.

**FISH (Fluorescence In Situ Hybridization).** This test is used to examine genes and chromosomes in cells and tissues. Doctors use FISH to find certain abnormal changes in the chromosomes and genes of cancer cells.

**Molecular Testing.** Molecular testing is used to find mutations (changes) in the DNA of cancer cells. Certain mutations are linked with a better or a worse outcome. Doctors use the results of molecular testing to help plan treatment.

## Tracking Your MDS Tests

These tips may help you save time and learn more about your health:

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports in a folder or binder. Organize the reports by date.
- Find out if and when follow-up tests are needed.
- Mark appointments that are coming up on your calendar.

### WANT MORE INFORMATION?



You can view, print or order the free LLS book *Understanding Lab and Imaging Tests* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Subtypes of MDS

MDS is diagnosed based on the features of the bone marrow and blood cells. These features include:

- At least one low blood cell count (red blood cells, white blood cells or platelets)
- Dysplasia (cells that have an abnormal shape or size)
- The number of blast cells (immature blood cells) in the blood and bone marrow
- Certain changes to the chromosomes in bone marrow cells that are associated with MDS

The World Health Organization (WHO) divides MDS into six subtypes based on the results of blood and bone marrow tests. The subtypes are:

1. MDS with single lineage dysplasia (MDS-SLD)
2. MDS with ring sideroblasts (MDS-RS)
  - Single lineage dysplasia (MDS-RS-SLD)
  - Multilineage dysplasia (MDS-RS-MLD)
3. MDS with multilineage dysplasia (MDS-MLD)
4. MDS with excess blasts (MDS-EB)
  - MDS with excess blasts-1 (MDS-EB1)
  - MDS with excess blasts-2 (MDS-EB2)
5. MDS with isolated del(5q)
6. MDS unclassifiable (MDS-U)

For definitions of these subtypes, see *Health Terms* on page 27-29.

### WANT MORE INFORMATION?



For more detailed information on MDS, you can view, print or order the free LLS book *Myelodysplastic Syndromes* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Prognostic Scoring Systems

Doctors often use scoring systems for people who have MDS. These scoring systems were created to figure out the severity of a patient's MDS.

The International Prognostic Scoring System (IPSS) was the first widely used scoring system for MDS. A patient's score is based on three factors:

1. The percentage of blasts (immature cells) in the bone marrow
2. The type of chromosomal abnormalities in the cancer cells
3. Low blood cell counts

Each factor is given a score. Then the scores are added up to place patients into four risk groups:

- Low
- Intermediate-1
- Intermediate-2
- High

Doctors also use the International Prognostic Scoring System-Revised (IPSS-R), an updated version of the IPSS. A patient's score is based on five factors:

1. The percentage of blasts (immature cells) in the bone marrow
2. The type of chromosomal abnormalities in the cancer cells
3. The level of red blood cells (measured as hemoglobin) in the blood
4. The level of platelets in the blood
5. The level of neutrophils (a type of white blood cell) in the blood

Based on these factors, patients are placed into the following risk groups:

- Very low
- Low
- Intermediate
- High
- Very high

## PART 2 TREATMENT

### Overview of This Section

- People with MDS should choose a doctor who specializes in treating MDS. This type of doctor is called a **hematologist-oncologist**.
- Ask questions about your treatment options and do not be afraid to be involved in making decisions about your care. See the question guides *My First Doctor's Visit* and *Treatment and Follow-Up Care* on pages 34-39.
- People diagnosed with MDS can be treated by observation (watch-and-wait approach), clinical trials, supportive care, drug therapy or allogeneic stem cell transplantation.

### Finding the Right Doctor

Choose a doctor who specializes in treating MDS and knows about the most up-to-date treatments. This type of specialist is a **hematologist-oncologist**. A hematologist is a doctor who has special training in disorders of the blood. An oncologist is a doctor who has special training in cancer. A hematologist-oncologist has special training in diagnosing and treating blood cancers.

If your local medical center does not have a hematologist-oncologist, ask the cancer specialist you see if they can consult with a hematologist-oncologist at another medical center. Always check to see if your health insurance covers the services of the doctors (and the hospitals associated with them), or the hospital you choose for your treatment.

### How to Find a Hematologist-Oncologist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- Reach out to doctor and/or health plan referral services.
- Call an LLS Information Specialist at (800) 955-4572.
- Use online doctor-finder resources, such as
  - The American Medical Association’s (AMA) “DoctorFinder” online at <https://doctorfinder.ama-assn.org/doctorfinder/home.jsp>
  - The American Society of Hematology’s (ASH) “Find a Hematologist” online at <https://www.hematology.org/Patients/FAH.aspx>

When you meet with the specialist, ask questions to get a better idea of the doctor’s experience and to understand how the office works. Some sample questions are below. See pages 34-35 for a full list of questions.

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. Is there a release form available so my family/caregiver can be given medical information?

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time speaking with this staff at this treatment center.

#### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Choosing a Blood Cancer Specialist or Treatment Center* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists at (800) 955-4572 for a copy.

# Ask Your Doctor

Talk with the doctor and ask questions about how they plan to treat your MDS. This will help you become actively involved in making decisions about your care.

When you meet with your doctor:

- Ask questions. Below are a few questions to ask. See pages 34-39 at the end of this Guide for a full list of questions. Visit [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) to find other "What to Ask" healthcare question guides.
  - What are my treatment choices?
  - Are there any clinical trials that I can join?
  - When do you think treatment should begin?
  - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later on. Ask the doctor and staff if you can record the conversation (cell phones have a "record" function; ask someone how to use it).
- Bring a caregiver, friend or family member who can listen to the doctor along with you and to take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain it again.

If you need more information or are not sure about your treatment choices, consider getting another opinion (a "second opinion") from a different qualified doctor. If you are unsure or feel uncomfortable about how to tell your doctor you are getting a second opinion, call our Information Specialists at (800) 955-4572 to discuss a way that makes you comfortable. You may also want to check with your health insurance plan to ensure that a second opinion will be covered.

## About MDS Treatments

New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be participation in a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. By considering all your treatment options, including clinical trials, you will be taking an active role in your health care.

Not everyone with MDS receives the same type of treatment. Your doctor will tailor your treatment based on you MDS subtype, your prognostic score and other factors such as your age and overall health.

Patients who have symptoms caused by low blood cell counts are given supportive care to relieve symptoms. Drug therapy may be used to slow progression of the disease. Some patients can be cured with a stem cell transplant.

There are many treatments for MDS. You may receive different drugs from those described in this Guide. This may still be considered proper treatment. Speak with your doctor to find out what treatment is best for you.

Our Information Specialists can help you plan questions to ask your doctor about treatment.

**Here are some questions you may want to ask your healthcare team.** See pages 36-39 for a full list of questions.

1. What subtype of MDS do I have?
2. What are the treatment options, including clinical trials?
3. What is the goal of treatment?
4. What are the benefits and risks of these treatments?
5. Is one treatment recommended over others?

Treatment options for MDS include:

- Clinical trials (new approaches under study)
- Supportive care
- Watch and Wait
- Drug therapy
- Allogeneic stem cell transplantation

**Supportive Care.** The goal of supportive care in MDS treatment is to improve quality of life by reducing symptoms caused by low blood cell counts.

**Treating Low Red Blood Cell Counts.** Patients with symptoms of low red blood cell counts such as severe tiredness, dizziness and shortness of breath may receive treatment to increase their red blood cell counts. These treatments may include:

- **Red Blood Cell Transfusions.** A red blood cell transfusion is a slow injection of donated red blood cells into a patient's body through a vein.

- **Red Blood Cell Growth Factors.** MDS patients with low blood cell counts may be given drugs called "growth factors" to help their body make more blood cells.

Drugs, called "erythropoietin-stimulating agents (ESAs)," are available to help the bone marrow make more red blood cells. Treatment with ESAs may decrease the need for red blood cell transfusions. Examples of ESAs include **darbepoetin alfa (Aranesp)** and **epoetin alfa (Procrit®)**.

- **Erythroid Maturation Agent.** This drug is used to treat anemia in adults who need to have regular blood transfusions. It is used when erythropoietin-stimulation agents are not effective in increasing red blood cell counts. One erythroid maturation agent used in the treatment of MDS is **luspatercept-ammt (Reblozyl®)**.

**Treating Low Platelet Counts.** Some MDS patients may have low platelet counts that can cause easy bruising or uncontrolled bleeding. These patients may receive treatment to increase their platelet counts.

- **Platelet Transfusions.** A platelet transfusion is a slow injection of donated platelets into a vein.
- **Platelet Growth Factors.** These drugs are used to help the body produce platelets. **Romiplostim (Nplate®)** and **eltrombopag (Promacta®)** are being investigated for treatment of MDS patients who have low platelet counts.
- **Antifibrinolytic Agents.** **Aminocaproic acid** and **tranexamic acid** are drugs recommended for episodes of bleeding that do not respond to platelet transfusion and for severe cases of low platelet counts.

**Treating Low White Blood Cell Counts.** MDS and MDS treatments often cause low white blood cell counts. This can increase the risk of infection. Your doctor will pay close attention to any infection or fever. If a bacterial infection is found, you will be treated with antibiotics.

White blood cell transfusions are generally not used for patients with MDS, so doctors sometimes use medications called growth factors to help increase a patient's white blood cell count. Granulocyte colony-stimulating factors (G-CSF), such as **filgrastim (Neupogen asta®)**, and granulocyte-macrophage colony-stimulating factors (GM-CSF), such as **sargramostim (Leukine®)**, can help patients increase their white blood cell counts.

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You can view, print or order the free LLS booklet *Blood Transfusion* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

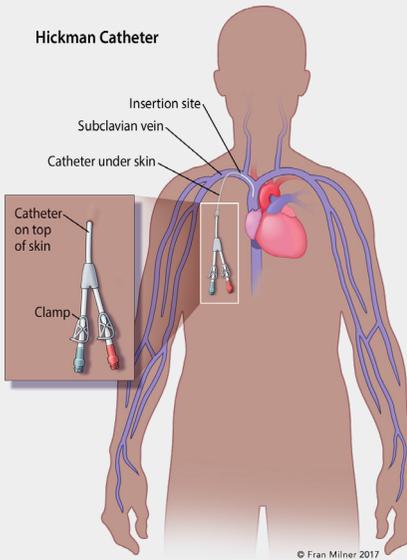
## Central Lines, Ports and PICCs

**Central Line (catheter)** — A thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. “Indwelling catheter” is another word for central line.

**Port** — This is a small device that is used to draw blood and give treatments, including fluids, blood transfusions, or drugs such as chemotherapy and antibiotics. A numbing cream can be put on the skin before the port is placed under the skin. A needle is inserted through the skin into the port to draw blood or give fluids and other treatments.

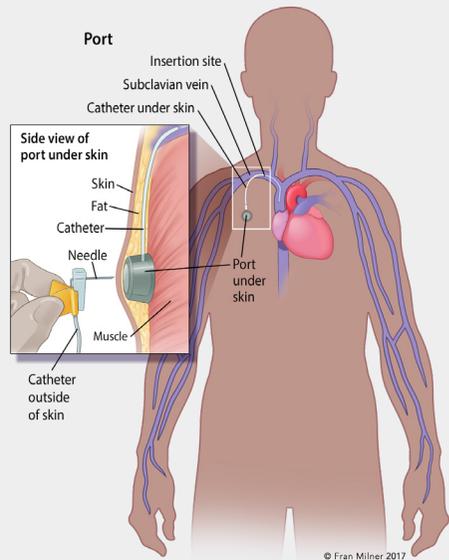
**PICC or PIC Line** (short for “percutaneously inserted central venous catheter”) — A PICC or PIC (not shown) is inserted through a vein in the arm.

### Hickman® Catheter



Hickman® Catheter: An example of a type of central line.

### Port and Catheter



Port: A port used with a central line.

**Iron Chelation Therapy.** Because some MDS patients get many red blood cell transfusions, they may be at risk for “iron overload,” a disorder that can damage the heart and liver. Iron chelation therapy uses medicine to remove the extra iron from the body.

The common FDA-approved drugs used for iron overload include:

- **Deferasirox (Exjade® or Jadenu®)**—This oral medication is in pill form and taken daily. Jadenu and Exjade are the same medication, but Jadenu may be easier to digest.
- **Deferoxamine mesylate (Desferal®)**—This drug is administered as a slow subcutaneous (under-the-skin, called SC) or intramuscular (into a muscle, called IM) infusion.

**Treatment of Lower-Risk MDS.** Lower-risk MDS are typically slow-growing. The primary goals for patients with lower-risk MDS are to improve blood cell counts, reduce the need for blood transfusions, lower the risk of infection and improve quality of life.

**Watch and Wait.** Some patients do not need treatment right away. A “watch-and-wait” approach allows your doctor to watch your condition but not start treatment until it is needed. Patients may think that they should have treatment right away. But watch and wait with monitoring allows the patient to avoid the side effects of therapy. Watch and wait involves careful monitoring that includes regular exams and blood tests. If you start to have signs and/or symptoms that appear or change, your doctor will recommend starting treatment.

**Beginning Treatment.** The decision to begin treatment is based on the patient’s signs and symptoms. For patients who need to begin treatment, treatment may include:

- **Hypomethylating Agents.** These drugs are a type of chemotherapy that may help improve blood cell counts, which may lead to fewer blood transfusions and improve quality of life. In general, they cause less severe side effects. **Azacitidine (Vidaza®), decitabine (Dacogen®) and decitabine and cedazuridine (Inqovi®)** are three FDA-approved hypomethylating agents used to treat MDS.
- **Immunomodulators.** These are drugs that modify different parts of the immune system and may help the body fight cancer. **Lenalidomide (Revlimid®)** is a drug, taken by mouth, that is approved for the treatment of patients with transfusion dependent anemia caused by low-risk or intermediate-1–risk MDS. This drug works best for patients who have certain chromosomal changes in their cancer cells. Talk to your doctor for more information.

- **Immunosuppressive Therapy.** Drugs that suppress certain parts of the immune system can help some patients with lower-risk MDS. **Antithymocyte globulin (ATG, Atgam®, Thymoglobulin®), cyclosporine (Neoral®, Sandimmune®)** and **tacrolimus (Prograf®)** suppress certain parts of the immune system and help the body make more healthy blood cells.

**Treatment of Higher-Risk MDS.** Higher-risk MDS tends to grow quickly and is more likely to progress to acute myeloid leukemia (AML). Treatment for higher-risk patients depends on whether they can receive a stem cell transplant.

**Not a Candidate for Stem Cell Transplantation.** Most higher-risk MDS patients are not eligible for stem cell transplantation. This may be due to many factors including advanced age, other major health problems, or no available stem cell donor.

Treatment for those not eligible for stem cell transplantation may include:

- **Hypomethylating Agents.** These drugs are a type of chemotherapy that may help improve blood cell counts, which may lead to fewer blood transfusions and improve quality of life. In general, they cause less severe side effects. **Azacitidine (Vidaza®), decitabine (Dacogen®)** and **decitabine and cedazuridine (Inqovi®)** are three FDA-approved hypomethylating agents used to treat MDS.
- **Intensive Chemotherapy.** For patients eligible for intensive therapy but who do not have a stem cell donor, the same intensive chemotherapy regimens used for the treatment of acute myeloid leukemia (AML) may be used. Because these agents tend to cause more severe side effects, they are generally used in higher-risk MDS that is likely to progress to AML. The drugs used may include:
  - **Cytarabine (cytosine arabinoside, ara-C; Cytosar-U®)**
  - **Idarubicin (Idamycin®)**
  - **Daunorubicin (Cerubidine®)**
  - **Mitoxantrone (Novantrone®)**

Chemotherapy regimens may consist of a single drug or a combination of two or three different drugs (combination chemotherapy).

- **Targeted Therapy.** This type of treatment uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells. Not all cancers have the same targets. Each type of targeted therapy works a little bit differently, but they all interfere with the growth and survival of cancer cells. To find the most effective treatment, your doctor may run tests to identify genes, proteins and other factors in your cancer cells. This helps the doctor choose the most effective treatment for you based on the specific factors

of your disease. Targeted therapy may be used alone or in combination with chemotherapy. Talk to your doctor for more information about targeted therapy.

**Candidate for Allogeneic Stem Cell Transplantation.** Allogeneic stem cell transplantation is a type of treatment that destroys cells in the bone marrow and then replaces them with new, healthy stem cells from another person. At this time, stem cell transplantation remains the only potential cure for MDS. This treatment is not for all patients, and it has a high risk of serious complications. Talk with your doctor to see if a stem cell transplant is a treatment option for you.

An allogeneic transplant is a treatment that uses stem cells from a donor. The stem cells in the donor's blood must be a "match" to the patient. The donor may be a brother or sister (siblings are most often the best match). The donor may also be an unrelated person with stem cells that match the patient's.

Allogeneic transplants are done in the hospital. After the patient achieves a remission, the process of allogeneic transplant is as follows:

- Stem cells are collected from a donor.
- The patient is given high-dose chemotherapy, with or without radiation therapy, to kill any remaining MDS cells in the body.
- The donor stem cells are given to the patient through an intravenous (IV) line or central line.
- The donor stem cells go from the patient's blood to the bone marrow and begin to start a new supply of red blood cells, white blood cells and platelets.

Some patients who receive a stem cell transplant can experience serious and life-threatening complications. Stem cell transplantation is not for every patient, but it can be helpful for some.

**Reduced-Intensity Allogeneic Stem Cell Transplantation.** This procedure uses lower doses of chemotherapy than a standard allogeneic transplant. This type of stem cell transplant is for patients who may not be able to tolerate the high doses of chemotherapy that are given to patients during a standard stem cell transplant. Some older or sicker patients may be helped by this type of treatment.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Blood and Marrow Stem Cell Transplantation Guide* and *Cord Blood Stem Cell Transplantation Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

### About Clinical Trials

There are new treatments under study for patients with MDS. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments, such as changing the dose of a drug or giving a drug along with another type of treatment. Some clinical trials combine drugs for MDS in new sequences or dosages.

There are clinical trials for:

- Newly diagnosed MDS patients
- MDS patients of all ages
- Patients who have relapsed, or patients who do not get a good response to treatment

A carefully conducted clinical trial may provide the best available therapy.

**Here are some questions you may want to ask your healthcare team.** See pages 37-39 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if insurance covers the cost of the clinical-trial treatment and treatment-related costs such as testing?
3. Who pays for the travel costs to get to the clinical trial?

Ask your doctor if treatment in a clinical trial may be right for you. For more information, please call **(800) 955-4572** to speak with an LLS Information Specialist who can provide more information about clinical trials and help search for a clinical trial for you. Personalized clinical-trial navigation by trained nurses is also available through the Clinical Trial Support Center. Visit **[www.LLS.org/CTSC](http://www.LLS.org/CTSC)** for more information.

#### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Knowing All Your Treatment Options and Understanding Clinical Trials for Blood Cancers* at **[www.LLS.org/booklets](http://www.LLS.org/booklets)**, or contact our Information Specialists for copies.

### Overview of This Section

- A side effect is an unintended result from a treatment or a drug.
- Treatment side effects vary depending on the type of treatment. For example, the side effects of chemotherapy are different from the side effects of targeted therapies.
- Common side effects of chemotherapy may include nausea, vomiting, diarrhea, constipation, fever, rash and tiredness.
- MDS patients will meet with their primary care doctor and hematologist-oncologist for follow-up care.

### Side Effects of MDS Treatment

The term **side effect** is used to describe a problem that occurs when cancer treatment affects healthy tissues or organs and causes symptoms that are uncomfortable or even harmful for the patient.

Treatment side effects vary depending on the type of treatment. For example, the side effects of targeted therapies are different from the side effects of chemotherapy. Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Some side effects are serious and last a long time. Usually side effects go away once treatment ends. Talk with your doctors about potential side effects before you begin any type of treatment.

**Here are some questions you may want to ask your healthcare team.** See pages 37-39 for a full list of questions.

1. What are the common side effects of my treatment?
2. What side effects should be reported to the healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?

**Low Blood Cell Counts.** MDS and its treatment may affect your blood cell counts:

- Red blood cell counts may fall below normal (this is called “anemia”). Red blood cell transfusions (red blood cells that are provided by a blood donor and given to the patient) and medication may be needed to increase red blood cell counts.
- Patients may have a drop in the number of platelets in their blood (this is called “thrombocytopenia”). A platelet transfusion and/or medication may be needed to prevent bleeding if a patient’s platelet count is very low.

- Patients may have a drop in the number of neutrophils, a type of white blood cell. This is called “neutropenia.” Neutropenia may lead to frequent infections. Infections can be very serious for anyone who has MDS. Patients at home should contact a doctor if any signs of infection develop. A fever of 100.4°F or higher (or the onset of chills), may be the only sign of infection in a patient with a very low white blood cell count. Patients with an infection may also have:
  - Coughing
  - Sore throat
  - Pain when urinating
  - Frequent, loose bowel movements

To lower the risk of infection:

- The patient, visitors and medical staff need to wash their hands often and well.
- The patient's central line must be kept clean.
- Patients with MDS are advised to receive certain vaccinations for pneumococcal pneumonia and the inactivated ("dead") vaccine for the herpes virus, called Shingrix. Current COVID-19 vaccines are also recommended. Talk to your doctor for more information.

**Other Treatment Side Effects.** Some other common side effects of treatment for MDS include:

- Fever
- Chills
- Nausea
- Vomiting
- Diarrhea
- Constipation
- Tiredness
- Rashes

Not all patients have these side effects. Treatment to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable.

There may be other side effects that are not listed here that you should watch for when taking a specific treatment. Talk to your healthcare team about the possible side effects of your treatment. You can also call our Information Specialists.

### WANT MORE INFORMATION?



Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) (filter by Side Effect Management) to view, print or order the full *Side Effect Management* series. Or contact our Information Specialists for copies.

## Follow-Up Care

MDS patients should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. At these visits, the doctor will check your health, blood cell counts and, if needed, perform or order other tests to evaluate your treatment progress and to see if more treatment is needed.

Talk with the doctor about how often to have follow-up visits. You can ask your doctor what tests will be needed and find out how often you need to have these tests. It is important to keep a record of your cancer treatments, including the drugs and procedures you received and the time period you received them, so that your doctor can follow up on specific long-term side effects that may be associated with your treatment. See page 33 for a place to list treatments.

**Here are some questions you may want to ask your healthcare team.** See pages 39 for a full list of questions.

1. Who will I work with to ensure life-long follow-up care?
2. Will I continue to see this healthcare team?
3. What information can be given to my primary doctor about past treatment and what may be needed in the future?

## Take Care of Yourself

- Keep all appointments with your doctor.
- Talk about how you feel with the doctor at each visit.
- Ask any questions you may have about side effects.
- People with MDS may have more infections than other people. Follow your doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat 4 or 5 smaller meals instead of 3 big ones.
- Keep a record of your cancer diagnosis, treatment, and follow-up care needs. This is often called a "survivorship care plan." Ask your doctor for a written survivorship care plan. Share this information with any new healthcare providers you see. The plan should include the following information:
  - A list of all healthcare providers
  - Diagnosis summary with specifics such as subtype and/or genetic markers
  - Treatment summary with specifics such as the names, dates, and dosages of chemotherapy or other drugs, surgery and/or transplantation information, response to treatment, and side effects

- Maintenance treatment information, if applicable
- List of possible late effects
- Schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
- Health and wellness recommendations such as nutrition, exercise or other disease screenings
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with you doctor before starting an exercise plan.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. See your primary care doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. When family and friends know about MDS and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a 2-week period, seek help. Depression is an illness. It can and should be treated even when a person is being treated for MDS. Treatment for depression has benefits for people living with cancer.

### WANT MORE INFORMATION?



For additional information about survivorship, visit [www.LLS.org/SurvivorshipWorkbook](http://www.LLS.org/SurvivorshipWorkbook) to reach the children and adolescent, young adult and adult books called *Navigating Life During and After a Blood Cancer Diagnosis*.

## RESOURCES AND INFORMATION

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists are highly trained oncology social workers, nurses and health educators. They offer up-to-date information about disease, treatment and support. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**One-on-One Nutrition Consultations.** Access free one-on-one nutrition consultations provided by a registered dietitian with experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Free Information Booklets.** LLS offers free education and support booklets that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support, including insurance premium and medication co-pay assistance, to eligible individuals with blood cancer. For more information, please:

- Call: (877) 557-2672
- Visit: [www.LLS.org/finances](http://www.LLS.org/finances)

**LLS Health Manager™ App.** This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Please visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**LLS Coloring for Kids™.** This free coloring app allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. The app includes blank canvases, general coloring pages and pages from LLS coloring books. This app can be used anywhere and may help pass time in waiting rooms or during treatment. Visit [www.LLS.org/ColoringApp](http://www.LLS.org/ColoringApp) to learn more and download.

**Podcast.** *The Bloodline* with LLS is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

## Community Resources and Networking

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**LLS Chapters.** LLS offers community support and services in the United States and Canada including the Patti Robinson Kaufmann First Connection® Program (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your chapter, please:

- Call: (800) 955-4572
- Visit: [www.LLS.org/ChapterFind](http://www.LLS.org/ChapterFind)

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to obtain the directory.

**Advocacy.** The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/advocacy](http://www.LLS.org/advocacy)

## Additional Help for Specific Populations

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

**Information for Veterans.** Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: [www.publichealth.va.gov/exposures/AgentOrange](http://www.publichealth.va.gov/exposures/AgentOrange)

**World Trade Center Survivors.** People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: [www.cdc.gov/wtc/faq.html](http://www.cdc.gov/wtc/faq.html)

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

## Health Terms

**Absolute neutrophil count (ANC).** The measure of the number of neutrophils in the blood. Neutrophils are a type of white blood cells that help the body fight infection. The lower a person's absolute neutrophil count is, the higher the risk of getting an infection.

**Acute myeloid leukemia (AML).** A fast-growing type of blood cancer in which there are too many immature white blood cells in the blood and bone marrow.

**Anemia.** A condition in which a person has less red blood cells than normal. Severe anemia can cause a pale complexion, weakness, tiredness, dizziness and shortness of breath.

**Antibiotic.** A drug used to treat infections caused by bacteria.

**Blast cell.** Immature (not developed) bone marrow cell. About 1 to 5 percent of normal bone marrow cells are blast cells.

**Bone Marrow.** The spongy material in the center of bones where blood cells are made.

**Bone marrow aspiration.** A test that checks to see if the fluid in a patient's bone marrow is normal. A sample of cells is taken from the patient. The cells are looked at under a microscope. Bone marrow aspiration and biopsy are usually done at the same time.

**Bone marrow biopsy.** A test that checks the bone marrow cells in the bone to see if they are normal. A very small amount of bone is removed from the body. The cells within it are looked at under a microscope. Bone marrow aspiration and bone marrow biopsy are usually done at the same time.

**Central line.** A special tube (called a "catheter") is put into a large vein in the patient's upper chest. It is used to give medicines, fluids or blood products, and to take out blood samples. Also called "indwelling catheter."

**Chemotherapy.** Treatment that stops the growth of cancer cells, wether by killing the cancer cells or by stopping them from dividing.

**Chromosomes.** The part of the cell that contains genetic information. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may not be normal in cancer cells.

**Clinical trial.** A careful study done by doctors to test new drugs or treatments. Clinical trials also find new uses for approved drugs or treatments. The goal of clinical trials is to improve treatment and quality of life for patients, and to find cures for blood cancer.

**Combination chemotherapy or drug therapy.** The use of 2 or more drugs given at the same time to treat MDS and other cancers.

**DNA.** The molecules inside cells that carry genetic information and pass it from one generation to the next. DNA stands for “deoxyribonucleic acid.”

**Dysplasia.** A term used to describe cells that have an abnormal shape or size when viewed under a microscope.

**FDA.** The short name for the US Food and Drug Administration. Part of the FDA’s job is to assure the safety and security of drugs, medical devices, and the US food supply.

**Growth factor.** A substance that causes new blood cells to grow in the bone marrow.

**Hematologist-oncologist.** A doctor who has special training in the diagnosis and treatment of blood cancers.

**Hemoglobin.** A protein inside red blood cells that carries oxygen.

**Leukemia.** A cancer of the blood and bone marrow.

**MDS, unclassifiable (MDS-U).** A subtype of MDS that includes patients whose blood and bone marrow test results do not fit any other type of MDS.

**MDS with excess blasts (MDS-EB).** A subtype of MDS that includes patients with higher than normal blasts (immature blood cells) in the bone marrow and at least one type of low blood cell count.

**MDS with isolated del(5q).** A subtype of MDS in which the chromosomes of the MDS cells are missing part of chromosome number 5, called “del(5q).”

**MDS with multilineage dysplasia (MDS-MLD).** A subtype of MDS in which there are too few of at least one type of blood cells (red blood cells, white blood cells, or platelets). In the bone marrow, at least two types of blood cells look abnormal under a microscope.

**MDS with ring sideroblasts (MDS-RS).** A subtype of MDS in which many of the immature red blood cells are ring sideroblasts (red blood cells that have rings of iron deposits).

**MDS with single lineage dysplasia (MDS-SLD).** A subtype of MDS in which the bone marrow shows abnormal changes in only one of the three types of blood cells and low numbers of one or two types of blood cells.

**Oncologist.** A doctor who has special training in diagnosing and treating cancer.

**Plasma.** The liquid part of the blood.

**Platelet.** A type of blood cell that helps the body stop bleeding.

**Radiation therapy.** A cancer treatment that uses high doses of radiation to kill cancer cells.

**Remission.** When signs and symptoms of a disease decrease or disappear, usually following treatment.

**Stem cell.** A type of cell that develops into different types of cells. Blood stem cells in the bone marrow can mature into red blood cells, white blood cells and platelets.

## My Healthcare Team Contact List

Use this list to remember names and contact information for members of your healthcare team.

CAREGIVER NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PRIMARY CARE DOCTOR NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PHARMACY NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Additional information: \_\_\_\_\_

### Information Specialists:

Phone: (800) 955-4572

Email and live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

HEMATOLOGIST-ONCOLOGIST NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Website/Portal: \_\_\_\_\_

Additional information: \_\_\_\_\_

NURSE/NURSE PRACTITIONER NAME:

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

SOCIAL WORKER NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

INSURANCE CASE MANAGER/  
CARE COORDINATOR NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Website or email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PHYSICIAN ASSISTANT NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email Address: \_\_\_\_\_

Additional information: \_\_\_\_\_

NURSE NAVIGATOR NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

OTHER:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

OTHER:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

## My List of Treatments

Use this space to list your treatments and when you took them.

DATE: \_\_\_\_\_

Treatment: \_\_\_\_\_

\_\_\_\_\_

## Question Guide: My First Doctor's Visit

Asking questions will help you take an active role in managing your (or your loved one's) care. If you do not understand any part of the information your healthcare provider gives you, ask them to explain it in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which patients may not be old enough or able to make their own decisions. A parent, relative, or caregiver may be assisting or making the decision.)

### Questions for the Doctor

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive a return phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form available so my family/caregiver can be given medical information?

## Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

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1. How long would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive a return phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.

## Question Guide: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how they plan to treat your (your loved one's) MDS. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which patients may not be old enough or able to make their own decisions. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

Write down your diagnosis:

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Write down your subtype of MDS:

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## Before Treatment Begins

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make decisions?
5. What is the subtype?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

## Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

## Treatment

1. Will this be an in-hospital or an outpatient treatment?
  - 1a. Is it alright to attend work or school during treatment?
  - 1b. Will someone be needed to drive me home after treatment?
2. What kind of testing will be done to monitor this disease and treatment? How often will testing be needed? Where is the testing done?
3. How will I (we) know if the treatment is effective? What options are available if the treatment is not effective?
4. What is the likely outcome of the disease (prognosis)?

## Side Effects

1. What are the common side effects for this treatment?
2. What side effects should be reported to the healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?
5. How should I report side effects (phone call, at the office visit, etc)?

## **Social/Financial Concerns**

1. Are there any side effects that will affect appearance or ability to do a job or go to school?
2. What kind of financial and social support services are available to me and my family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study (clinical trial) treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone I can speak to for assistance?
6. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical-trial drugs?
7. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs such as testing?

## **Follow-Up Care and Long-Term and Late Effects**

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I (we) be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If there are side effects later, how can the healthcare team be reached?
6. What information can be provided to a primary doctor about this treatment?

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.





# Get support. Reach out to our **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of highly trained oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individualized clinical-trial searches

Contact us at  
**800-955-4572** or  
**www.LLS.org/  
InformationSpecialists**  
(Language interpreters can be requested.)





For more information, please  
contact our Information Specialists  
**800.955.4572** (Language interpreters  
available upon request).

**National Office** 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).