

Talking About MDS

Introduction

On-screen text-message bubbles:

Caitlin: Girl!!!!!! I just got back from my doctor's appointment. I was just diagnosed with MDS!

Shelbi: What?! What is MDS?

Caitlin: I think it's a kind of blood cancer.

Shelbi: Cancer?!?! You're pregnant!! Are you okay? What about the baby?

Caitlin: I don't know. I don't know how this is going to affect my pregnancy. I'm scared. I need to talk to my doctor. I have so many questions.

Shelbi: How do they treat MDS when you're pregnant? Maybe you should see a specialist??

Caitlin: Ooh, good idea. Can you help me find someone? I'm so upset... I don't even know where to start.

Talking About MDS *Living with MDS*

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 group of disorders of the bone marrow in which the bone marrow, the factory in the bone marrow, which makes the cells in our bloodstream: the red blood cells that bring oxygen to our tissues – when those are low, you're anemic; the white blood cells – those fight infections, that's your immune system; and the platelets that help stop bleeding. That factory isn't working as well as it once did. It's broken. So, it doesn't make the normal levels of red blood cells, white blood cells, and platelets that we need to exist. It is technically a cancer.

Caitlin

MDS Survivor

I knew that you specialized in myelodysplastic syndromes, and I sought you out.

Dr. Sekeres

You're not like one of my typical MDS patients though.

Caitlin

Right. I'm a lot younger. I was diagnosed when I was pregnant.

Dr. Sekeres

You're a good 30, 40 years younger than my typical patients, but you had some anemia, your blood counts persisted in being lower, and your primary care doctor couldn't find any other causes for the

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anemia. So, eventually that led to a bone marrow biopsy that diagnosed your myelodysplastic syndromes.

And I suspect there are some people who may be watching this and saying, okay, well that's all well and good. You were pregnant. You're the one-in-a-hundred thousand people with MDS who's also going to be pregnant at the same time. But, from my perspective, as somebody who treats people who have MDS, I will tell you that having another medical problem in the setting of MDS is actually relatively common. I mean, if you think about it, most of my patients are in their seventies, eighties, and have other medical conditions that are going on. And I've taken patients through major surgeries: cardiac bypass surgery, hip surgeries, gallbladder removals, and I've taken patients through treatment for other cancers while they also have MDS. So, while I think it is absolutely unusual to be pregnant and have MDS, it isn't unusual to have MDS and another major medical condition going on. And, we generally use similar approaches to this to take people through that.

So, I bet that MDS was not exactly what you were expecting your OB to tell you that you had or your hematologist to tell you that you had. What was your reaction to it?

Caitlin

I was diagnosed at about 18 weeks during my first pregnancy. And I was really concerned. I had to have an amniocentesis. It was very scary hearing your child could not be carried to term. It was very scary hearing that I could have cancer, I could have heart disease, I could have all of these things that my anemia and my chromosomal abnormality diagnosis led to. There was something to wrap my head around. There was something to go forward with. There was an understanding of the diagnosis to a degree. I was so grateful to carry my child to term. I had this beautiful daughter; she's amazing.

And then after that, I came to you, and I talked about having another child. And you were concerned. And we discussed the fact that it would be more challenging as I got older. So, time was of the essence. I decided to have another kid. And when I was pregnant with my son, things weren't as easy as the first pregnancy.

Talk to your doctor about a customized treatment plan

Treating MDS

Caitlin

I knew that you specialized in myelodysplastic syndromes. And I had certain form of it called 5Q minus syndrome, which I thought might have been separate, I thought was in the umbrella of MDS.

Dr. Sekeres

And what you have is a special subtype of myelodysplastic syndromes. It does tend to affect women. Some of the cells in the bone marrow can look distinct and are specific for people who have the 5Q minus syndrome or deletion 5Q or whatever we're calling it today or tomorrow. And what is really special about this is that there is a drug that's approved by the FDA (United States Food and Drug Administration) specifically for the treatment of people who have the deletion 5Q abnormality.

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Caitlin

But we couldn't use it during my pregnancy.

Dr. Sekeres

No, we couldn't. And, and the reason we couldn't is because the drug that specifically treats this is a derivative of an infamous drug called thalidomide, which causes birth defects. And for that reason, this drug can only be ordered through a special mechanism and is very carefully monitored by the FDA. So, we absolutely could not in a million years prescribe this drug while you were pregnant. But once you've delivered, once you're no longer pregnant, the drug is relatively safe to use.

Caitlin

My second pregnancy was very different. My anemia was much more extreme, and it was really important for me to feel like I had an action plan.

Dr. Sekeres

And we sort of anticipated that, but sort of didn't. Also, because your first pregnancy went incredibly well. And it's not as if any of us has a world of experience in treating somebody who has myelodysplastic syndromes and who's pregnant. Because as we said before, you were 30 or 40 years younger than a typical patient I see. But you did get pretty anemic. And not just anemic, but if I'm remembering right, symptomatic. You were, you didn't feel good.

Caitlin

Did not feel good. Couldn't get out of bed. Just walking around-- it wasn't normal pregnancy symptoms. It was clearly beyond that.

Dr. Sekeres

We came up with a plan. And the plan wasn't a complicated plan. It was giving you transfusions.

Caitlin

Super straightforward.

Dr. Sekeres

But someone hearing, "I'm going to receive transfusions," at least what my MDS patients have reflected back to me. That's sometimes a big deal.

Caitlin

Well, pregnant, very much so. I mean, it was a huge concern for me. I didn't know what someone else's blood in my body was going to do to a baby, what it was going to do to me, that was a big concern.

Dr. Sekeres

But it went well. And, and not only that, but you also would come back and say, "oh my gosh, I felt great after getting that transfusion."

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Caitlin

Completely. Felt so much better.

Dr. Sekeres

What's life like before getting a transfusion and then afterwards?

Caitlin

I mean, it really just completely changes your everyday energy. I mean, at first, I was concerned, the blood coming into my system, what's that going to do to myself, to my baby? But then it was more about, "How am I going to feel? How am I going to feel each day?" And it let me get up, bring my daughter on the school run. You know, just do the general stuff that you need to do as a parent to get through your day.

Dr. Sekeres

And I remember you saying when you were anemic that it was hard for you to do the things you wanted to do with your daughter.

Caitlin

That was the hardest thing. A hundred percent. I mean, I'm so active with my daughter and to not get to be the parent that I wanted to be to her every day because I was so – it's a different kind of lack of energy when you're anemic versus just being tired. I mean, every new parent understands being tired. Every parent understands being tired. But being anemic tired is a true loss of energy, it's not a lack of sleep. And so that was important to deal with. And also, not just give me the energy to be with my daughter but give me the energy to continue creating my son.

Dr. Sekeres

I really like what you just said about the difference between a lack of energy and a lack of sleep. Because I've had a lot of patients who say to me, "I'm anemic. I took a nap in the afternoon. I slept for two hours, woke up, and I didn't feel any more refreshed than when I laid down." It's different than lack of sleep. And I think that's how we finally together came up with the decision to, to go with blood transfusions.

Caitlin

Yeah. I think it was inevitable with my numbers and my energy level. And I mean, like we just discussed, it's not about being tired. It's about a complete depletion of energy. And so, the blood transfusions was the right way to go for me. And it worked.

I have so many questions

Living with MDS

Dr. Sekeres

So, as healthcare providers, I think we can always do a better job communicating with our patients and learning from our patients how we can communicate very complicated information in a way that's more digestible. What is it that you wish you had known when you were first diagnosed about myelodysplastic syndromes?

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Caitlin

I think when you hear the C word it's scary. It's, my life is over. I think that there's a lot of people who can live with conditions like mine that could use a little bit more information on to how that's possible.

Dr. Sekeres

It's hard when you have a limited amount of time with a doctor. You know, even to say you feel as if you're a confident person, but it's still hard for you. I think people really empathize with that. And then some concrete things that I've seen patients do is, do some reading beforehand. So, you come in educated. Write questions, come in with questions and say to the doctor, "Is it okay if I ask these questions?" Bring another person with you who can help out with that.

Caitlin

It's really scary when you're confronted with a diagnosis. You want to ask your doctor questions. You want to become familiarized with what your diagnosis is without going to school for it. I'm not going to be a doctor; I'm not going to be a medical professional who's going to understand this completely. But I want to have an understanding of what's going on with me, my life, how I can do the best in my set of circumstances.

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://www.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://www.lls.org/InformationSpecialists).