

Speakers:

Jane Liesveld, MD

Emily Knight, RN, BSN, OCN

Emily Knight: I think it would be helpful if we just looked through the Quick Tips part of the binder. If you have your binder and want to turn to that. It's the third tab in. It goes through some of the symptoms and things that while you're living with MDS you may at some point or may have already experienced. So, we'll give you some helpful tips on how to manage and live with these different symptoms. So, the first one is anemia in MDS. It's decreased or low hemoglobin. So, patients with MDS may have anemia and there's varying degrees as you can see. Mild anemia is the hemoglobin between 9.5 and 13 and then there's moderate, 8 to 9.5 and then severe anemia with a hemoglobin less than 8. So, patients with MDS often require transfusions and may need red blood cell support and that's how some people are diagnosed. They have symptoms of fatigue, shortness of breath. They go to their doctor and the CBC shows a low red blood cell or low hemoglobin and one of the treatments of MDS, low risk MDS, is the Procrit or Aranesp injection. I think you mentioned you get Aranesp every couple weeks to try to help with your anemia. So, things you can do. Just be aware. A lot of patients who have anemia know when their blood counts get low. They feel more tired, more short of breath. So, know the symptoms. Keep your appointments. Go to your lab appointments and then keep track of your blood counts. In here we give you the forms to keep track of them and watch the trends. Balance periods of activity with rest and important ask your friends and family for help. When your blood counts are low, you're not going to have a lot of energy and you're going to need help from people. The next one is Neutropenia and that's low white blood cells or low neutrophil count. So, that's the white cell line and then there's again severity. There is mild neutropenia which is an absolute neutrophil count between 1,000 and 1,500, moderate which is a neutrophil count of 500 to 1,000 and then severe neutropenia is less than 500. So, this is part of the white cells. So if you look at your CBC, your lab reports, it's under differential. So, that's how you find the ANC, your absolute neutrophil count, and symptoms of neutropenia that are important and to be aware of is a fever. Because you don't have the white cells to protect your body from infection, you're going to be at risk of infection. So, you need to let your doctor know if you have any temperatures, chills and they may place you on antibiotics if that neutrophil count gets too low.

Q1: Can I ask something?

Emily Knight: Yes.

Q1: Almost since from day one when I was diagnosed, the (inaudible 3:41) part of it (inaudible 3:43).

Emily Knight: Fatigue.

Q1: I'm not fatigued. I was up all night. Still up. What's the opposite of that? An anxiety? I don't know what to do with it. Is that part of MDS? It doesn't say it anywhere.

Emily Knight: Well, yeah. I mean... symptoms of anxiety, fatigue. Everyone's different and copes differently. So, did you have problems...?

Q1: I'm a night owl and I've never really feel tired. Last night I wanted to get up early this morning so we can get here on time. The whole thing hadn't changed. Well, I couldn't sleep at all.

Emily Knight: Sure. Sure. Is it because you constantly thinking about things?

Q1: I don't know. I just could not relax. My eyes are wide open.

Emily Knight: Now, I would say most people have the opposite problem where they're fatigued, but it definitely it could be (inaudible 4:43)

Q1: Do you think it's part of the MDS?

Emily Knight: I think it's probably more how you're coping. It's probably from thinking about the MDS and more anxiety.

Q1: That's what I thought. We've been going through a lot (inaudible 5:08).

Q2: I think anytime you want to go to bed and go right to sleep because you're going to get up early, you don't. Now, we can ask your husband. Has she always been a night owl?

Q3: Even before she was diagnosed.

Emily Knight: So, the other thing I'll say about neutropenia because I heard someone talking about it, neutropenic diet. At our clinic we don't really push a neutropenic diet. We tell our patients to eat at home if you can. If you're eating out, make sure it's a clean restaurant, a nice restaurant. If you're eating fruits and vegetables wash them before you eat them. If it can be peeled, peel it. Cook your meats thoroughly. Don't eat raw meat, raw sushi. So, that's kind of what we say regarding the neutropenia diet.

Q3: We've heard that exactly as you just put it.

Emily Knight: And then thrombocytopenia or low platelets. With thrombocytopenia there's a risk for bleeding. So, a mild thrombocytopenia is a platelet count of 50,- to 100,000, moderate would be 25,- to 50,000 and then severe thrombocytopenia is a platelet count less than 25,000. Generally at our clinic, we don't transfuse platelets unless there's 10 or below or a person's

bleeding because platelets don't... When you get transfused platelets the lifespan isn't very long. So, you'll every week some patients need them a couple times a week. It just depends on...

Q4: That's not the one that causes the iron problems, is it?

Emily Knight: No. That's the red blood cells. So, a couple of things you could do. Let your doctor or let your nurse know if you have any unusual bleeding or bruising. Again, keep your appointments. Keep track of your labs. Avoid injuries. So if your blood counts are low, stay away from heavy lifting, any contact sports. Use a soft toothbrush. Sometimes we tell people like a pediatric baby toothbrush. Avoid flossing. Avoid constipation or straining with bowel movements and the next page over is fever and that goes right along with the neutropenia or the low neutrophils. So again, just be aware of the symptoms. Fevers, chills. Let your doctor's office, your nurse know because you may need antibiotics.

Q5: Emily, for a second. Does anyone want anything else?

Q6: The food, it was very good.

Q7: (inaudible 8:26) tell however it was delicious.

Q5: Oh, thank you.

(Inaudible chat 8:30 – 8:39)

Q5: There's an evaluation form in the back of your notebook. It's big though. No, in the front. I'm sorry. It's in the front. If you get a chance to fill this out and send it back, I'm going to send it to you online anyway, so you can fill it out online or you can do this card (inaudible 9:03), but it's real lengthy.

Emily Knight: So, the next tab over then is tracking your blood counts. The CBC, the complete blood count. The forms were included here in the My MDS Plan. So, it's a good idea to keep track and watch the trends on how your blood counts are doing. The next couple pages are diarrhea, constipation and nausea and vomiting. Basically, these are... would be the same as if you didn't have MDS on how we treat them not necessarily specific to MDS. Diarrhea, you're just going to want to stay hydrated. Keep track of how much free stools or diarrhea you're having. Let your physician know and then for constipation, again with the low platelets, you're going to want to be careful with that and get on a bowel regimen, stool softeners and such. Now, with nausea and vomiting this could be treatment related if you're on a treatment for your MDS. Some patients have problems with nausea and vomiting. There are oral anti (inaudible 10:32) nausea medicines available and also it may just be adjusting your diet. And then injection site reactions. A lot of the treatment for MDS are subcutaneous injections. The Procrit, Aranesp are subcutaneous. The Vidaza, do you get it through a shot. It's subcutaneous or intravenous. So,

you may notice a little bit of redness, irritation with those injections, but it should be pretty mild site reaction. So if there's anything more severe, definitely you're going to want to point that out to your physician. And then skin rashes are not really specific to MDS, but I guess one thing I will point out if you don't... the one treatment for a specific MDS is Lenalidomide or Revlimid, that oral medication can cause skin rashes and that's treated a specific deletion 5Q MDS is what that treatment is for and then the next page over is fatigue which seems to be a common symptom or a common problem that a lot of patients have with MDS and it's varying degrees of fatigue where maybe mild fatigue to severe fatigue where you really don't even feel like getting out of bed and that can be associated with the blood counts. As the blood counts are lower the fatigue is generally worse. So, it's important to stay as active as you can, maintain your muscle strength and stamina, try to get into a routine such as daily walks or whatever kind of activity you enjoy doing. Limit the naps during the day so that you can get a good night sleep at night. Small frequent meals, stay hydrated. All of those things help with fatigue. And then with the diagnosis of MDS, you can have feelings of anxiety, depression. It's just important we talk about support groups to have someone you can talk to whether it be family, a friend, a doctor, just to be able to reach out to someone and have that support there because it's a lot to take on yourself and then when should you call your healthcare provider. Fevers, chills, shortness of breath, chest pain, any skin changes, bruising, bleeding, headaches, changing in your vision. Any changes in your bowel function or uncontrolled nausea or vomiting are all... it's important to keep your doctor aware on any symptoms you may be having. So, these are just some of the quick tips, helpful tips, on how to manage some of the side effects that you might have because of the MDS. I don't know if anyone has any questions or comments on any of those, anything you've experienced or any tips you found helpful? The other part of the topic was quality of life. In MDS if you're on treatment or even if you're not treatment, MDS impacts your day to day living. If you have fatigue, you might not be able to enjoy the things you used to enjoy doing. If you're on treatment that might interfere with work or what you would normally do. So again, it's crucial and important that you have that support system to help you through and be there for you.

Q8: Is there a time like... you said two to three years, is there a time of things that I'm sure you had on the board when things start going the other way? Just looking and seeing...?

Jane Liesveld, MD?: Yeah. There's so much variability, it's hard to say. I (inaudible 15:35) people who've been stable for a decade or more and have really saw them differently during that time. It has to do so much with the just the course of the disease itself, how the blood counts are doing. It's over 10 years and we all age and start feeling fatigued from that.

Q9: The subject they do or can't do?

Jane Liesveld, MD?: No. I think the things she suggested in terms of just maintaining your general health is really the best thing to do.



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Emily Knight: So, we don't really have any specific agenda for the rest of the afternoon. If anyone has any further questions or anything, (inaudible 16:18) information. I'd be happy to get that for you. It's all the information we have for you today.

(General chat 16:40 – 22:14)

Q10: ... have a test or something. Would you get in touch with people or would you not do that?

Jane Liesveld, MD?: The MDS Foundation has a list of available clinical trials that include not only multisite trials, but those are open in individual centers. For example, I don't have one right now but three years ago we had a trial open here. We had published it on the MDS Foundation website. So, I'm not sure everything gets there, but it's a good source for a starting point and also if you go to... We're all required now by the government when we do clinical trials to register them at a site that's called clinicaltrials.gov. So if you're ever looking for a trial that's open at a geographic area or at a specific center, that's a good source of information. Thank you all.

(General chat 23:05 – 23:21)