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FOR PATIENTS & CAREGIVERS

The MDS Guide:

Information for Patients and Caregivers

Revised **2024**

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

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

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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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.

This booklet will provide you with basic information about MDS. It also provides information about clinical trials, blood and bone marrow, and questions to ask your doctor. Some words in this guide may be new to you. Find definitions in the list of *Health Terms* beginning on page 32, or call our Information Specialists at (800) 955-4572, with your questions.

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

WANT MORE INFORMATION?

For more information on MDS, go to www.LLS.org/booklets to view, print or order the free LLS booklet *Myelodysplastic Syndromes* or call an LLS Information Specialist at (800) 955-4572 for a copy.

Feedback. Visit www.LLS.org/PublicationFeedback to make suggestions about the content of this booklet.

PART 1 MYELODYSPLASTIC SYNDROMES

Overview

- Myelodysplastic syndromes (MDS) are a group of cancers of the blood and bone marrow.
- Blood cells begin as stem cells, which develop 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 and platelets. Then the blood cells 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 several subtypes of MDS. Knowing your MDS subtype helps doctors determine the best treatment options for you.

About Bone Marrow, Blood and Blood Cells

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

Bone marrow is the spongy center located inside the 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 blood 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. A low white blood cell count may cause repeated infections and fever. There are two major types of white blood cells: lymphocytes and germ-eating cells.

- Lymphocytes are infection-fighting cells. The three main types of lymphocytes are:
  - B cells
  - T cells
  - NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria and viruses. There are two types of germ-eating cells:
  - 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. Low platelet counts 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)

- Measures the amount (percentage) of each of the 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: 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood

About MDS

Myelodysplastic syndromes (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) into an MDS cell (also called an "MDS blast cell")
- The mutated cell multiplies into many MDS cells. These cells are often abnormal in shape and size. This condition is called **dysplasia**.
- The MDS cells build up in the bone marrow so there is less room for healthy blood cells to develop.
- The abnormal MDS cells do not grow into normal healthy blood cells, and they may die earlier than normal blood cells. As a result, people with MDS do not have enough healthy red blood cells, white blood cells and/or platelets.

While doctors do not know what causes most cases of MDS, certain factors may increase the risk of developing MDS. A **risk factor** is something that increases the chance of getting a disease. 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.
- **Genetic disorders.** Certain genetic conditions present at birth seem to increase the risk of developing MDS. These include: Down syndrome, neurofibromatosis type 1, Bloom syndrome, trisomy 8, Fanconi anemia, Klinefelter syndrome, Wiskott-Aldrich syndrome, Kostmann syndrome and Shwachman-Diamond syndrome.

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.

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 symptoms of MDS are similar to other blood disorders or medical conditions. If you have any of these symptoms, see your doctor to make sure you obtain the correct diagnosis and treatment.

Diagnosis

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

Here are some questions you may want to ask your healthcare team. See pages 39-44 for a full list of questions.

1. What kind of testing will be done to diagnose my disease?
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 Counts. 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 are not normally found in the blood.

Bone Marrow Tests. MDS starts in the bone marrow. A diagnosis of MDS is confirmed by removing samples of bone marrow and examining them under the microscope. **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 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 a diagnosis of MDS and to help make treatment decisions.

Visit www.LLS.org/3D and click on “Bone Marrow Biopsy and Aspiration” to view an interactive 3D image that 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.

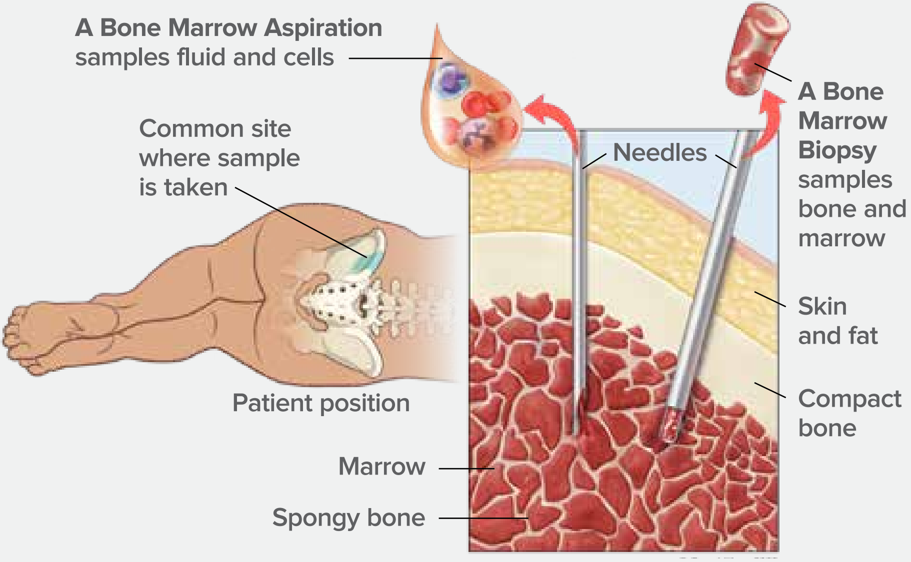
Bone Marrow Aspiration—The removal of a sample of fluid with cells from the bone marrow.

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. Most patients are awake for the procedure, but some patients are given a drug that makes them sleep. They get medication first to numb the part of the body where the sample of cells will be removed. 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:** One needle goes into the bone marrow to get a liquid sample for aspiration (the needle on the left) and the other needle goes inside the bone for a bone marrow biopsy (the needle on the right). The needle for the aspiration is thinner than the one for the biopsy.

Cell Examination. At the laboratory, the cells from the blood and bone marrow samples are examined under a microscope. The types of cells and their shape and size are important findings. Another important finding is the percentage of immature MDS blast cells in the bone marrow and the blood.

Additional tests are done on the blood and bone marrow samples to determine the subtype of MDS.

Biomarker Testing. These laboratory tests check for changes in the proteins, genes and chromosomes of the cancer cells. Each person's cancer has a unique pattern of biomarkers. Biomarker testing is used to determine the MDS subtype and help plan treatment.

- **Cytogenetic Analysis (Karyotyping).** Each cell in the body has chromosomes that carry genes. Genes give the instructions that tell each cell what to do. Cytogenetic analysis is used to look for abnormal changes in the chromosomes in the MDS cells.
- **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 the MDS cells.

- **Next-Generation Sequencing.** This test looks for mutations in the genes of MDS cells. Certain mutations are markers that can help doctors identify a patient's MDS subtype and predict how the disease will progress.

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 how to get copies of your lab reports. You can ask for copies of your test results at the doctor's office. Many hospitals and treatment centers now offer digital patient portals where you can view your medical records online.
    - Keep test reports in a file folder or binder and organize by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Understanding Lab and Imaging Tests*, *Biomarker Testing for Cancer Treatment* and *Understanding Genetics*. Go to www.LLS.org/booklets or call an LLS Information Specialist at (800) 955-4572 for copies.

Subtypes of MDS

There are several subtypes of MDS. The subtypes are determined by the following:

- Low blood cell counts (red blood cells, white blood cells and/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

- Changes to the chromosomes and genes in bone marrow cells that are associated with MDS

It is important to know your MDS subtype because it can affect both your prognosis (outlook) and your treatment plan. If you are not sure of your MDS subtype, ask your doctor what it is and to explain how your MDS subtype affects your treatment plan.

The World Health Organization (WHO) divides MDS into several subtypes. For a comprehensive list of the WHO classification system of MDS subtypes see the free LLS booklet *Myelodysplastic Syndromes* at www.LLS.org/booklets.

Write down your MDS subtype here: ______________________________

Prognostic Scoring Systems

A prognosis is a prediction of the likely outcome of a disease. Doctors often use scoring systems for people with MDS. These scoring systems were created to predict overall survival and whether the disease will develop into a fast-growing cancer called **acute myeloid leukemia (AML)**.

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 patients 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

In 2022, the IPSS-R was updated to include MDS-associated gene mutations. **The International Prognostic Scoring System-Molecular (IPSS-M)** considers blood counts, such as anemia and low platelet counts, the percentage of bone marrow blasts and the presence of certain chromosomal abnormalities. Unlike the IPSS-R, the IPSS-M also considers whether certain gene mutations are present and how many are mutated. The IPSS-M classifies MDS into six risk groups:

- Very low
- Low
- Moderate Low
- Moderate High
- High
- Very High

For more information on MDS prognostic scoring systems, see the free LLS booklet *Myelodysplastic Syndromes* at www.LLS.org/booklets.

Overview

- 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 39-44.
- People diagnosed with MDS can be treated by observation (watch-and-wait approach), clinical trials, supportive care, drug therapy and/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 called 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 your local cancer specialist to 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 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 39-40 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, or contact our Information Specialists at (800) 955-4572 for a copy.

Ask Your Doctor

Talk with your 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 39-44 at the end of this Guide for a full list of questions. Visit 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. Ask the doctor and staff if you can record the converstation (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, 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 a second opinion (another 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 should also 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 booklet was printed. Check 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 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 your MDS subtype, your prognostic score and other factors such as your age and overall health.

Some people who do not have very low blood cell counts or other symptoms at diagnosis, may not need to start treatment immediately. Instead, the doctor may recommend regular exams and tests to monitor their condition.

Patients who have symptoms caused by low blood cell counts are given supportive care to relieve symptoms. For most MDS patients, treatment can improve blood cell counts, relieve symptoms and slow disease progression. Certain patients may be cured with allogeneic stem cell transplantation.

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 doctor. See pages 39-44 for a full list of questions.

1. What is my MDS subtype?
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?

Some drugs are given orally (by mouth). Other drugs are inserted directly into the patient's body through a **central line**, a **port**, or a **PICC**. Central lines, ports, and PICCs can be used to give medications, nutrition and blood cells. These devices can be used in the reverse to take blood samples out of the patient. Central lines, ports and PICCs can stay in place for weeks or months. The purpose of these devices is to avoid the constant use of needles and IVs for giving medication and taking necessary samples. Talk to your doctor about how drugs will be given.

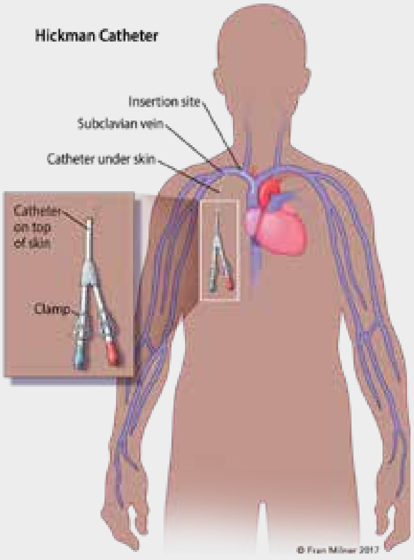
Central Lines, Ports and PICCs

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

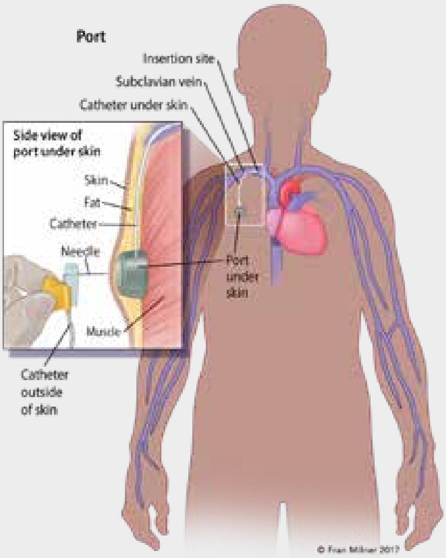
PICC or PIC Line (short for “percutaneously inserted central venous catheter”)—A PICC or PIC (not shown) is inserted through a vein in the arm.

Hickman® Catheter



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

Port and Catheter



Port: A port used with a central line.

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.

Blood Transfusions. Many people with MDS receive blood transfusions to help relieve symptoms of low red blood cell counts and/or low platelet counts. A transfusion can help relieve symptoms for a short time.

- **Red Blood Cell Transfusions.** Patients with symptoms of low red blood cell counts such as severe tiredness, dizziness and shortness of breath may receive red blood cell transfusions to increase their red blood cell counts. A red blood cell transfusion is a slow injection of donated red blood cells into a patient's body through a vein.

  Red blood cells contain iron. When a person receives many red blood cell transfusions, too much iron can build up in their liver, heart and other organs, affecting how these organs work. This condition is called **iron overload**.

  Iron overload requires special treatment to remove the extra iron from the body. The treatment is called **iron chelation therapy**. The most common drugs used in iron chelation therapy include:

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

- **Platelet Transfusions.** 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. A platelet transfusion is a slow injection of donated platelets into a vein.

  For patients with severe low platelet counts or who have uncontrolled bleeding that does not respond to platelet transfusions, the doctor may recommend the drugs **aminocaproic acid** and **tranexamic acid**.

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. **Filgrastim**, **pegfilgrastim** and **sargramostim (Leukine®)**, are growth factors that can help patients increase their white blood cell counts.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Blood Transfusion* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for a copy.

Treatment of Lower-Risk MDS. For patients with lower-risk disease based on their prognostic score, MDS is typically slow growing. The primary goals of treatment are to improve blood cell counts, reduce the need for blood transfusions, lower the risk of infection and improve quality of life.

Lower-risk patients without symptoms may not need to start treatment right away. A **watch-and-wait** approach allows the doctor to monitor the MDS but not start treatment. Once there are signs and symptoms of the disease, the doctor will start treatment.

Erythropoietin-Stimulating Agent (ESA). This type of drug stimulates the bone marrow to make more red blood cells. It is used to treat people with low red blood cell counts. Treatment with ESAs may decrease the need for red blood cell transfusions. Examples of ESAs include **darbepoetin alfa (Aranesp®)** and **epoetin alfa**.

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

Immunomodulators. These are drugs that modify different parts of the immune system. People with MDS who need frequent red blood cell transfusions and have MDS cells that are missing a part of chromosome 5 may be treated with **lenalidomide (Revlimid®)**.

Platelet Growth Factors. MDS patients with low platelet counts can bruise easily and have uncontrolled bleeding. Platelet growth factors are drugs 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.

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.

Hypomethylating Agents. If other treatments are not increasing low blood cell counts, hypomethylating agents may be a treatment option. They are a type of chemotherapy that may help improve blood cell counts, which may lead to fewer blood transfusions and improve quality of life. **Azacitidine (Vidaza**®**), decitabine (Dacogen**®**)** and **decitabine and cedazuridine (Inqovi**®**)** are three hypomethylating agents used to treat MDS.

Allogeneic Stem Cell Transplantation. Certain patients may be cured with an allogeneic stem cell transplantation. Some lower-risk patients, particularly younger patients, may benefit from allogeneic stem cell transplantation. Patients may be considered for this treatment if they have had many therapies and have not responded to treatment. See *Candidate for Allogeneic Stem Cell Transplantation* on page 20 for more information on allogeneic stem cell transplantation.

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. **Azacitidine (Vidaza**®**), decitabine (Dacogen**®**)** and **decitabine and cedazuridine (Inqovi**®**)** are three hypomethylating agents used to treat MDS.

Intensive Chemotherapy. Patients who are eligible for intensive therapy but who do not have a stem cell donor may receive chemotherapy regimens used to treat acute myeloid leukemia (AML). 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. Some targeted therapies for treating MDS include:

- **IDH Inhibitors.** In some people with MDS, the cancer cells have a mutation of the *IDH1* or *IDH2* gene. These patients may receive:
  - **Ivosidenib (Tibsovo®)**, for adult patients with an *IDH1* mutation with relapsed or refractory MDS.
  - **Enasidenib (Idhifa®)**, an **off-label** treatment for MDS with an *IDH2* mutation. Off-label describes the legal use of a prescription drug to treat a disease for which the drug has not been approved by the FDA.
- **BCL2 Inhibitors.** Some studies have shown that the BCL2 inhibitor **venetoclax (Venclexta®)** in combination with hypomethylating agents may reduce the number of cancer cells in the bone marrow for patients with high-risk MDS.
- **FLT3 Inhibitors.** Some MDS patients have a mutation in the *FLT3* gene that can increase the growth and division of cancer cells. FLT3 inhibitors are drugs that target these gene mutations. For patients with *FLT3* mutations, **midostaurin (Rydapt®), gilteritinib (Xospata®), Quizartinib (Vanflyta®)** or **sorafenib (Nexavar®)** may be prescribed. These drugs are not FDA-approved to treat MDS, but they are being studied in clinical trials and are also available as off-label treatments.

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.
- 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 booklet *Blood and Marrow Stem Cell Transplantation Guide* at 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
- Patients who did not have a good response to treatment (refractory disease)
- Patients whose cancer returned (relapsed disease)

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

Here are some questions you may want to ask your healthcare team. See pages 39-44 for a full list of questions.

1. Is a clinical trial a treatment option for me?
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. Clinical trials can be difficult to navigate and figure out, but The Leukemia & Lymphoma Society is here to help. Patients and caregivers can work with **LLS Clinical Trial Nurse Navigators** who will help you find potential clinical trials. Visit www.LLS.org/CTSC to learn more about this service.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Knowing All Your Treatment Options* and *Understanding Clinical Trials for Blood Cancers* at www.LLS.org/booklets, or call an LLS Information Specialist at (800) 955-4572 for copies.

Overview

- 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.
- People with MDS should see their primary care doctor and a cancer specialist regularly for follow-up care.

Side Effects of MDS Treatment

The term **side effect** describes the way treatment affects healthy cells and often describes the negative or undesirable effects from a treatment.

Treatment for MDS can also affect healthy cells in the body. Treatment side effects depend 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 39-44 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 cause low blood cell counts.

- Red blood cell counts may fall below normal. This is called **anemia**. Red blood cell transfusions and medication may be needed to increase red blood cell counts.
- Platelet counts may fall below normal. This is called **thrombocytopenia**. If you have very low platelet counts, you may need a platelet transfusion and/or medication.

- You may have drop in the number of neutrophils, a type of white blood cell that is important in fighting infection. 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. Symptoms of an infection may also include:
    - Coughing
    - Sore throat
    - Pain when urinating
    - Frequent, loose bowel movements

  To lower your risk of infection:
    - You, your visitors and medical staff need to wash their hands often and well.
    - Your central line must be kept clean.
    - You should take good care of your teeth and gums.
    - You 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 doctor about the possible side effects of your treatment. You can also call our Information Specialists.

WANT MORE INFORMATION?

Visit www.LLS.org/booklets (filter by Side Effect Management) to view, print or order the full *Side Effect Management* series. Or call an LLS Information Specialist at (800) 955-4572 for copies.

Long-Term and Late Effects

Long-term effects are side effects of treatment that may last for months or years after treatment ends. Fatigue is an example of a long-term side effect.

Late effects are side effects of treatment that may not show up until years after treatment ends. Heart disease is an example of a possible late effect.

Not everyone who is treated for MDS develops long-term or late effects. It depends on the person's age, overall health and specific treatments. Patients should talk with their doctors about any long-term or late effects that they experience.

Here are some questions you may want to ask your healthcare team. See pages 39-44 for a full list of questions.

1. How will I be monitored for long-term and late effects of treatment?

2. What types of long-term and late effects should be brought to my healthcare team's attention?

WANT MORE INFORMATION?

Visit LLS.org/SurvivorshipWorkbook to find workbooks for adults, young adults, and children and adolescents, which contain sections on long-term and late effects. Or call an LLS Information Specialist at (800) 955-4572 for a copy.

Follow-Up Care

Medical follow-up care is important for every MDS patient. Follow-up care is given to patients after finishing their treatment.

You should see your primary doctor and your cancer specialist regularly for follow-up care. Follow-up care involves regular medical checkups, which may include a physical exam, blood tests, and if needed, other tests to evaluate your treatment progress as well as to see if there are any signs of relapse.

Talk with your 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 38 for a place to list your treatments.

Here are some questions you may want to ask your healthcare team. See pages 39-44 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?

WANT MORE INFORMATION?

For additional information about survivorship, visit 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.* Or, call an LLS Information Specialist at (800) 955-4572 for a copy.

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.

RESOURCES AND INFORMATION

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

For Help and Information

Consult with an Information Specialist. Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. 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

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. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators, who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Nutrition Consultations. Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients and caregivers of all cancer types. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit www.LLS.org/nutrition for more information.

Free Information Booklets. LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit 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 for more information.

Financial Assistance. LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc.

For more information, please:

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

Resources for Families. Blood cancer occurs in a small number of children. Families face new challenges, and the child, parents and siblings may all need support. LLS has many materials for families including a caregiver workbook, children's book series, an emotion flipbook, dry erase calendar, coloring books and a coloring app, a school re-entry program, and other resources.

For more information, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/FamilyWorkbook

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 for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

3D Models. LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs, and lab and imaging tests. Visit www.LLS.org/3D for more.

Free Mobile Apps.

- LLS Coloring For Kids™—Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ ColoringApp to download for free.
- LLS Health Manager™—Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit www.LLS.org/SuggestedReading to find out more.

Connecting with Patients, Caregivers and Community Resources

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 to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit www.LLS.org/chat for more information.

Local Programs. 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 region, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/LocalPrograms

Advocacy and Public Policy. Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit www.LLS.org/advocacy for more information.

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 to view the directory.

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). Please visit 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

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. 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

People With 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 and enter “depression” in the search box

Health Terms

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 the number of red blood cells is below 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. An immature blood cell.

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

Bone marrow aspiration. A test to remove and examine a liquid sample of bone marrow cells to see if they are normal. Bone marrow aspiration and biopsy are usually done at the same time.

Bone marrow biopsy. A test to remove a sample of bone containing bone marrow. Bone marrow aspiration and bone marrow biopsy are usually done at the same time.

Central line. A flexible tube that is put into a large vein in a 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, either by killing the cancer cells or by stopping them from dividing.

Chromosome. 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 goals of clinical trials for blood cancers are to find cures and to improve treatments and quality of life for patients.

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 ensure the safety and security of drugs, medical devices and the US food supply.

Growth factor. A substance made by the body to stimulate the growth of cells. Some growth factors are made in the laboratory for use in cancer treatment. For example, some MDS patients may receive growth factors to increase the number of blood cells in their body.

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.

Immune system. Network of cells, tissues and organs in the body that work together to defend the body against infection.

Late effect. A health problem that occurs months or years after treatment has ended.

Leukemia. A cancer of the blood and bone marrow.

Off-label. The legal use of a prescription drug to treat a disease for which the drug has not been approved by the FDA.

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

Platelet. A type of blood cell that helps prevent or stop bleeding.

Prognosis. The likely outcome of a disease.

Prognostic scoring system. A method that doctors use to rate the severity of MDS and classify it into groups based on the likely prognosis (outcome).

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

Relapse. A return of cancer after a period of improvement.

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.

Targeted therapy. A type of treatment that uses drugs to target specific molecules that help cancer cells grow and survive.

White blood cell. A type of cell found in the blood that helps the body fight infection.

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: ____________________

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: ______________________________

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:

DATE:

Treatment:

DATE:

Treatment:

DATE:

Treatment:

DATE:

Treatment:

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:

____

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 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:

____

____

____

Write down your subtype of MDS:

____

____

____

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 my subtype?
6. What is the goal of treatment?
7. What are my treatment options?
8. Are there any clinical trials I can 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 my disease and treatment?
2. How long does it take to get the results back?
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?
    - ○ Can I attend work or school during treatment?
    - ○ 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.)?

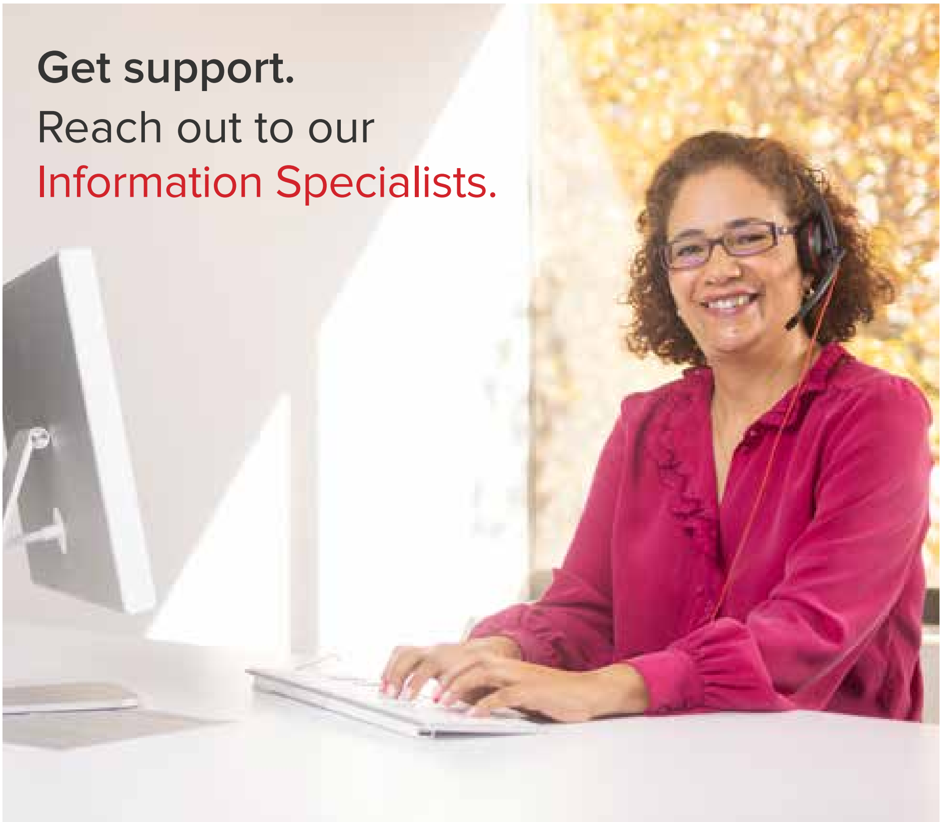
Social/Financial Concerns

1. Are there any side effects that will affect my appearance?
2. Are there any side effects that will affect my ability to work or go to school?
3. What kind of financial and social support services are available to me and my family?
4. How can I (we) find out if insurance will cover the costs of the treatment?
5. Who is the best person to speak to about bills and insurance coverage?
6. 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?
7. If I (we) get in a clinical trial, will I (we) be responsible for paying treatment-related costs, such as tests, travel or clinical-trial drugs?
8. 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 lifelong 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?

LEUKEMIA &
LYMPHOMA
SOCIETY®



Get support.
Reach out to our Information Specialists.

The Leukemia & Lymphoma Society© team consists of highly trained oncology social workers and nurses who are available by phone, email and live chat 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
- Get connected to resources

Contact us at
800.955.4572
or **www.LLS.org/InformationSpecialists**

(Language interpreters can be requested.)

LEUKEMIA &
LYMPHOMA
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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.

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