Understanding Lower-Risk Myelodysplastic Syndrome (LR-MDS)

A guide for patients and care partners

MOVING YOUR LR-MDS JOURNEY FORWARD

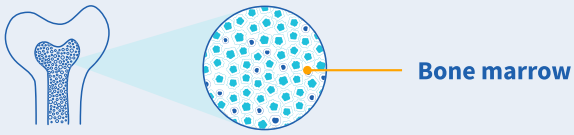
Hearing that you or someone you care about has been diagnosed with myelodysplastic *(my-low-diss-plastic)* syndrome *(or MDS)* can be overwhelming. You may have been told that it's a rare form of blood cancer. We know those words can feel scary and confusing. It's normal to have questions and to wonder about what happens next.

Throughout your care, you may hear the terms MDS and lower-risk MDS *(or LR-MDS)* used to refer to your condition. This guide is designed to focus specifically on LR-MDS. It can help you understand what LR-MDS is and empower you to move forward with confidence. Remember, the more you know about your health, the more you can take an active role in your care journey.

What is LR-MDS?

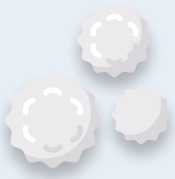
LR-MDS is an uncommon type of blood cancer where the bone marrow doesn't make enough healthy blood cells or makes cells that don't work as they should.

Bone marrow is the soft, spongy tissue inside your bones where many kinds of blood cells are made.



Inside your bone marrow are early, immature cells *(called stem cells)* that can develop into different kinds of blood cells. This includes **red blood cells, white blood cells, and platelets.** Each of these cells has an important role within your body:

Red blood cells (RBCs)
carry oxygen to your tissues



White blood cells (WBCs)
help your body fight infection

Platelets
help your blood clot to stop or prevent bleeding

In LR-MDS, the stem cells in your bone marrow don't grow and mature as they should. As a result, some of your blood cells may be abnormal in shape and size. This is called *dysplasia.* You also may not have enough of 1 or more types of healthy blood cells. Having low blood cell counts is called a *cytopenia.* There are 3 common types:

- **Anemia—**low red blood cell counts
- **Leukopenia—**low white blood counts
  - **Neutropenia—**low neutrophils, a type of white blood cell
- **Thrombocytopenia—**low platelet counts

Myelo = bone marrow | **Dysplastic** = growing abnormally

Are all forms of MDS the same?

Just as each person is unique, not all cases of MDS are the same. Some types of MDS grow slowly. Others have a higher risk of changing into a faster-growing type of cancer called *acute myeloid leukemia* (AML).

- **Lower-risk MDS (LR-MDS)** has a low risk of progressing to AML. However, "*lower*-risk" MDS doesn't mean "*no* risk." The disease may still need ongoing care or treatment, especially because of symptoms like anemia.
- **High-risk MDS** is more likely to turn into AML, especially without treatment.

Lower-risk MDS, or LR-MDS, is the most common form of MDS. *It affects about* ***7 in 10*** *people who are diagnosed with MDS.*

Who gets LR-MDS?

LR-MDS occurs most often in older adults. On average, most people are diagnosed later in life, usually in their 70s. It is more common in men than women.

What causes LR-MDS?

In most cases, the cause of LR-MDS is not known. It is not a contagious disease that can be passed from person to person. Genetics rarely play a role. This means it's unlikely that MDS can be passed down to a child or grandchild. There are, however, certain factors that may increase a person's risk of developing the condition. This includes:

- Exposure to certain chemicals, like benzene, certain solvents, insecticides, or herbicides
- Tobacco smoke/use
- Personal history of autoimmune disease
- Certain cancers
- Certain types of chemotherapy

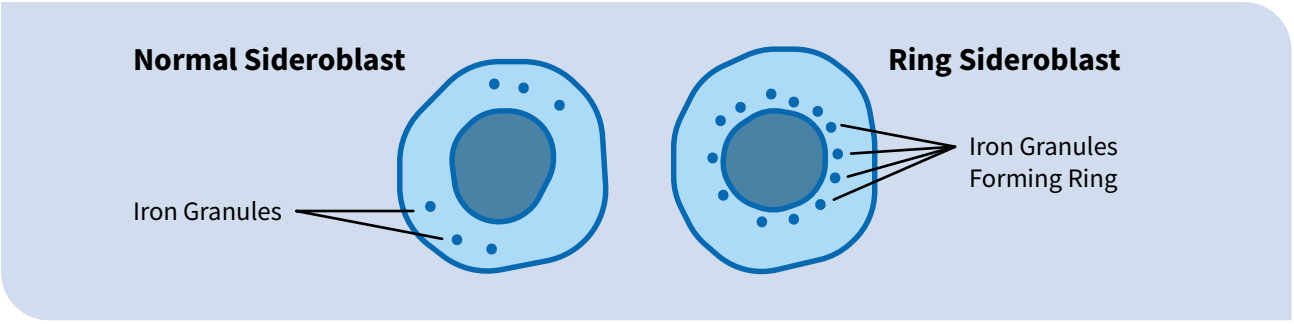
What factors affect how my LR-MDS may change over time?

Doctors classify MDS in different ways to better understand each person's situation. One thing they may look at is the *severity* of your disease (or *risk level*). Your care team may also use certain "scoring systems" to estimate how your MDS may behave in the future. Your "score" may depend on:

- Your blood counts
- The percentage of certain cells in your bone marrow
- Certain changes in your genes (called *mutations*)

What should I know about ring sideroblasts?

In addition to your risk level, your care team may also look at a feature in some developing red blood cells called *ring sideroblasts* (or *RS* for short). These are ring-shaped iron deposits inside your red blood cells.



- **RS+** patients are those people who test positive for ring sideroblasts
- **RS−** patients test negative for ring sideroblasts

Ring sideroblasts are developing red blood cells that have unusual iron buildup inside them. Some people with LR-MDS may also develop too much iron in their body, especially after receiving many blood transfusions, which may require additional treatment.

Your risk score—along with your RS subtype (RS+ or RS−)—can help your care team develop a treatment plan that makes the most sense for you.

About 1 in 3 people with LR-MDS have ring sideroblasts (RS+).

What are the symptoms of LR-MDS?

MDS is a progressive disease, which means it may change or get worse over time. In its early stages, there may be few or no symptoms. For some people, low blood cell counts revealed through a routine blood test may be the first sign. However, symptoms may change as the disease progresses.

Symptoms of LR-MDS are often related to low blood cell counts. They may depend on which blood cell type is affected. For example:

Low red blood cell counts (anemia) can cause:

- Extreme tiredness
- Dizziness
- Weakness
- Shortness of breath
- Headache
- Rapid or irregular heartbeat
- Pale skin

Low white blood cell counts (neutropenia) can cause:

- Frequent infections
- Infections that don't go away
- Fever

Low platelet counts (thrombocytopenia) can cause:

- Bruising easily
- Nosebleeds
- Bleeding that doesn't stop
- Bleeding gums
- Pinhead-shaped red spots on the skin (called *petechiae*)

LR-MDS can change over time

Because of the progressive nature of LR-MDS, it's important to prioritize your healthcare appointments and lab work. Being aware of changes in blood counts and symptoms can help you have more informed conversations with your care team. It can also empower you to participate in treatment decisions with your care team.

How is LR-MDS treated?

How your LR-MDS is managed depends on many things. This includes the severity of your symptoms and your overall health.

Supportive Care: This is special medical care that helps you feel better and manage symptoms. It does not treat the disease itself. It can be used on its own or along with other treatments. Examples include:

- Blood transfusions to raise your blood cell counts
- Growth factor medicines that help your body make more blood cells
- Antibiotics to prevent or treat infections
- Help with healthy eating (nutritional support)
- Spiritual and emotional support

Medicines that target LR-MDS: Different kinds of medicines can change how LR-MDS acts in your body. Your care team will pick the right ones for your type of MDS. These medicines may help:

- Slow down or kill cancer cells in your bone marrow
- Help your bone marrow make healthier blood cells
- Calm down your immune system if it's hurting your blood cells

Always discuss the benefits and risks of any treatment with your care team to ensure that it's right for you.

Stem cell transplants: This is a medical procedure where doctors replace sick bone marrow with healthy stem cells from a donor. Over time, those new cells may grow into healthy blood cells. It is a serious procedure with serious risks and it's not right for everyone. Your care team will look at your age, health, and type of MDS to help you decide.

Clinical trials: These are research studies that test new treatments. Joining one may give you a chance to try treatments that aren't yet widely available. There are rules about who can join. Your care team can help you find out if one is a good fit for you.

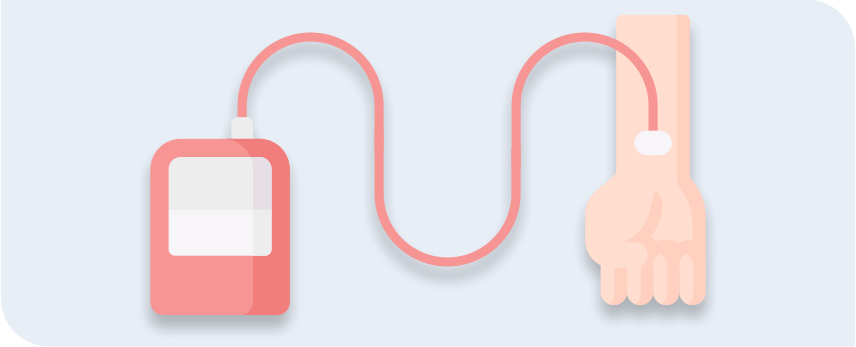
Taking an active role in your care

If you have been told that you have LR-MDS, it's important to take an active role in your own care. That starts with learning about your disease and asking your care team if your current treatment approach is the right one for you.

Does everyone with LR-MDS need blood transfusions?

A blood transfusion is when donated blood cells are injected into your body through a vein. They are used to increase your own blood counts. Many people with MDS may require blood transfusions at some point during their disease course.

Having blood transfusions can help with some LR-MDS symptoms. However, they also add extra iron into your blood. **This can increase the risk of iron overload, which can be harmful.**



Some people with LR-MDS rely heavily on transfusions to manage symptoms. An example would be a person who has a red blood cell transfusion every 2 weeks. This is called *transfusion-dependence*.

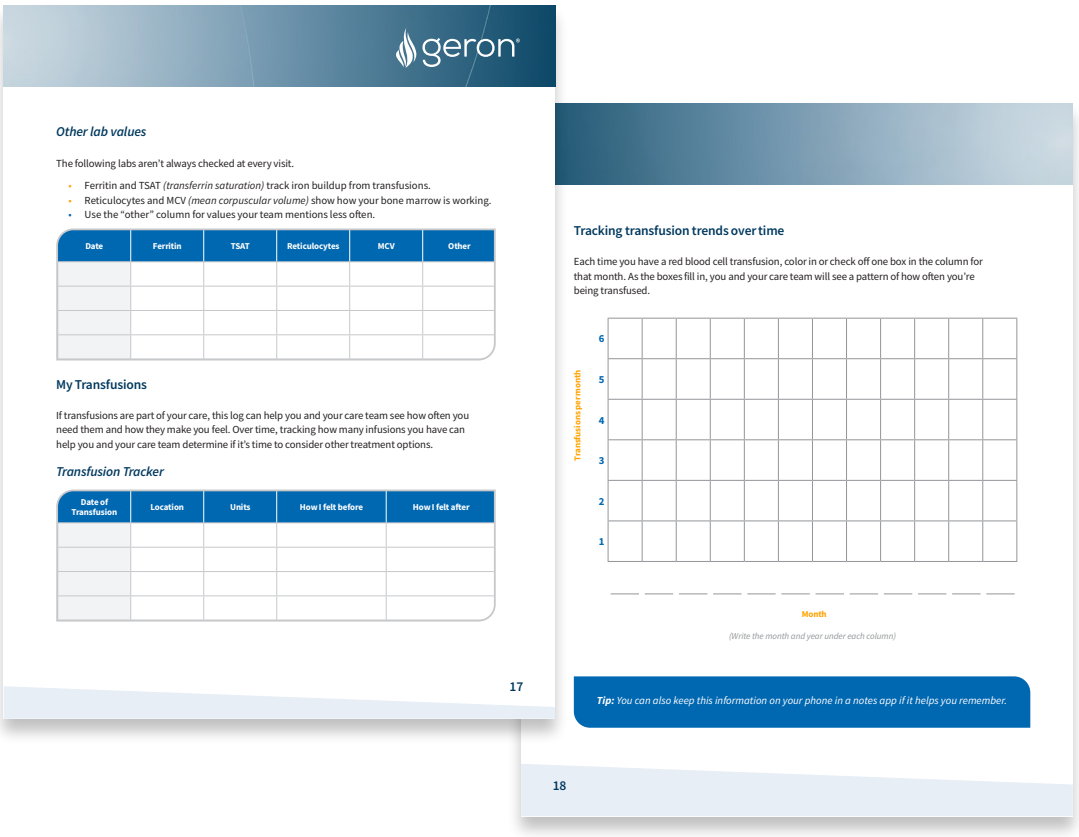
Transfusions can be helpful, but they also may put a burden on your quality of life due to:

- Frequent visits to the hospital or infusion center
- A cycle of feeling better, then worse, between transfusions
- A buildup of iron in your body over time, which can be harmful and may need treatment
- The emotional toll of repeating the same treatment cycle
- Increased healthcare costs

Treatment goals for LR-MDS often include reducing or, for some people, eliminating the need for transfusions. *They also focus on improving quality of life and helping people live longer. If transfusions are a regular part of your care, ask your care team about other options. This may include refining your current treatment plan to include options specifically designed to help reduce transfusion dependence.*

Tracking trends in your health

Keeping track of transfusions and lab results are important ways to help you stay informed about your disease. You can use the included transfusion tracker tool to record changes in disease activity.



Other lab values

The following labs aren't always checked at every visit.

- Ferritin and TSAT *(transferrin saturation)* track iron buildup from transfusions.
- Reticulocytes and MCV *(mean corpuscular volume)* show how your bone marrow is working.
- Use the "other" column for values your team mentions less often.

Date	Ferritin	TSAT	Reticulocytes	MCV	Other

My Transfusions

If transfusions are part of your care, this log can help you and your care team see how often you need them and how they make you feel. Over time, tracking how many infusions you have can help you and your care team determine if it's time to consider other treatment options.

Transfusion Tracker

Date of Transfusion	Location	Units	How I felt before	How I felt after

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Tracking transfusion trends over time

Each time you have a red blood cell transfusion, color in or check off one box in the column for that month. As the boxes fill in, you and your care team will see a pattern of how often you're being transfused.

Transfusions per month: 6, 5, 4, 3, 2, 1

Month

(Write the month and year under each column)

Tip: *You can also keep this information on your phone in a notes app if it helps you remember.*

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Knowledge is power

No matter where you are on your MDS journey, knowledge is one of the most powerful tools you have. The more you learn about your condition, the more clearly you can ask questions, weigh your options, and feel confident about your treatment decisions.

TAKING AN ACTIVE ROLE IN YOUR LR-MDS JOURNEY

If you or your loved one has been diagnosed with LR-MDS, getting the facts is an important first step. The next is becoming an active partner in your own care. This includes knowing where to turn for support. Staying informed about the disease will help you play an active role within your care team. Remember, you are not alone on this journey and your care team is an important part of your support system.

You are not alone

Managing LR-MDS is not something you need to do on your own. Know that there is a community of support ready to help. A *hematologist* (blood specialist) or *oncologist* (cancer specialist) will usually lead your care. You may also receive support from a care team that includes the following support staff:

- **Nurses** assist your doctors with your overall care. This may include preparing and administering treatments, providing supportive care, and giving helpful information to patients and care partners.
- **Nurse navigators** help coordinate your care to help you stay organized. This may include tracking appointments and tests, as well as helping you plan questions for your care team.
- **Social workers** may offer emotional support through counseling and support groups.
- **Pharmacists** fill your prescriptions and offer guidance on how and when to take medications, and potential side effects.
- **Care partners, friends, and family** are your personal support system. They may take you to appointments, help take notes, provide meals, and offer physical and emotional support.

Tools to help move your journey forward

The following section includes a variety of printable tools designed to help you better understand your LR-MDS, and keep track of it over time. Each resource can be customized to your individual needs. Additional printable copies can be found at geron.com.

Doctor Discussion Guide—a list of important questions to ask your care team. It includes space to write down answers, log follow-up items, and capture notes

Infusion and lab values tracker—a diary to track the dates of your infusions, symptoms, and lab values. Over time, this information can help you and your care team identify important trends in your health

Symptom assessment form—a journal to keep track of your symptoms—and how they may change—to share with your care team

Glossary of terms—a list of important words that can help you have more informed discussions with your care team

DOCTOR DISCUSSION GUIDE

This guide is designed to help you have more meaningful conversations with your care team. Use it to capture any questions—and answers—about your health and treatment plan. Remember, when it comes to your health, there are no "wrong" questions, only the ones that go unasked. Don't be afraid to speak up and share what's going on.

Questions about my diagnosis

- What type of MDS do I have, and what does that mean?

  _____

  _____

- Are there possible health complications that I should know about?

  _____

  _____

- Do I have ring sideroblasts? How does that affect my treatment options?

  _____

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- What are my current blood counts? How have they changed since my last visit?

  _____

  _____

- How often will I need to have tests or other procedures?

  _____

  _____

- What is my risk score, and what does it tell us?

  _____

  _____

- How will my MDS be monitored over time?

  _____

  _____

- What information should I keep track of?

  _____

  _____

- What symptoms do you want to know about right away?

  _____

  _____

- What should I do when I feel weak or tired?

  _____

  _____

- Where can I find support if I feel overwhelmed?

  _____

  _____

Questions about my treatment

- What types of tests or procedures will I need to have?

  _____

  _____

- What are my treatment options right now?

  _____

  _____

- What are the benefits of treating now versus waiting?

  _____

  _____

- What side effects should I watch for, and how would we manage them?

  _____

  _____

- Are there clinical trials I should consider?

  _____

  _____

- If my current treatment isn't working well enough, do I have other options?

  _____

  _____

- Have I become transfusion-dependent? If so, what are my next steps?

  _____

  _____

Questions about what's next

- How often will I need to come in for visits?

  _____

  _____

- What signs or symptoms should make me call you between appointments?

  _____

  _____

- Who else is on my care team, and who do I call for what?

  _____

  _____

- Is there a nurse navigator or social worker I can talk to?

  _____

  _____

- Are there any follow-up items that I need to remember?

  _____

  _____

My own questions

_____

_____

_____

_____

Notes

_____

_____

_____

_____

Next appointment(s):

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

[Day] _____ [Date] _____ [Time] _____

[Doctor Name] _____[Location] _____

Tip: *Bring a friend, family member, or caregiver to take notes. Two sets of ears are better than one.*

MY LR-MDS HEALTH DIARY

Use this tracker tool to keep a record of your lab values, infusions, and symptoms over time. You don't need to fill them in every day; just often enough to see patterns. Bring the completed forms to your appointments so your care team can see how things may be changing between visits. This information can help inform and guide your ongoing care.

My Lab Values

Keeping track of your lab values (eg, blood counts, etc) is an important part of taking charge of your LR-MDS. Be sure to ask for a copy of your blood work after each appointment. You can also write down the numbers your team shares with you. Logging this information over time can help you and your care team work together to spot trends in your health. Remember, overall patterns matter more than any single result.

Blood counts

Date	Hemoglobin	Hematocrit	Platelets	White Blood Cells	Neutrophils

Other lab values

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- Reticulocytes and MCV *(mean corpuscular volume)* show how your bone marrow is working.
- Use the "other" column for values your team mentions less often.

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Tracking transfusion trends over time

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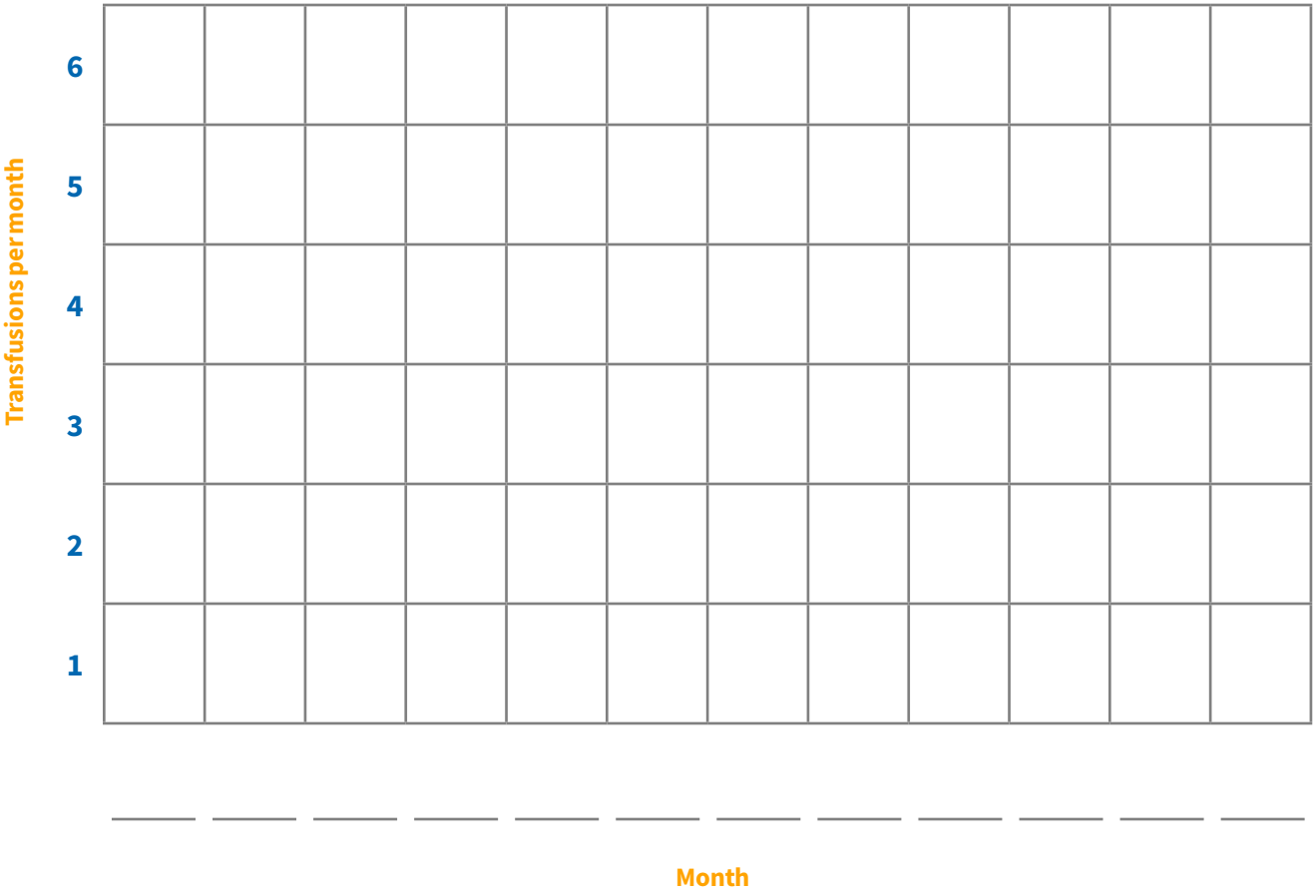

(Write the month and year under each column)

Tip: *You can also keep this information on your phone in a notes app if it helps you remember.*

My Symptoms

When tracking your symptoms, it's important to note:

1) Which symptoms am I experiencing?
2) How are my symptoms impacting my activity levels and/or quality of life?
3) How often do my symptoms impact my quality of life?

Rate each symptom on a scale from 0 to 3: 0=none; 1=mild; 2=moderate; 3=severe

Be sure to note anything else that you want to share with your care team. This information will give them a better understanding of how your LR-MDS is making you feel and how to help you manage symptoms.

SYMPTOM	SEVERITY (0-3)	HOW IT AFFECTS ME (0-3)	NOTES
Fatigue			
Shortness of breath			
Lightheadedness or dizziness			
Heart racing or pounding *(tachycardia)*			
Bruising			
Bleeding more easily			
Fevers or infections			
Other: _____			
Other: _____			

HELPFUL TERMS TO KNOW

Some of the words your care team uses can sound complicated. Below are simple meanings for the most common terms. Understanding these terms can help you stay more informed about your MDS journey and confidently ask questions of your care team.

GLOSSARY TERMS

Acute myeloid leukemia (AML): A faster-growing type of blood cancer. In some cases, MDS can turn into AML over time. People with lower-risk MDS are less likely to have this happen soon.

Anemia: When you don't have enough red blood cells. Anemia can make you feel tired, short of breath, dizzy, or weak.

Bone marrow: The soft, spongy tissue inside your bones. It's where your body makes blood cells. In MDS, the bone marrow doesn't make enough healthy blood cells.

Clinical trial: A research study that tests a new treatment, dose, or combination. Joining one can be a way to access treatments that aren't yet widely available.

Cytopenia: A medical word for low blood cell counts. You can have one or more types of cytopenia at the same time.

Dysplasia: Cells that have an abnormal shape or size. It's one of the things doctors may check to confirm a diagnosis of MDS.

Hematologist: A doctor who specializes in blood diseases. Many people with MDS work with a hematologist or a hematologist-oncologist.

Hemoglobin: The part of your red blood cells that carries oxygen. Your team checks your hemoglobin number to see how anemic you are.

High-risk MDS: A form of MDS where the chance of turning into AML soon is higher than in lower-risk MDS. It often needs more active treatment to manage symptoms and slow progression.

Immune system: The body's internal defense system for protecting against infections and disease.

Intravenous (IV): A type of injection given through a vein.

IPSS-R and IPSS-M: Scoring systems doctors use to estimate how MDS may behave in your case.

Iron overload: Too much iron building up in your body. It can happen after many blood transfusions and may need treatment.

Leukopenia: A low total number of white blood cells. Leukopenia can make it harder for your body to fight off infections.

Lower-risk MDS (LR-MDS): A form of MDS where the chance of turning into AML soon is lower. About 7 in 10 people with MDS have lower-risk MDS.

Mean corpuscular volume (MCV): A test that measures the average size of your red blood cells. Cells that are too big or too small can be a sign of MDS or other health issues.

Myelodysplastic syndromes (MDS): A group of blood cancers in which the bone marrow doesn't make enough healthy blood cells, or makes blood cells that don't work the way they should.

Neutropenia: Low levels of a type of white blood cell called a neutrophil. Neutropenia is a type of leukopenia that makes it harder for your body to fight off infection.

Oncologist: A doctor who specializes in treating cancer. Many people with MDS see a hematologist-oncologist.

Petechiae: Tiny red or purple dots on your skin. They can be a sign of low platelets and unusual bleeding under the skin.

Platelets: Blood cells that help stop bleeding by forming clots. Low platelets can cause bruises and bleeding more easily than usual.

GLOSSARY TERMS (continued)

Red blood cells (RBCs): Blood cells that carry oxygen from your lungs to the rest of your body. Low red blood cells cause anemia.

Reticulocytes: Young, new red blood cells. A reticulocyte count shows how well your bone marrow is making new red blood cells.

Ring sideroblasts (RS): Developing red blood cells in the bone marrow that contain abnormal iron deposits. About 1 in 3 people with lower-risk MDS have ring sideroblasts.

Stem cells: An early-stage cell in your bone marrow that grows up to become a red blood cell, a white blood cell, or a platelet. Stem cells are the starting point for every blood cell in your body. In MDS, stem cells often don't mature or work the way they should.

Supportive care: Treatments that help manage your symptoms but do not treat the disease itself. This includes but is not limited to blood transfusions, treatments for iron buildup, or steps to prevent infection.

Thrombocytopenia: Low platelet count. It can cause bruising and bleeding more easily than usual.

Transfusion: Receiving blood—most often red blood cells — through an IV. Some people with MDS need repeated transfusions to manage anemia.

Transfusion-dependent anemia: When your anemia is severe enough that you need transfusions on a regular basis to feel better and stay safe.

Additional Notes

Find More Support for Your MDS Journey

To learn more about LR-MDS and to find additional information and resources to support your MDS journey, **visit geron.com.**

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