

Speakers:

Roger M. Lyons, MD, FACP
Virginia E. Aguilar, NP

Virginia E. Aguilar, NP: So, I'm Ginny Aguilar. I'm a nurse practitioner with Texas Oncology. I recently joined the practice, so bear with me. You all have been living with this disease a lot longer than I've known about this disease. Not really, but sort of. So, if I get anything wrong feel free to correct me. Okay? Because you're living this. Okay? So, and not only that. I'm substituting for the person who came up with this whole presentation and everything else. So, I am not Sandy Curtain. I'm Ginny Aguilar. Okay?

Q1: She, by the way, is working with Dr. List (inaudible 0:42)

Virginia E. Aguilar, NP: Dr. who?

Q1: List.

Virginia E. Aguilar, NP: Yes.

Q2: Alan List from Moffett.

Virginia E. Aguilar, NP: Okay. Alright. Kay. Wait a second. This isn't the slide show I had. It looks like the first slide, but after that it doesn't look right, but we can go with it because it's pretty quick. Okay.

So, when to start treatment? So, that was one of the questions I heard and most of you all are probably under treatment, but that's a decision between you, your physician and based on your risk factors and Dr. Lyons when through all those risk factors. I read them. The first time I read them I went, "Oh, my gosh. How do you even differentiate which one you'd start and which one you won't?" It's pretty complex. It used to be five categories. Now, there's seven and then there's some unknowns. So, that's where you and your doctor talk. There's a lot of things that go into that. You've got your risk disease. You've got... of course it includes the blasts, how bad your anemia, cytopenias are, what your risk is, but then you've got are you fit enough to do some of these treatments? They're toxic. Are you... do you have other comorbidities, a kidney disease or whatever that would preclude you from having some of these treatment? What are your personal preferences? What I want and what you want are completely different. So, you have to take that into account. Everybody's different. This is a choice... This is a discussion that you have to have with your oncologist because then they can present you all the options and you can make a decision together that way you're a partner in your treatment.

Of course, he already talked about the transplant is the only potential cure and we have a transplant person here and he told you his story. So, it is a potential cure. It is not always a cure and the side effects can be horrific. Luckily, he didn't have severe side effects until he relapsed, but they can be very horrific. Age, again, does not preclude you from anything. It is performance status. At one of the clinics I go to there's a 98 year old getting treatment. He's doing fine. So, that is... he's great. His performance status is phenomenal.

We talked about the cycles. They take time to work. How long is a cycle? I have patients ask me that every single time I do chemo teaching. A cycle, one cycle is 28 days. Yes, we treat you for the five days or how many days you and your oncologist decide, but the whole cycle length is 28 days. That's a month. So, for you to get a full effect or start seeing if there's effect you're looking at four to six months. I'm thinking oh, a cycle, a couple of weeks. Oh, I got my five injections. I'm done. That's a cycle. No. It's the 28 days. So, you got to be realistic about what your expectations are of how quick you're going to get better. And that's another discussion with either the nurse practitioner or the oncologist. So, then you know we're attacking the marrow, you know we're going to kill all the bad cells and probably kill the good cells, too, because we're killing rapidly dividing cells. So, you're actually going to probably get a little bit worse before you get better and that's an expectations you need to have. You need to realize we're going to be supporting you with transfusions, injections, whatever we need to do to keep you strong through the worst part so that then you get better. So, you need to be realistic in expectations.

So, before the treatment starts your blood counts are getting low because all the bad cells are crowding out the good cells. A nice pretty picture. I can see the colors.

(Laughing)

(Inaudible comment)

So, then we start killing... I'm not sure how to use this pointer thing. Oh, well. So, then we start killing everything and we're leaving a little bit of residual. We've killed all the bad stuff or stripped the slime off so to speak, but we've dropped your counts tremendously. You're going to be neutropenic. You're going to be anemic. You're going to be thrombocytopenic. You have low white count, low blood cells and low platelets. We're going to support you. We're going to make sure we're going to watch you like a hawk that every couple of days, every week coming in for the blood draws. I know that's a pain and then those copays it's a pain, but it's really important that we make sure that you're going to make it through this treatment because you can get really sick really quick. You have no immune system and then slowly they start recovering and then we know the treatment's working good and that's the four to six months and then hopefully we keep you at a good response for however long and then maybe you're not transfusion dependent which is our goal. It's very discouraging. You're coming in all the time. You feel like you live at our place and we're sticking needles in you every time we see you. Sometimes when we don't see you we're sticking needles in you and we're putting stuff in you. We're transfusing, sending

you to the hospital, but that's so that we can get you through this part. It's supportive care. It's not a lot of fun.

Yes, sir?

Q1: There's a good story I like to tell before I get my transplant and they were doing the work up and all that. I walked in here one day and (inaudible) had his... you know, they got the table where you put your arm to give blood. He had 27 different empty vials waiting for me. I said, "Do, I have that much blood in me?"

Virginia E. Aguilar, NP: Wow.

Q1: He said, "Oh, yeah. You got that and more. Don't worry about it."

Virginia E. Aguilar, NP: Wow.

Q1: I took a look at (inaudible 6:01) and said, "Oh, this is going to be interesting."

Virginia E. Aguilar, NP: We always draw two or three.

Q1: No, this was 27. I counted them.

Q2: That's a good number.

Virginia E. Aguilar, NP: Twenty-seven?

Q1: I like that.

Virginia E. Aguilar, NP: Yeah. I bet you do. I try to minimize it. If you come see me and you've already been stuck and I need more blood I'm going to try to take it out of a port of you have one. I'm pretty good at begging.

So, we've talked about this. Time is required. The reason why is you need four to six cycles, one cycle is a month, for to six months. They get worse before they get better. That is the nature of the beast. That's how we're treating you. Another reason you have to come in is to make sure that the toxicities, the neuropathies, any issues you're having are tolerable because we're doing this so you can live. It's not curable, but we want you to live and if you're not living because you're suffering because of what we're doing to you that's no good either. So, all of this is so that you can live. So, if we need to make dose modifications so that your quality of life is better that's important. That's a discussion you have to have with your oncologist. Gritting your teeth and pushing through it you could end up with permanent disabilities. You don't want that because we're doing this, again, so that you can have a life.

So, this is a really busy slide, but it's actually pretty good. It shows the hemoglobin which is the pink; the yellow, the platelet count and then the white count and how they dip down and around cycle four – cycle five they start crawling back up. That's pretty consistent. This is from a study back in 2012. This is pretty consistent for what we see and it's with the as Azacitidine that Dr. Lyons was talking about and then here's a response with 10 years of Lenalidomide. I can't talk. Dry tongue. But you can... Ten years. So, these responses can last for a long time. That longevity is individually based. I worked at Parkland for five years and I had a patient that was oncology patient and the doctor went in there and told him, it was a first year resident said, "You have 11 days to live." Now, I don't know where he got the 11 days but I was the oncology team and I didn't know where he got the 11 days. So, I went in there. You know when that patient died? Eleven days later. Why is that? Because he had in his mind that that doctor knew what he was talking about. He was a first year. He didn't know anything and so he just let himself go. He died. So, don't... I mean, you can look at these numbers. They're expectations, but every person is different. You're the one living this, not us. So, you keep that in mind and when you look at those graphs. We also have one of the older oncologists I worked with the patient would say, "How long do I have, doc? How long do I have?" and he'd go, "I don't know. That's between you and your god. I don't know," and that's exactly how it should be. I never look at how long people are going to think they're going to live.

What can you do to make everything through this process, this four to six months, better? Balanced diet. I know nobody does that, but at least eat. Don't lose weight. Exercise. It is so hard when you feel bad to get out there and just do a little brisk walk or whatever, but you feel so much better after and it's so good for your body and especially if you're wanting to do a transplant you got to be active. Avoid infection. Hand washing, hand washing, hand washing. I know you all heard it. I have to do chemo teachings every day and that is the one thing I emphasize. Avoid, obviously, sick people. Hand wash. Does that mean walking around with a mask on? Not unless your doctor tells you to and I'm not going to tell you to. I want you to live. If you start noticing blood on your toothbrush, we probably need to check your platelet count. Yeah, you were there yesterday. We still need to check. Enjoy. Live. This is your life not your prison. This is your life. Try to get enough sleep. It's hard to sleep. I'm having issues with sleeping and I have nothing wrong with me. I can't imagine if I had to worry about a disease. We want you to sleep. So, whatever we can do to help you with that we want to do that.

This Building Blocks of Hope. I'm going to, hopefully, have enough time to show you a clip from that, but that is one of the best websites I've had the privilege of looking at. It is so well designed. They will send... It's got all kinds of resources on there. If you're not computer literate or you like printed material they'll mail it to you. You can call them and they'll mail it to you. They have all kinds of tools, all kinds of information. It changes every day. They update it. It is a phenomenal website and I suspect the book is every bit as phenomenal and the ladies that are hosting this they're the ones that put all this together. It is phenomenal. I bet every one of you all somebody says can I help you do anything? No, no, I got this. I got this. Ask for help. Cleaning

your house is not hard. Anybody can do it. Maybe not to your standards, but they can do it. People like to help people. People like to cook for you if they can cook and they'll bring you something if they can't. If you're just not feeling good and you have a family member or a friend that says what can I do to help? Ask. Do you mind cooking me dinner tomorrow night? Do you mind taking me for a steak dinner? I mean, just ask for help. Don't be afraid to. There's actually on this Building Blocks of Hope, I believe, there's a calendar that one of your friends can fill out and they can put like when you need help like somebody come in mow your yard, somebody come make you dinner and they can just volunteer for different things based on what your needs are. We can't all do this alone. That's why it's caregivers and patients with MDS, this lecture.

My MDS Manager. That's on that website, too. It's that book and I see a couple of people have them. It gives you a spot to... you read the book, the pamphlet and then it gives you things so that you can determine what your diagnosis is and what the treatments are, what's changing, the new information. They also have it I looked up on my phone there's an app for this. I don't know how many of you all like apps, I don't, but there's an app you can fill all this information in and put your contacts, your physician numbers, your data, everything in there and then it's all at your fingertips if you happen to like phone apps. There's also a place to handwrite it in these books. The website's phenomenal. I mean, almost everybody has a computer. You can get on it on your phone, but it tells you your risk, it helps you understand, any questions you have, you can E-mail them, they have a phone number you can call for help. It tells you different treatment options that are on the horizon. I'm sure they update it all the time because it said that they did and then it helps you with other things. It makes it so that you are the captain of your ship. You own the ship and you've got your physician as your co-captain, but you are running this ship. This is your life. This isn't our life. This is yours. You're the partner here. So, anytime you think that you're not the boss at the doctor's appointment, you are. You're the boss. You're your partner. You're employing them. We don't have a job if you all don't come to it. It helps you track your progress.

I think it's really a good idea if you can to have somebody go with you to the appointment because I know when I got to my physicians' appointments, I don't hear half of what they say and I probably understand their lingo. Probably is the operative word. Sometimes you don't understand what they're saying or you just only get part of it. I can't tell you how many times I've done a teaching and then the patient will come back and ask me some of the stuff that we just went through because they just... they only can absorb so much and that's true of human nature. So, take somebody with you then you hear two different things or somebody can take notes while you're there. I think that's great. Anytime you go to your doctors' appointments, I don't know how many of you understand your labs or ask for a copy of your labs. We will explain them to you. These are your labs. You should ask for a copy. If you want a copy and put it in that little... in your book or whatever and then you can see what your trends are and I'll explain, anybody will explain what everything we're looking at and what they mean and what we're going to do about them if they're low. That's how we work and as you track your progress you can make extra copies or whatever, let your family member see it. The app, I think, you can

get your family to sign in on, but this gives you an idea of where you are and then that four and six months of treatment before you actually start responding, assuming you're going to respond, but if you start responding you can see that oh, wow, my counts are a little higher this time it's not so discouraging. Four to six months sounds easy to me because I'm not having to go through it. It's not so easy.

This is the app I talked about. I got in there. It's a good app if you like apps, but it has everything in there, your symptom tracker, everything, how to manage your appointment. It's good with Apple phones and the Androids and it's free and it's an easy download. It didn't take long at all. I did it without Wi-Fi and it was up in no problem. I didn't really go into the Google account for saving data. I save everything on my phone or on my computer and I like to write stuff down. So, I mean, there's a lot of potential for more versatile usage of your computer, but I'd have to be that guy in the back to do all that. I can barely open my E-mail.

The MDS Foundation, this Building Blocks of Hope, I'm going to try to run that video if we have a moment, but it is really, really excellent and that's her E-mail. She is actually that one that was... well, she's over here, but the ladies, this whole group, the lady that came up with these slides it's like five members of this group and they call you and they E-mail you back. They're phenomenal and the website they created is just... it's really good.

I went through that in a lickety split. Let's talk about you. Questions. No questions? Yes, sir?

Q3: I have something that I never seen written down but I can't emphasize it too much. Positive attitude. The first time I was diagnosed with MDS I looked at the doctor in the eye and I said, "It's me against that disease and I'm going to win," and that's been my attitude every day since and sometimes you go backwards a while. You bang your head. I'm going to wish... Maybe if you're not going to beat me, I'm going to beat you and I've actually had a couple doctors say, "You have no idea what effect that has, but it's all good."

Virginia E. Aguilar, NP: It does and that's why we never told people when they were expected to die because I don't know. Your individual attitude plays a tremendous amount, your will to live.

Q3: Well that and I found out that everybody's different.

Virginia E. Aguilar, NP: Everybody's different.

Q3: The way they react to things, side effects, it's all different.

Virginia E. Aguilar, NP: It's 100 percent different.

Q3: (inaudible 17:40) that you had.

Virginia E. Aguilar, NP: Right.

Q3: It's probably not going to work that (inaudible 17:43)

Virginia E. Aguilar, NP: And we were talking about how complex the diagnosis is. There's seven categories and then there's subcategories on top of that. I mean, it's going to take a hematologist to figure out what you actually have and your risk factors. Yes, ma'am.

Q4: Well, on that note about positive attitude. Surround yourself with people that have positive attitude. I have been going from doctor to doctor because I was sick and getting infections and then I went to his office and I was a mess and the first thing he said to me, "I've seen worse."

(Laughter)

Virginia E. Aguilar, NP: See, that's good.

Q4: And that was the first time... I thought, oh, okay.

Virginia E. Aguilar, NP: I have (inaudible 18:29) here.

Q4: Yeah.

Virginia E. Aguilar, NP: Yeah. Exactly.

Q5: Well, I guess I'll do the politically incorrect version...

Virginia E. Aguilar, NP: You go right ahead.

Q5: (inaudible 18:83) of religion and, again, I don't care what anybody says prayer makes a difference. When you got 2,000 people from church praying for you it makes a difference. My doctor every time I say something to him he kind of looks at me like oh, okay. It's not the drugs then. It's... but it makes a difference. You got to pray that the drugs are going to do their job. We don't want to go on our own way with a too positive of an attitude and say, oh, I got to beat it without the drugs or anything. No, no, no. God put doctors here and medicine here for a reason.

Virginia E. Aguilar, NP: Right. Yes, sir.

Q5: Talked about positive attitude from people around you. I love my doctor at MD Anderson, the leukemia (inaudible 19:20) because he has never yet and I've seen him a bunch of times walked in and go over me, didn't have a smile on his face. How are you doing? And his attitude



San Antonio, TX Patient & Family Forum – November 18, 2017 - Session 2 Page 8 of 10

is is if what we're doing now quits working we're going to find something else. We're going to keep on going with this.

Virginia E. Aguilar, NP: Well, you heard is talk. There's a bazillion things... well, not maybe a bazillion, but a whole bunch on the horizon and it's all been developed in the last couple of years. So, doctors are really... and scientists are really making progress and that's awesome.

Q6: It makes a huge difference. One of his doctors before we went to Anderson we were... he was getting an infusion, his blood transfusions and he walks up and says, "We need to talk about sudden cardiac death." It wasn't hi, how are you today. It was oh, we do?

Q5: Well, that's not (inaudible 20:07). The hospital's require (inaudible)

Virginia E. Aguilar, NP: And part of my...

Q5: Have the form signed and somebody has to present it.

Q6: But we're so... and I say (inaudible 20:18) does happen to one person. It does happen to the family.

Virginia E. Aguilar, NP: Happens to the family and that's why this is for caregivers, too.

Q6: So, fragile about things like that.

Virginia E. Aguilar, NP: So, when I do the chemo teaching I have to talk about living wills and medical power of attorney. I talk about that to the family members. I have that. My dentist has a copy of mine because that's what they ask for. Every person in this room, every one of us should have one. The medical power of attorney is important because it's effective if you can't make your own decisions and then that tells all of us who's going to make your decisions. The living will is just because you've told your medical power of attorney wanted and you may have told your family what you wanted, but what about that family work that comes climbing out of the woodwork after 20 years hadn't seen you and they're making a big stink? I worked ICU for 13 years. I can tell you I've seen it. It's on paper what this person wanted and that also takes the onus off of the medical power of attorney because then they're second guessing is this really what they wanted. I know they told me, but is this really what I wanted? It's black and white. We know what you want. Now, the medical power of attorney can override it, but at least it's written out so that you don't have the family from 25 years ago show up at the bedside fighting about everything. That's the only reason and I tell everybody that. I have one. Everyone in this room should have one because...

Q6: But a living will, that doesn't control. Right? That just guides.

Virginia E. Aguilar, NP: Just guides. Exactly. It tells them what you want what your wishes are if you can't make your own decision.

Q6: You know, I don't disagree that it's a very good thing, but the thing is I have known people like minutes before their death or shortly before that they changed their minds that what they said they wanted was what they wanted.

Virginia E. Aguilar, NP: But if you are still alert and able to make your own decision nobody's going to make them for you. You can do that. That's 100 percent. That's why people say well, I'm not going to give up my will, my medical... I'm not going to give somebody power of attorney of me. They don't have power of attorney unless you can't make decisions. My mom is my medical power of attorney because my husband won't pull the plug. I don't want any of that and so she's my medical power because he won't do it and neither will my kids and that... I made that decision because I know what I want, but I mean... but my mom will pull that plug out.

(Laughing)

Virginia E. Aguilar, NP: But it's true and it's just because I know my husband. I know he loves me. He's not going to let me go. I don't know why, but anyway he won't let me go and so...

Q6: If you do that as guidance and maybe 10 years later when you're... and you maybe... maybe that's not what I want then you have to remember to change that.

Virginia E. Aguilar, NP: And that's the thing you can change it at your kitchen table with a nonrelative witness. You don't have to have it notarized, you don't have to go to a lawyer. It costs you nothing except for the paper to print it and if you come to the office I'll give it to you. So, that's absolutely not a problem.

Any other comments, questions? Yes, ma'am.

Q7: In your experience do people do better... do patients do better when they are educated about things or worse because they worry about...

Virginia E. Aguilar, NP: It depends on the patient. Again, everybody's an individual. Depends on the patient. One hundred percent.

Audrey Hassan: So, if Ginny is fine with this we're going to show a little clip.

Virginia E. Aguilar, NP: Yes, please. You'll want to see this.



San Antonio, TX Patient & Family Forum – November 18, 2017 - Session 2 Page 10 of 10

Audrey Hassan: And in the afternoon session, Ginny is actually going to lead a nurse led quality of life session. So, I think all your concerns will be taken care of at that point and I just wanted to recap briefly, but like Ginny said I know when I'm in a doctor's office sitting in that paper gown, sitting on a paper sheet I forget to ask questions. So, I just want to reiterate what Ginny said about bringing a caregiver with you or even when you leave the MDS Foundation, we're all here. Dr. Lyons is here as an expert for you all to get a second opinion, but when you get home and you forget to ask anything for sure, contact us and we're happy to help you afterwards.

Virginia E. Aguilar, NP: And the other thing is is how many of you have that annoying child that wants to know every detail, but they're not in the state? Put them on speakerphone. I'm that annoying child for my dad and my mom. Put me on speakerphone. If I can't get to the office I will listen to the conversation. If I have any questions I'll ask. Yeah. That's the whole purpose of it.

Audrey Hassan: So, I think that you can started, Sam, if you want to start the video that...