

The MDS Guide

Information for Patients and Caregivers

Myelodysplastic Syndromes



Michael, MDS survivor

A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Since 1954, we have invested more than \$1 billion in research specifically targeting blood cancers to advance therapies and save lives. We will continue to invest in research for cures, programs and services to improve the quality of life for people who have myelodysplastic syndromes (MDS).

We know that understanding MDS can be tough.

We are here to help and are committed to providing you with the most up-to-date information about MDS, your treatment and your support options. We know how important it is for you to understand your health information and to use it, along with the help of members of your healthcare team, as you move toward good health, remission and recovery.

Our vision is that one day all people with MDS will either be cured or will be able to manage their disease with good quality of life.

Until then, we trust the information in this guide will help you along your journey.

We wish you well.

A handwritten signature in black ink, appearing to read "Louis J. DeGennaro". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

Louis J. DeGennaro, PhD

*President and Chief Executive Officer
The Leukemia & Lymphoma Society*

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This LLS guide about MDS is for information only. LLS does not give medical advice or provide medical services.

Introduction

Myelodysplastic syndromes (MDS) are a group of blood diseases that start in the marrow. An MDS is a type of blood cancer.

Between 2009 and 2013 there were about 76,755 new cases of MDS in the United States (an average of about 15,351 cases per year).

Today, there are many treatments to help people who have MDS. Yet there is more work to be done. New treatment options are available through clinical trials.

People who have MDS need to see special blood cancer doctors, called **hematologist-oncologists** to help them.

Please use this guide as a resource to help you

- Understand MDS
- Find good doctors and other healthcare providers
- Understand complicated healthcare terms
- Find and use our healthcare information, booklets, resources and Information Specialists.

This Guide includes

- Information on how to contact our Information Specialists: call (800) 955-4572
- Links to important free LLS books: www.LLS.org/booklets
- Information about MDS, diagnosis, treatment and care
- Simplified glossary of healthcare terms (See page 27).
- List of suggested questions to ask the doctor (see *Question Guides* on page 30)

We are here to help.

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 master's level 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, from 9 am to 9 pm ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/information specialists
- Visit: www.LLS.org/information specialists

Free Information Booklets. LLS offers free education and support booklets that can either be read online or ordered. For more information, please visit www.LLS.org/booklets.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients.

For more information, please

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

Sign Up for an E-Newsletter. Read the latest disease-specific news, learn about research studies and clinical trials, and find support for living with blood cancer. Please visit www.LLS.org/signup.

Community Resources and Networking

LLS Community. The one-stop virtual shop for chatting with other patients and staying up-to-date on the latest diagnosis and treatment news. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. To join, visit www.LLS.org/community.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. For more information, please visit www.LLS.org/chat.

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), in-person 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

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.

Clinical Trials (Research Studies). New treatments for patients are under way. Patients can learn about clinical trials and how to access them. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches. When appropriate, personalized clinical-trial navigation by trained nurses is also available.

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

Additional Help for Specific Populations

Información en Español (LLS Information in Spanish). For more information, please visit www.LLS.org/espanol.

Language Services. Let your doctor know if you need a language interpreter or other resource, such as a sign language interpreter. Often, these services are free.

Children. MDS are rare in children. Families face new and unfamiliar treatments and care protocols. The child, parents and siblings may all need support. For more information, please

- Call: (800) 955-4572.
- Visit: www.LLS.org/booklets
 - Filter by Topic and choose Childhood Blood Cancer and choose *Coping With Childhood Leukemia and Lymphoma*

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

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 2 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, enter “depression” in the search box

Feedback. To make suggestions about the content of this booklet, go to www.LLS.org/publicationfeedback.

Understanding MDS

About Blood

Blood is the red liquid that circulates in our bodies. It is created inside the bones, in a special spongy place called **marrow**.

Blood is made up of plasma and blood cells.

Plasma. This is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals.

Blood cells. Each blood cell starts as a stem cell. Then it turns into one of three types of blood cells. They are

- Blood platelets (help blood to clot)
- White blood cells (fight infection)
- Red blood cells (carry oxygen).

Normal Blood Cell Count Fast Facts

The ranges of blood cell counts given 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 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

- 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 cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

What Are MDS?

MDS start in the bone marrow. There is no way to prevent MDS and you cannot catch them. An MDS is a cancer. This means

- A normal cell changes (mutates)
- Changed cells act differently in the body.

Doctors also believe MDS are more frequently found in people who

- Are older
- Have had certain types of cancer treatment, such as chemotherapy and radiation
- Have rare inherited bone marrow disorders, such as Fanconi anemia, aplastic anemia or dyskeratosis congenital.

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 a **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.

Diagnosing MDS can sometimes be hard. Often the signs and/or the symptoms can also be caused by another disease.

Signs and symptoms of MDS may include

- Fatigue
- Shortness of breath during physical activity
- Pale skin
- Dizziness
- Increased risk of bleeding and bruising
- Infection.

Diagnosing MDS

There are many tests that will confirm a diagnosis of MDS. These may include

- A physical exam
- Blood tests. A common blood test is called a **complete blood count (CBC)**. This lab test counts the number of red blood cells, white blood cells and platelets in the blood. Usually, patients with MDS have lower-than-normal numbers of red blood cells, neutrophils (a type of white blood cell) and platelets.
- Bone marrow tests. These tests are used to find the percentage of abnormal blood cells in the bone marrow. The two tests are
 - Bone marrow aspiration. This is done by removing a sample of cells from the marrow.
 - Bone marrow biopsy. This is done by removing a very small amount of bone filled with marrow cells.

Both bone marrow tests are done with special needles. Some patients are awake during the procedure. They are given medication first to numb the part of the body that will be used to get the sample of cells. Some patients are sedated (asleep) during the procedure. The sample of cells is usually taken from the patient's hip bone.

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

- FISH: Fluorescence in situ hybridization. This is a test that uses light and probes to identify damaged DNA in chromosomes.

It is important to talk to your doctor about the results of these tests. The results are needed for treatment planning.

Once all the tests are complete, a hematopathologist (special type of doctor who studies disease of the blood and blood tissues) will review the results.

A diagnosis of MDS requires that one of the following problems must be present in your bone marrow:

- Blast cells (not matured cells) making up more than 5 percent of the marrow cells
- Damage to the chromosome DNA
- Changes to the structure or form of the bone marrow.

The International Prognostic Scoring Systems and MDS Classification

Doctors often use different types of scoring systems for people who have MDS. They were created to figure out the severity of a patient's disease. These definitions and information may be useful for you to learn about your MDS.

The International Prognostic Scoring System (IPSS) is a guide used, along with your doctor's observation, to determine how to best treat you. It is the guide most commonly used by doctors. It does not take into account many factors, such as aging and its effect on the treatment of older patients. It assigns patient risk (how quickly the disease will progress) to one of four categories.

These categories are

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

Doctors also use The International Prognostic Scoring System-Revised (IPSS-R) score, a recent update of the IPSS. It assigns patient risk into five groups.

These groups are

- Very low

- Low
- Intermediate
- High
- Very high.

An earlier classification was the French-American-British (FAB) Work Group, which classifies MDS into five subtypes. Some doctors still use these terms. The subtypes are based on what the patient's marrow looks like and results of blood counts.

The subtypes are called

- Refractory anemia (RA)
- Refractory anemia with ring sideroblasts (RARS)
- Refractory anemia with excess blasts (RAEB)
- Refractory anemia with excess blasts in transformation (RAEB-T)
- Chronic myelomonocytic leukemia (CMML).

In 2001, the World Health Organization (WHO) proposed another classification that was modified from the original FAB and that incorporated molecular and cytogenetic factors. Since then, the WHO classification has been updated twice, once in 2008 and again in 2016.

The current WHO classification guidelines identify six subtypes of MDS based on the results of tests of the blood and bone marrow.

The subtypes are called

- MDS with single lineage dysplasia (MDS-SLD)
 - Refractory anemia (RA)
 - Refractory neutropenia (RN)
 - Refractory thrombocytopenia (RT)

- MDS with ring sideroblasts (MDS-RS)
 - Single lineage dysplasia (MDS-RS-SLD)
 - Multilineage dysplasia (MDS-RS-MLD)
- MDS with multilineage dysplasia (MDS-MLD)
- MDS with excess blasts (MDS-EB)
 - MDS with excess blasts-1 (MDS-EB-1)
 - MDS with excess blasts-2 (MDS-EB-2)
- MDS with isolated del(5q)
- MDS unclassifiable

Want more information?



You can view, print or order the free LLS booklet *Myelodysplastic Syndromes* at www.LLS.org/booklets. Or, contact our Information Specialists for a copy.

Treating MDS

Finding the Right Doctor

Patients with MDS are treated by special doctors who understand cancer and the blood. They are called **hematologists-oncologists**.

Finding the right doctor, one that you like and feel comfortable with, is important. Try these resources to help you find the right hematologist-oncologist:

- Your primary care doctor
- The community cancer center
- Your health plan and its referral services
- Online doctor-finder resources, such as
 - The American Medical Association’s (AMA) “DoctorFinder.”
 - The American Society of Hematology’s (ASH) “Find a Hematologist.”
- LLS resources, such as our Information Specialists who can be reached Monday to Friday, from 9 am to 9 pm ET at (800) 955-4572.

Your doctor will help you to understand your MDS and create a treatment plan. When you meet with your doctor

- Ask questions
 - Use the *Question Guides* starting on page 30 to help
 - Read and print LLS question guides at www.LLS.org/whattoask.
- Take notes or audio record your visits.
- Bring a friend or family member who can help you understand and take notes.

- Make sure you understand what the doctor is saying. If you don't, ask the doctor to explain things in another way so that you can understand.
- If you need additional information or more information, consider getting another opinion (a second opinion).

Want more information?



You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center* at www.LLS.org/booklets. For a list of questions to ask your doctor, see the *question guides* on page 30. You can also access and print *Question Guides* about second opinions and other topics at www.LLS.org/whattoask. Or, contact our Information Specialists for copies.

Treatment Planning

There are many treatments for MDS. Your doctor will create a plan that is best for you.

Treatment goals for lower-risk MDS patients include

- Managing the disease by reducing transfusion needs
- Improving blood counts
- Decreasing the risk of infection
- Increasing the number of good-quality years of life.

Treatment goals for higher-risk MDS patients include

- Increasing the life expectancy, which is much shorter than it is for low-risk MDS patients
- Improving the quality of life.

Treatment Options

Work with your doctor to create a plan. Make sure you understand it or, if you don't, ask questions. Call our Information Specialists to help you understand the plan and know what questions to ask. You may be treated with drugs that are different than the ones you see in this *MDS Guide* and still be getting good treatment.

Treatment options include

- Observation with regular blood counts (watch and wait)
- Blood transfusions
- Iron chelation therapy
- Erythropoietin-stimulating agents (ESAs) and other growth factors
- Managing infections
- Drug therapy
- Chemotherapy
- Stem cell transplantation
- New approaches under study (clinical trials).

Observation (Watch and Wait). Sometimes patients do not need treatment right away. This watch-and-wait approach allows the doctor to check the patient's condition and blood count, but not actually start treatment with drugs or other therapy until it is needed. Patients may think that they should have treatment right away. But this type of monitoring allows the patient to avoid side effects of therapy until treatment is becomes necessary. Patients in watch-and-wait protocols

- Need to continue to see their doctor regularly
- Undergo regular tests and exams, as needed
- Tell their doctor about any changes or symptoms
- Understand that if there are signs that their MDS is progressing, treatment may become necessary.

Blood Transfusions. For some patients with symptoms, increasing blood counts with either transfusions (the process of taking blood from a donor and putting it into the patient intravenously) or growth factors can help make them feel better.

Before a blood transfusion, doctors will

- Check a patient's hemoglobin levels (the protein in the red blood cells that carries oxygen)
- Look for symptoms, such as fatigue or shortness of breath as well as identify other health problems, such as heart disease. For more information, please see the LLS free booklet, *Blood Transfusion*.

Platelet transfusions may be needed.

Iron Chelation Therapy. Iron chelation therapy uses medicine to remove the extra iron in the body (iron-overload). These FDA-approved medicines are called **iron chelators**. This therapy may be used for anemic patients who depend on frequent transfusions. These patients, who get many blood transfusions, may be at risk for iron-overload, a disorder that can damage the heart and liver.

The common drugs used include

- Deferasirox (Exjade® or Jadenu®)—This is an oral medication that is taken daily. Jadenu may be easier for patients to digest and is the same medication as Exjade.
- Deferoxamine mesylate (DFO; Desferal®)—This drug is administered as a slow subcutaneous (SC) or intramuscular (IM) infusion.

Erythropoiesis-Stimulating Agents (ESAs) and Other Growth Factors. Agents called **growth factors** help your body make blood cells. There are red blood cell and white blood cell growth factors. These agents are used to treat some patients whose blood cell counts show decreased numbers of cells.

Red Blood Cell Growth Factors

- Erythropoietin (EPO) is a hormone created in the kidneys. It helps red blood cell production when your body has low oxygen levels. A shortage of EPO can also cause anemia.

- Erythropoiesis-stimulating agents (ESAs) are red blood cell growth factors. They are used to treat MDS patients who have anemia associated with low EPO levels. Examples of these include darbepoetin alfa (Aranesp®) and epoetin alfa (Procrit®).

Most patients with MDS do not have low EPO levels, so administration of ESAs is not useful in treating their anemia. Nonetheless, all MDS patients should have their EPO levels checked.

White Blood Cell Growth Factors

- Granulocyte-colony stimulating factor (G-CSF) is a hormone that increases white blood cell production. Some MDS patients with low EPO levels may not benefit from ESAs alone, but ESAs with G-CSF may increase their hemoglobin levels.
- Granulocyte macrophage-colony stimulating factor (GM-CSF) is another growth factor.
- These drugs can help patients with low neutrophil (white blood cell) counts who develop infections.

Managing Infections. A low number of white blood cells can increase the risk for infection. In some cases, infection occurs frequently or it can be severe. It is important for patients to pay close attention to any infection or unexplained fever as antibiotics or antiviral drugs may be needed.

Drug Therapy. The following drugs have been approved by the FDA for patients who have MDS:

- Azacitidine (Vidaza®)—This drug is approved for the treatment of both low- and high-risk patients. It helps the bone marrow to begin to work more normally. It also kills the unhealthy cells in the bone marrow. In studies, treatment with Vidaza has led to improved quality of life with transfusions, as needed. It also reduced the need for transfusions.
- Decitabine (Dacogen®)—This drug is approved for the treatment of both low- and high-risk patients. In studies, Dacogen reduced transfusion needs and improved blood counts in some patients.

- Lenalidomide (Revlimid®)—This drug is approved for the treatment of patients with transfusion-dependent anemia due to low- or intermediate-1-risk MDS. This drug works best for patients who have certain cytogenetic changes. Talk to your doctor for more information.

In specific situations, imatinib mesylate (Gleevec®) is FDA-approved for adult patients with myelodysplastic syndromes/myeloproliferative neoplasms (MDS/MPN) associated with platelet-derived growth factor receptor (PDGFR) gene rearrangements.

Chemotherapy. Chemotherapy is treatment with drugs that kill or damage cancer cells. Each drug type works in a different way. Combining drugs can make a treatment work better. Newer drugs are being tested in clinical trials.

Patients with intermediate-2 and high-risk IPSS categories may need treatment similar to that given to patients who have acute myeloid leukemia (AML).

Some of these drugs include

- Cytarabine (cytosine arabinoside, ara-C; Cytosar-U®)
- Idarubicin (Idamycin®)
- Daunorubicin (Cerubidine®)
- Mitoxantrone (Novantrone®).

Want more information?



You can view, print or order the free LLS booklets *Myelodysplastic Syndromes* and *Acute Myeloid Leukemia* at www.LLS.org/booklets. Or, contact our Information Specialists for a copy.

How Patients Receive Treatment

Sometimes patients can take drugs by mouth. Other times, doctors will use a special tube put into the patient to give medicines. These ports (see below) are also used to give nutrients or to take blood samples. Blood for lab tests can also be taken from these lines. Lines (catheters) can stay in place for weeks or months. They include:

Central Line — A thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. It is also called a **catheter**.

Port — This is a small device attached to a central line. The port is placed under the skin of the chest. After the site heals, no dressings are needed and no special home care is needed. To give medicines or nutrition or to take blood samples, the doctor or nurse puts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used.

PICC or PIC Line — PICC or PIC line is short for **percutaneously inserted central venous catheter**. A PICC is inserted through a vein in the arm or hand. These catheters have a “tail” that allows access to give nutrients, take blood samples or give medication.

Talk to your doctor about the best way for you to receive treatment.

Stem Cell Transplantation. Your doctor will talk with you about whether stem cell transplantation is a treatment option for you. Intensive radiation and/or chemotherapy followed by an allogeneic transplant has the best-known potential to cure MDS. But this procedure has a high risk of serious complications. This treatment is not for all patients. Talk to your doctor to see if this is a treatment option for you.

Allogeneic Stem Cell Transplantation. In this procedure stem cells from another person (a donor) are infused into your body. The donor may be a brother or sister. Or, the donor can be an unrelated person with stem cells that “match” the patient’s. Stem cells may also come from a cord blood unit (the blood in the umbilical cord retrieved after a baby’s birth).

The goals of an allogeneic transplant are to

- Restore the body’s ability to make healthy blood cells after high-dose chemotherapy
- Cure the patient of MDS by killing remaining MDS cells.

This procedure may be done in the hospital. First, the patient is given high-dose chemotherapy and/or radiation therapy. Stem cells are collected from a donor. The donor stem cells are given to the patient through an IV (intravenous) line or a central line. The donor stem cells go from the patient’s blood to the marrow. They help to start a new supply of healthy red blood cells, white blood cells and platelets.

It may be an option for MDS patients if

- They are either IPSS intermediate-2 or high-risk category or have therapy-related (secondary) MDS
- The expected benefits of an allogeneic transplant exceed the risks
- There is a stem cell donor.

Reduced-Intensity Allogeneic Stem Cell Transplantation. Your doctor will talk to you about whether a reduced-intensity allogeneic stem cell transplant is a treatment option. This procedure uses lower doses of chemotherapy than the doses that are used in a standard allogeneic transplant. Some older and sicker patients may be helped by this treatment. Yet, many centers do not offer a reduced-intensity allogeneic transplant to patients who are 70 years and older. The goal of a reduced-intensity allogeneic transplant is to cure the patient of his or her MDS by killing remaining MDS cells and to start a new supply of healthy cells.

Autologous transplant, using the patient’s own stem cells, is not used for patients who have MDS.

Want more information?



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

Part 3

About Clinical Trials

Doctors may recommend that a patient joins a clinical trial. Clinical trials are careful studies done by doctors to test new drugs or treatments or new uses for approved drugs or treatments. For example, changing the amount of the drug or giving the drug along with another type of treatment might be more effective. 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 treatment. Ask your doctor if treatment in a clinical trial is right for you. You can call our Information Specialists for information about clinical trials. When appropriate, personalized clinical-trial navigation by trained nurses is also available.

Want more information?



You can view, print or order the free LLS publication *Knowing All Your Treatment Options* at www.LLS.org/booklets. Or, contact our Information Specialists for a copy.

Side Effects and Follow-Up Care

Side Effects of MDS Treatment

A side effect is an unintended result from a treatment or a drug. Sometimes the side effects are bad, but often they go away once the treatment ends. Ask your doctor about what side effects to expect from your treatment. Learn what they are. Side effects can be managed.

Side effects that affect your blood counts include

- **Anemia.** A health condition when there is a reduction in the number of red blood cells. People with severe anemia can be pale, weak, tired, and become short of breath very easily. To help increase the red blood cell count, doctors often use a red blood cell transfusion, a process when red blood cells are donated and given to the patient intravenously.
- **Thrombocytopenia.** A health condition when there is a drop in the number of platelets. To help increase the number of platelets, doctors often do a platelet transfusion, a process when platelets are donated and given to the patient intravenously.
- **Neutropenia.** A health condition when there is a big drop in the number of white blood cells (WBCs). A big decrease in the number of WBCs may result in an infection. The doctor may talk about the “absolute neutrophil count” (ANC), which is the number of neutrophils (a type of white blood cell) a person has for fighting an infection. Infections are usually treated with antibiotics.

MDS patients are more likely to get an infection than other people. Look out for the following symptoms and tell your doctor right away if you experience any of them:

- Fever
- Chills

- Coughing
- Sore throat
- Pain when urinating
- Frequent, loose bowel movements.

To lower the risk of infection

- Use good hand washing skills—patients, their visitors and medical staff need to wash their hands well.
- Keep the patient’s central line clean.
- Practice good dental hygiene—patients should take good care of their teeth and gums.

Chemotherapy-Related Side Effects. Chemotherapy affects the parts of the body where new cells are forming quickly. This includes the inside of the mouth and bowel, and the skin and hair. These associated side effects are common during chemotherapy:

- Mouth sores
- Diarrhea
- Hair loss
- Rashes
- Nausea
- Vomiting.

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.

Want more information?



You can view, print or order the free LLS publications *Understanding Side Effects of Drug Therapy* and *Long-Term and Late Effects of Treatment in Adults Facts* at www.LLS.org/booklets. Or, contact our Information Specialists for copies.

Follow-Up Care

MDS patients will meet with their primary care doctor and hematologist-oncologist for follow-up care. At these visits, the doctor will check you and learn how you are doing. Additional blood tests or even marrow tests may be needed to evaluate your treatment progress and to learn if more treatment is needed. The doctor may advise longer periods of time between follow-up visits; however, they should be ongoing. For each follow-up visit you should

- Track each visit and record what was discussed.
- Ask your doctor if and 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 file folder or binder.
- Organize the reports in date order.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

Ongoing Care

Whether you still have an MDS or if you have been treated for one, it is very important that you take good care of yourself. Review the following tips to keep yourself healthy and happy:

- Keep all doctors' appointments.
- 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. Follow the doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.

- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest.
- Exercise, but first talk with your doctor before starting an exercise program.
- 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. If you feel sad or depressed every day for a 2-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for an MDS. Treatment for depression has benefits for people living with cancer.

Health Terms

Absolute neutrophil count (ANC). The number of neutrophils (a type of white blood cell) that a person has to fight infection. It is calculated by multiplying the total number of white blood cells by the percentage of neutrophils.

Acute myeloid leukemia (AML). A fast-moving cancer that starts with a change of a young cell in the bone marrow.

Anemia. A health condition when the blood has lower than normal number of red blood cells.

Antibiotics. Drugs to treat infections. Penicillin is a type of antibiotic.

Blast cells. Early (or immature) bone marrow cells. About 1 to 5 percent of all normal marrow cells are blast cells.

Blood cell count. A laboratory test that uses a small blood sample to measure the number and types of cells circulating in the blood. The term **complete blood count** or **CBC** is often used to refer to this test.

Bone marrow aspiration. A procedure to remove liquid from the bone marrow. Experts examine these cells under a microscope to look for abnormal cells.

Bone marrow biopsy. A procedure to remove a small amount of bone from the marrow. Experts examine this sample under a microscope to look for abnormal cells.

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

Chemotherapy. The use of chemicals to kill cancer cells.

Chromosomes. Threadlike structures in each cell that carry a person's genes. Genes tell the cells what to do. In each cell, there are 23 basic

structures (chromosomes). When a patient has blood cancer, the number or shape of chromosomes may be changed.

Clinical trials. Studies done by healthcare experts who test new drugs or treatments and explore new uses and combinations of drugs with the hope of either finding a cure or improving quality of life.

Clonal. A group of cells that first came from one parent cell. Clone cancers include MDS, leukemia, and lymphoma.

Combination chemotherapy or drug therapy. Using two or more drugs together to fight MDS and other cancers.

Diagnose. To detect a disease from a person's signs, symptoms and test results.

DNA. The genetic matter found in all cells.

Drug resistance. When a drug either does not work or stops working.

FDA. The short name for the US Food and Drug Administration. The FDA is a federal agency that assures the safety and security of drugs, medical devices and the US food supply.

Growth factor. A chemical used to help your body make blood cells. There are red blood cell and white blood cell growth factors.

Hematologist. A doctor who treats blood cell diseases.

Hemoglobin. The part of the red blood cell that carries oxygen.

Immune system. A system within the body that works to fight disease and infection.

Leukemia. A cancer of the marrow and blood.

Marrow. The spongy material in the center of bones. All blood cells are made in the marrow.

Oncologist. A cancer doctor.

Pathologist. A doctor who identifies disease by looking at body tissue and fluids under a microscope.

Plasma. The liquid part of the blood.

Platelet. A type of blood cell that stops bleeding. Platelets cause plugs to form in the blood vessels at the site of an injury.

Radiation therapy. Treatment with x-rays or other high-energy rays.

Refractory anemia (RA). A clonal myeloid disorder that mostly affects red blood cell production in the marrow. A subtype of MDS.

Refractory anemia with excess blasts (RAEB). Also called oligoblastic myelogenous leukemia. This type of MDS shows signs of blast cells in the blood and marrow.

Refractory anemia with excess blasts in transformation (RAEB-T). A subtype of MDS in which the bone marrow blast count ranges from 20 to 30 percent.

Refractory anemia with ring sideroblasts (RARS). This type of MDS is a form of anemia where the bone marrow produces ringed sideroblasts (an abnormal amount of iron granules around the nucleus of the cell) rather than healthy red blood cells.

Resistance. See Drug resistance.

Signs and symptoms. Changes in the body that show disease. A sign is a change that the doctor sees in an exam or as a result of a lab test. A symptom is a change that a patient can see or feel.

Stem cell. A type of cell in marrow that makes red blood cells, white blood cells and platelets.



Questions to Help You Choose a Specialist

Asking questions will help you take an active role in managing your (or your child's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Doctor's name _____

Date of appointment or call _____

- 1.** What is your board certification and licensing? Are you a member of any professional societies?

- 2.** How much experience do you have treating patients who have my disease?

- 3.** Is your hospital, university, center or clinic accredited and experienced in treating blood cancers?

- 4.** How long would I usually have to wait for appointments or return of my phone calls?

5. Will there be nurses, social workers and case managers available to help me with support needs and quality-of-life concerns?

6. Do you know of other oncologists who specialize in treating blood cancers? Would you recommend that I speak to any of them?

7. What types of things should I call you about? What types of things should I call my family doctor about?

8. How should I contact you when I have questions?

9. How do I contact you at night? On weekends? On holidays?

To print additional copies of this question guide, or to print copies of question guides on other topics, go to www.LLS.org/whattoask. You may also request that copies be sent to you by contacting our Information Specialists at (800) 955-4572.



Questions to Ask Your Healthcare Provider About Treatment

Asking your healthcare provider questions at any phase of your treatment will help you take an active role in managing your (or your child's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Doctor's name _____

Date of appointment or call _____

- 1.** What are my (my child's) treatment options? What is the goal of the treatment?

- 2.** What are the FDA-approved treatments, and are there treatments being studied in clinical trials (study treatments), for my (my child's) diagnosis?*

- 3.** What are the benefits and risks of the treatment(s) available to me (my child)? What are the expected side effects?

- 4.** Is there one treatment option (FDA-approved or study treatment) that you recommend over the others? Please explain.

5. If I (my child) enroll(s) in a clinical trial, who will be in charge of my (my child's) treatment?

6. When do you think I (my child) will need to begin treatment?

7. How long will I (my child) be treated and how many treatments will be needed?

8. Will I (my child) need to be hospitalized for all or part of the treatment?

9. What kind of testing will be done to monitor my (my child's) disease and treatment? How often will testing be needed?

10. If I am treated at an out-patient clinic or at the doctor's office, will I be able to drive/get myself home after treatments or will I need someone to assist me?

11. What are the risks if I don't (my child doesn't) get treatment?

12. How will I know if the treatment is effective? What options are available if the treatment is not effective?

13. How do I find out if my insurance will cover the costs of my (my child's) treatment or the study treatment? Who can help answer any medical questions my insurance company or health plan asks?

14. If I do not have insurance coverage, how can the healthcare team help me (my child) get treatment? Is there someone I need to speak to for assistance?

15. If I'm (my child is) getting a study treatment, will I be responsible for paying any treatment-related costs, such as tests, travel or the clinical trial drug(s)?

16. Will the healthcare team continue to check on me (my child) after the treatment is over? If so, for what period of time?

17. I (My child) would like to continue some type of lifelong follow-up care in order to be monitored for long-term and late effects of treatment. Can I (my child) follow up with you?

*For definitions of an FDA-approved treatment and a clinical trial (study treatment), visit www.LLS.org or contact an Information Specialist.

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Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

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