

Speakers:

Jayshree Shah, APN-C, RN, MSN, BSN, BS

Jayshree Shah: So, our group has gotten a bit smaller. So, this is quite informal again as a reminder and this slide deck is actually just developed in reference to... it was made for patients and caregivers as just a teaching reminder tool in regards to what else can you do if you are diagnosed with MDS and our... Sandy who developed this theme is *Building Blocks of Hope* is things that patients and caregivers can do on a daily basis to keep the hope alive in addition to living with MDS in conjunction. So, this is that whole Nurse Leadership Board that we have and it's all over the country and the world, actually, with nurses all over and we collaborate with each other about learning about MDS in different ways, attending different sessions via teleconference or conferences in general about MDS.

Individualized treatment which you guys heard from Dr. Gore, treatment triggers, individualized treatment selection. So again, in this room along with the other people that were here before every person's MDS is going to be different. Your husband's MDS, your MDS, (Attendee)'s, lovely lady in the back, everybody's MDS is not going to be the same. So, it does require individualized treatment plan to be developed and it's going to cater to that and that's what sometimes it makes a bit complicated because, again, your recipe for treatment will be different than hers and it just needs a little fine tuning in different ways and finding out how you can fine tune it is going to be important.

Key principles you guys already learned of transplant. Allogeneic transplant, not auto. Allogeneic transplant remains the only cure. Age alone should not exclude active therapies. All active therapies for MDS require time for it to work. You guys learned that this morning from Dr. Gore's presentation. Blood counts often get worse before they get better. So while patients are receiving the Vidaza treatment or Decitabine treatment, in the beginning they may require a lot of blood and platelet transfusions. Why? Because the bone marrow is still cleaning up. Bone marrow is where your red blood cells, white blood cells and your platelets are made. This is right here. That's where the bone marrow is and you also have a little bit of bone marrow in the sternum. So, sometimes people can take bone marrows from the hip over here. Sometimes they could take a bone marrow biopsy from the sternum. Those are the old school doctors. They don't do that no more. Proactive management of side effects in the early phases of treatment are really key to obtaining the best response and, again, that's why you guys are here today to learn about the different treatments and what to do, what are the different options, what's in the pipeline.

And this is just a nice kind of slide, an overview about what happens to the bone marrow. So, blood counts are dropping as MDS develops and it crowds out the normal cells. So, once you start a therapy it cleans it out and it starts to recover, but it takes time for it to recover. So, early toxicities may be difficult or discouraging for the patient. That's why you as caregivers, mom, dad, wife, family member, whoever spouses, you guys are really key players because they help patients to get through because we need cheerleaders. We need people to help to have patients get through because it's not easy in the beginning. Again, time for response. It may be anywhere from four to six months, sometimes longer. Cytopenias, again, as I mentioned get worse before they get better. Supportive care, supportive care, supportive care whether it be transfusion support, whether it be making

chamomile tea every day. Whether it be getting a massage every other day, who knows. Something of that sort to help them through to get through treatments. Setting expectations is very important. Knowing what the recipe is is going to be important.

So, we already saw this. I'm going to fast forward to this about seeing different response. Dr. Gore already presented his case studies in regards to his patients and his responses. I like this slide for you guys to know as a reminder what can I do to stay healthy? Balanced diet, daily activity, exercising. Keep moving. I can't encourage you enough. Keep moving. Yes, your hemoglobin's eight, yes I feel tired. Keep moving as much as possible. Avoid infection. Don't stay in a bubble. Don't stay home. Go out, just be cautious. Just use common sense. If people are sick around you, carry Purell. Don't be in crowds. Continue enjoying the things you love and you live. If you enjoy spending time with your dog and going for dog walks with other people in your neighborhood go do that. Get enough rest. If those naps you take in the middle of the day is what gets you through, so be it. Take that hour nap. Hopefully, you feel refreshed to keep you going for another six – eight hours then that's what you do. Take advantage of available resources. That's why you guys are here today. You got MDS Foundation as number one resource right here. Explore the *Building Blocks of Hope*. That's why you have the lovely booklets to go through. It's great reading because it breaks it down for you and understanding and having you understand about MDS and what it's about.

Q1: (inaudible 6:37)

Jayshree Shah: Yes. Yup. Ask for help when needed. You may have made a friend or two here today and you may have contacted each other or say when are you going to be coming to the next forum or when is the next meeting or who do you see? Who do I see? It's just about interrelationships and seeing what you could do to help you understand. Be an active participant in building hope. We're not giving up. We want to keep fighting, but we need your help. Help meaning for you guys to spread the word about MDS. It's not like breast cancer or breast cancer has a whole month. We do, too. Breast Cancer... October is dedicated to breast cancer. Everything pink and anything else is just outside. That's not to say MDS doesn't exist.

Q2: (inaudible 7:35)

Jayshree Shah: That's very true, ma'am and you are very correct because it's new. It's new. Breast cancer has been around for God knows how long, ages. MDS is new. We knew it as preleukemia and they now categorized it as MDS. So, it's still in the formation and it's rolling out. You guys have heard of Robin Roberts.

Q3: Yes. She had (inaudible 8:00).

Jayshree Shah: She had this and she may not be an outspoken person per se, but she speaks about breast cancer that she had it and then developed MDS as a secondary cancer. So, she does speak every now and then about it and how she went through the transplant. Her book tells us a lot about it, her experience and stuff. So, we need some spokesperson like Robin Roberts to speak on it to spread the wealth... spread the word. So, be nice to hear more from her hopefully about it. Become a partner

in your care. Building your MDS plan. Again, your plan is going to be different than hers. Every person's plan is going to be individualized.

Number one, you have to understand the disease. What is your MDS? What kind do you have? What score do you have? Do you have DNA typing done already? What are your EPO levels? What is your baseline hemoglobin, white blood cell and platelets before you got sick? Were you getting routine checkups? Maybe you can compare to understand your disease and how many other people are in the same boat as you? Do you guys have a patient forum in the nearby community? Are there support groups? All of those questions can come about to develop a plan. Possible side effects if you were to start treatment. So, he may be on Vidaza and she may be on Dacogen. What are the side effects? How do we manage those kinds of things? Ask questions because if you don't ask questions you won't know and you may be left with unknown and sometimes the unknown is the scariest thing to go with. Consider lifestyle change. Again, this is hard to go through for an MDS patient and caregivers and how to adjust because you may be used to running a marathon and now you can only run a 5K. So, your lifestyle may need to change and adjust to what it is now which is okay. It just may take some time. Transportation, a big thing, a big concern. Living in New York City area we were just talking at our lunch table. It takes so long to get one point, A to B nowadays. So, a simple thing like having help, a friend or somebody to take you or once in a while to take the burden away. That might be beneficial. Again, ask for your help. Become a partner in your MDS journey and build your own MDS plan.

This is a nice reminder. In the binder there's a tab five, it's called My MDS Plan and, again, it's just a reminder to kind of use that as guide to set to track your monitoring tools, your labs and your visits and what happened in those visits just to keep a diary of some kind and we have MDS patient outreach and advocacy programs available. Again, you have Audrey at MDS Foundation to reach out to and she can be a liaison, the middle party, to helping you through.

And now let's talk about you. It's time to take over and again, this is an open forum. So, you guys, again, if you have any questions from the morning talk or anything else, feel free to ask. Again, every MDS patient that's here right now you guys have started at a different time potentially. (Attendee) has had it for many years now. (Attendee) has had it for many years as well. (Attendee) is new. Forgot your name.

Q4: (Attendee)

Jayshree Shah: (Attendee) is new. So, everybody's journey is different points, but we're all here for the same reason. It's to keep the hope and build your own journey along the way.

Q5: Just a quick... How often can you have a blood transfusion?

Jayshree Shah: So, the question was how often can you have a blood transfusion? Now, it depends on, again, what type of MDS you have. How do you feel? Your hemoglobin of eight as Dr. Gore mentioned earlier may be different than what I may feel at eight because I may have different issues along with eight. So, comorbidities. Do you have diabetes? Do you have high blood pressure? Do

you have kidney issues? Heart issues? If you have all of those things combined, you may need a level of 10 or above for you to feel better.

Q5: Are you talking 10 units or 10 transfusions.

Jayshree Shah: The number 10 is your hemoglobin, not 10 units of blood. Normally, we give about two units as tops for patients with MDS on a daily basis. Daily basis meaning usually once a week, two units. We try to cap it off. We don't try to do more than that because the body takes time for it to hold onto and help you with your symptoms. Now again, things may change if there's a trauma or something like that where in the OR they may be transfusing 10 units at a time depending on the situation.

Q6: ... a question about IVIG because obviously because mine is my platelets. That's what they keep going to and I'm kind of resisting. I don't want to do it only because of things that I've read on the Internet. I don't know anybody personally who's got an IVIG.

Jayshree Shah: Her question was how does IVIG relate to her as far as patient and what does it mean to receive it? What does it mean? What is it exactly? IVIG is immunoglobulin therapy. So, it actually boosts the immune system. Patients who have a diagnosis of low platelets call ITP. I don't know if you guys have heard of that term. It's called idiopathic thrombocytopenia purpura. Fancy word.

Q6: What was the (inaudible 14:53)?

Jayshree Shah: Purpura which is a black and blue, purple. Back in the day... and they broke it down to a synonym of ITP. Patients who develop ITP for many different reasons in different ways. It's an autoimmune component. So, what they're trying to say is that possibly patients who have an autoimmune component they may benefit from receiving IVIG therapy which is the immunoglobulin. It's given as an intravenous for over a couple hours. They monitor you. It's not a blood product, but it's considered as a blood product because patients can have really strong reactions with anaphylaxis is as a possibility. So, you want to be tested to make sure you tolerate the dosing appropriately and they escalate the dosing as well as the rate that patients get. We give lots of premedication before. In addition to that, some patients may benefit from a little touch of steroids with it to stimulate the bone marrow to turn it up. So, they're hoping that giving that immunoglobulin therapy and the half-life for immunoglobulin therapy just FYI is three weeks, but it's different for an ITP patient versus patients who don't have it. So, there's a whole component to it.

Q6: (inaudible 16:17)

Jayshree Shah: Half-life in how it excretes out of your system for it to stay in your system like a Z-Pak, Zithromax antibiotic. When you take it for five days you're thinking oh, it's good for five days. Well, guess what? The half-life for Z-Pack is 10 days. So, that's why it stays in your system for longer for it to stay and help you with your respiratory infection if you were to get one. Your type of MDS is very specific to a different kind than the ones that we presented today. That's not to say you

don't have some part of it. It's just a separate niche and your design of your treatment plan will include possibly having IVIG therapy to stimulate your immune system to turn up to make the platelets. Similar to like Procrit or Aranesp like him. That makes sense? Right. Okay.

Anybody else? Any comments? Anything that I can share or MDS Foundation can share with you? If you do, Deborah and Sue and myself, we're available. I do this as a volunteer because I love teaching and I love sharing experiences and I get to learn actually. So, I learned something from her today that there is a person out here with an MDS that has developed it and she's trying to find her own recipe to cure it. So, good luck to you and to everybody else.

Q7: Do shots only work for certain type of MDS?

Jayshree Shah: Do shots only work for certain type of MDS? Are you referring to which one? The Procrit and the Aranesp? Okay. The erythropoietin. So, erythropoietin is either the drugs are called Procrit, Epogen.

Q7: (inaudible 18:21)

Jayshree Shah: They are injections. They're subcutaneous.

Q7: (inaudible 18:29)

Jayshree Shah: No. Erythropoietin injections, Procrit and Aranesp. A-R-A...

Q7: Oh, A-R-A. Those are injections?

Jayshree Shah: They are injections. They're subcutaneous injections. The IV that Dr. Gore was speaking about treatment is Azacitidine, Vidaza. That's the other name for it. The DNA methylating agents.

Q7: Is that a... That's a shot also.

Jayshree Shah: That was studied as subcutaneous injection. That's a treatment. The Procrit and the Aranesp those are supportive care treatments. They are treatments. Yes. They're given in a different way. That's all.

Q8: The supportive treatments are not meant to cure you. They're meant to make your life... quality of life better.

Jayshree Shah: Right and for you to (inaudible 19:32)

Q8: And the other thing is I'm a little surprised that you haven't given commercials for the MDS Foundation and the webinars that are out there.



Jayshree Shah: You are so right, (Attendee). He was suggesting about offering MDS Foundation commercials, but it takes dollars, lots of dollars to do that and MDS Foundation is a small little entity. Not to say it's not big enough for to support you guys, but we need lots of dollars, millions of dollars in support similar to breast cancer awareness for it to be huge like that, but you know what? You never know. We may get a benefactor who'd be willing to support and donate and make it big. You're welcome. Good luck to you. Well guys, thank you for your time. I hope you get home safe and enjoy the rest of your weekend.