

Understanding MDS

TRANSCRIPT

Mikkael A. Sekeres, MD, MS

*Professor, Clinical Medicine
Chief, Division of Hematology
Department of Medicine
University of Miami Miller School of Medicine,
Sylvester Comprehensive Cancer Center*

The myelodysplastic syndromes (MDS) are a collection of disorders of the blood and bone marrow. Now the bone marrow is the factory that makes all the cells that wind up in our bloodstream: the red blood cells that bring oxygen to our tissues – when those are low, you're anemic; the white blood cells – that's our immune system, it fights infections; and the platelets that help stop bleeding. When we have myelodysplastic syndromes, that factory is broken. It's not making the normal levels of red blood cells, white blood cells, and platelets that we need.

Caitlin

MDS Survivor

How is MDS different from anemia?

Dr. Sekeres

Myelodysplastic syndromes can include anemia. In fact, most people with myelodysplastic syndromes have anemia, and that's how the MDS was diagnosed. Probably about 80% of people with MDS have some degree of anemia; the remaining 10 to 20% may have a low platelet count, a low white blood cell count, and an even greater percentage of people have more than one thing going on. There are a lot of causes for anemia. Once those other potential causes of anemia are eliminated – it's not blood loss, it's not vitamin deficiency – that usually prompts a primary care doctor to send someone to a hematologist for a bone marrow biopsy. We simply can't make a diagnosis of myelodysplastic syndromes without that bone marrow biopsy, and that bone marrow biopsy will show these dysplastic – bad growing – cells in the bone marrow that are diagnostic of MDS.

Caitlin

So, is it blood cancer?

Dr. Sekeres

Well, there's cancer and then there's capital letters cancer with an exclamation point. So, it is technically a cancer. Cancer involves the uncontrolled growth of cells. If that happens with cells in the breast, a woman gets a lump; it outgrows other cells around it. If it happens in someone's lungs, that person gets a mass; it's outgrowing other cells around the tissue of the lungs. When it happens in the bone marrow, the bone marrow is a fixed space. It's inside the bone. It can't expand like other tissue in the body. So those cells fill up the bone marrow and as they fill up the bone marrow with these dysplastic – bad growing – cells, the normal cells in the bone marrow start to die out. That's why people tend to have low blood counts.

But there are different types of myelodysplastic syndromes. So, there's lowercase letters cancer with lower-risk myelodysplastic syndromes, where some people may not even require any therapy. Then there's capital letter, exclamation point cancer. With higher-risk myelodysplastic syndromes, it starts to look more and more like acute leukemia, and that's something we pretty much always have to treat to try to prevent it from going into acute leukemia.

Understanding MDS

Caitlin

Does all MDS lead to acute leukemia?

Dr. Sekeres

Actually, it doesn't. So, it's a bit of a misnomer. Myelodysplastic syndromes used to be called pre-leukemia, and those of us who practice this every single day hate that term because most myelodysplastic syndromes actually doesn't go into acute leukemia. Lower-risk myelodysplastic syndromes people can live with for years, and most of the time it doesn't turn into acute leukemia. It doesn't become something much more serious than where we started. But for higher-risk myelodysplastic syndromes, it actually, biologically and even clinically, the labs that a person has are very similar to acute myeloid leukemia and has much more of a tendency to go into acute myeloid leukemia. That puts the urgency on us to treat it and try to prevent that from happening.

Caitlin

What would you say to patients who are coming to you with a bunch of questions, not knowing what's going on, how they feel about, you know, something that is potentially very scary in their lives, giving them a practical approach to just going forward, figuring it out?

Dr. Sekeres

I love when people bring questions. To me, that means it's someone who's engaged in her health, and that's a great patient to partner with. And I ask people to bring questions, to write them down. Because personally, when I go to the doctor, my mind goes blank. And I know that sounds ridiculous, but I've had, for example, orthopedic procedures just from, you know, a life of trying to be athletic beyond the years when we probably should still be athletic. And I'm not going to pretend that I'm an orthopedist. I don't know that field as well as someone else. So, personally, my approach, I don't do a lot of reading because I don't want to, in a weird way, I don't want to trick myself into thinking that I understand it better than I do, but I want to do enough reading so I can know the questions to ask my doctor.

And I love it when patients do that. So, we make sure that we answer all of those questions. And, when I see a patient – listen, we're no longer in the paternalistic era of medicine for two reasons. One, as healthcare providers, we're not telling people what to do. We're engaging them in a conversation about what they want to do. And secondly, paternalism was from a time when all the doctors were men, and 50% are women. So, I look at my role as providing education as much as I can and allowing my patients to make decisions about their care. And I honestly do believe if you are seeing a doctor who isn't open to questions or tries to shut you down or overtalks you, you're with the wrong person and should try to find another doctor.

Narrator

For tips to help you communicate with your healthcare team, including a list of suggested questions to ask your doctor, please visit The Leukemia & Lymphoma Society's website at [LLS.org](https://lls.org) to download and print our patient-friendly guides.

For more information about MDS and other blood cancers, please contact an Information Specialist at 1-800-955-4572 or visit us on the Web at: [LLS.org/InformationSpecialists](https://lls.org/InformationSpecialists).