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Elizabeth Smith: It's on the fourth floor.

Q1: And how many rooms do you have...?

Elizabeth Smith: Twelve. We have twelve.

Q1: You do 12 transplants at a time.

Elizabeth Smith: Yes. Absolutely.

Q1: And those rooms they're not (inaudible 0:16)... They never can come...

Elizabeth Smith: Yes, they can.

Q1: Is there a special air system that you use?

Elizabeth Smith: Yes, they're all by guidelines for bone marrow transplant and you have all the supplies that you will need to have your family or friends come in. It's beautiful rooms. I wish that we would have been able to do a little tour today of the area. However, all our 12 rooms are occupied plus seven... plus five of our ICU rooms, but it's a gorgeous room and it has a beautiful couch that it turns into a bed for family members to stay and everything is... once a patient leaves, we bring everything down, curtains and everything and it's all put back for the new patient even stethoscope that they're in. It's only for that patient while they're there and it's all the system required to be able to ensure that the patient is safe.

Q1: How does work if the family is coming and going because I understand a family member staying for long periods of time like parking, how is someone is staying here...

Elizabeth Smith: We validate. We can validate the ticket.

Q1: (inaudible 1:31) here for me how does that work?

Elizabeth Smith: Well, either they could be drop off and have somebody or they could keep the car down there and then we just validate when they leave, but a lot of times what happens is they drop the family off and they stay here. Some people come from out of town, so they have a hotel and then sometimes they go back and forth, but we make any arrangements we have to do to ensure that the families are also well taken care of.

Question?

Q2: How many... if they get a transplant, how many days are they (inaudible 2:08)?

Elizabeth Smith: It depends on like Dr... We've had patients that been here for almost 120 days. It depends on the type of transplant and also depends on the patient. So, we've had patients here for a long time. You were here for 30 days?

Q3: How many transplants have you done at the hospital?

Elizabeth Smith: How many have we done so far? It's been over 200 that we've done. It's growing every year. Every year it grows more and more and our ratios for our patients are when they're not being transplanted, there's only one nurse for three patients and the day of that transplant is a one to one ratio and it could be lower, but no more than three at a time.

Q4: Once you're discharged from the hospital, you have still stay in the area for additional...?

Elizabeth Smith: I believe so. Yes, and then you... I believe so and then you...

Q4: Do you have combinations for that time?

Elizabeth Smith: Not in the hospital. That's a lot of people...

Q4: (inaudible 3:12) around...

Elizabeth Smith: We have hotels around the hospital that we could accommodate the patient. Yes.

Q5: (inaudible 3:24)

Elizabeth Smith: Over. Yes.

Q5: Over how much time?

Elizabeth Smith: Let's see. I came back... I was recruited back for this position back in 2003... 2013 because I was here before as a director of nursing. I left and then I was recruited back as

the Chief Nursing Officer and I believe the transplant was almost here a year before that. So, I think they started around 2012 and they've done a lot. I mean, it's over 200. So, that's good for a three year program and it's booming. I mean, we're booming every day like... I'm telling you, right now we're completely full upstairs and sometimes we even have to put patients on the second floor and we have rooms prepared for that, too, because we don't have enough space and then we transfer them as soon as we get a room.

Q6: (inaudible 4:19)

Elizabeth Smith: And our nurses... the nurses from our second floor cross train so that we have appropriate staffing everywhere.

Q7: That's the only place as far that does transplant?

Elizabeth Smith: No. Moffitt does transplant. Gainesville does transplant. So, there's other centers that do transplant in Florida.

Q8: Cleveland Clinic (inaudible 4:43).

Elizabeth Smith: Cleveland is getting ready. Memorial is getting ready.

Q8: Everybody (inaudible 4:48)

Elizabeth Smith: Everybody is getting ready. Yes. But not because I work here and I did most of my career at the medical center and I'm not saying it for that, but if I had to take anything for myself I would come here to take care of it. My husband had cancer 10 years ago and he was treated here and he is a survivor. So, I believe in the care that is provided here and I believe in the physicians that provide the care and the multidisciplinary team what is given. So, I speak not as an employee or a nurse that I've been working here for many years, but I'm speaking as the wife of a patient who had cancer. I wouldn't go anywhere else. That's my personal opinion.

Q9: As a patient who has been here, this is definitely a center of excellent services. The facilities are top notch. The nurses are excellent. I mean, they're like, "Are you in pain? Do you need anything for pain? What can we get you?" A warm blanket, whatever. They were on top. Even the... what's the next lower level nurses that...

Elizabeth Smith: The CNAs, the certified nursing assistants.

Q9: (inaudible 6:10) on top. Watch everybody who comes in, make sure you're wearing your mask, everything. I mean, you're exercising. They're really an excellent nursing (inaudible 6:22). This is a model hospital and I'm telling you because I've been to different hospitals.

Elizabeth Smith: Well, thank you.

Q9: (inaudible 6:30)

Elizabeth Smith: Thank you so much and our hospital right now is going through the Journey of Magnet. I don't know if you've heard about that. We're right now going through our magnet journey and hopefully if we have everything in place, we should get our certification for magnet. Magnet is a... it's done through the American Nurses Association. However, it's a recognition for excellence in nursing care, but it's not just for nursing. It's an award that is given for the entire hospital and it's very stringent and we have to meet a lot of criteria in order to even be granted. So, we're working that because I will always be a nurse first. Even though I'm the head of nursing, nursing has been my passion for 38 years and I believe what nursing stands for, I believe that we have to have excellent nursing care and we have to be the best because we are the advocates of every patient that comes in this institution and we need to be... provide very good care. So, I'm a firm believer of that. Any questions? I know we're going outside of topic. Go ahead.

Q10: For everybody that is contemplating a stem cell transplant or even thinking about it this is probably one of the finest places it could happen because the doctors and the staff. I lived it for a while. My husband is proof that it does work. Don't even think twice to come here.

Elizabeth Smith: Well, thank you.

Q10: You're welcome.

Elizabeth Smith: You just came for free lunch. That's always good. Anything else? Is the other speaker here? Okay. Well, thank you so much and it's a pleasure to have met all of you and I'm very happy that you all came here today to hear this wonderful lecture.

(Applause)

?: Now, we're just going to have Sandra Madden speak and then a little different perspective on the caretaker perspective.

Sandra Madden: I don't have a PowerPoint presentation. I'm sorry. I'm going to have to work that out for next time.

I can't believe I'm back here where we started. I met my husband at the University of Miami. At the time it was the only broadcast school. I think there are three others in the whole country. So, this is where we started and I'm back. My mother was a former nurse and I was growing up she would tell me, "Don't even think about it. You can't be a nurse. You're not cut out for it. Forget it," and if she could have seen me two years ago she would have been, well, maybe laughing

even. My husband, Dave Madden, as I said I met him here. He passed away a year ago in January. We did not know... We were living and I still am, in Jacksonville. We moved from... Well, he was in Los Angeles for 40 years. We moved to Jacksonville because I believed I should follow my grandchildren and that's what we did. He was always a very, very easy going kind of man, but unlike some folks when they say my husband's a comedian, he really was. He started in standup and then he went on to do four television series and countless television programs like "Love Boat," those famous little things from the '60s. "Laugh In" probably was the most fun for him because he got to meet a lot of his heroes, but as you can imagine when we went into waiting rooms and there were more than two people waiting for the doctors there, my husband performed and he continued to do that until probably the last office visit as long as there were people to listen to him and he could make laugh, but my journey as a caregiver and his... we didn't really know what was happening. We kind of backed into it. He had other problems. He had diabetes, Type 2, which had done some damage to his kidneys. He had several other, but when problems started happening like he would just collapse and we'd go to the emergency room, he would tell the doctor... When the doctors asked him what was wrong, he would say, "I feel weak. I'm weak," and, well, of course, that... they didn't know what to do with that, but usually there was a small infection perhaps, always inflammation. So, we started the round of doctors. Went to many, many doctors and at the time, I didn't have one of these. This is... I can't say enough about this for caregivers. This is wonderful. What I had was a pocket calendar and I would be writing INRs and blood hemoglobin tests. I ended up with a loose leaf notebook because my husband was not interested. So, I became the statistician. I kept track of the drugs because every time we went to the hospital and that was frequent, the doctors wanted to know what medication he was on and it was important to know to be able to tell them or to hand them a piece of paper that was great with everything then there went so many mistakes as it climbed up the ladder there in the hospitals. I think we saw every specialist possible. Infectious disease doctors, nephrologists. I think what I'm most grateful for is the relationship with the doctors. That became very, very important. The nephrologist and the oncologist, hematologists were our two best friends. They talked to each other. They communicated with each other which was very, very helpful to me especially and they would call me. I was kind of flabbergasted when that happened, but they were very good about keeping me in the loop and keeping me informed and I think the relationship with the doctors are super, super important for every caregiver.

Support. I was very, very fortunate to have among my friends two nurses. They both were operating room supervisors in Miami and both wonderful, wonderful nurses. Susan helped me out a great deal in times when I... in the middle of the night what do I do? What do I do? Support and not everyone needs a nurse, but the support of family and friends is so, so super important. I can't even tell you. Now, my other nurse friend who helped me as well is suffering with MDS now herself. She has platelets problem and I'm going to be going to see her in a couple of weeks, but I'm not her caregiver. Her husband is her caregiver and from what I understand he's doing an excellent job. So, the support, the knowledge, I... because no one knew what was happening at first, I was going online all the time. The Internet became my best friend and I learned a lot about MDS and I think the more you know, the better it is. I mean, Dave had

red blood... it affected his red blood cells. So, at first a shot of Procrit, man, he was... let's go on a cruise. We did a lot of cruising and we always had... always had a goal whether it was dinner with friends. I always had something we were going to do. I guess as much for me as for him, but he was also amateur magician. He liked to go on the cruises and he and his friend would do magic at the tables for people. So, he kept his hobby which was important and we kept a goal. The last time... One of the last times he was in the hospital he was saying, "But I'm going to Hawaii tomorrow," and the doctors were saying, "No, but we might give you oxygen, maybe a couple of days. No." So, that goal, having a goal, was, I think, really important. As I said, he wasn't interested. He did everything he was supposed to usually. I remember one time it was a Friday appointment. The doctor, the hematologist, was saying, "Okay, Dave. I think we need to put you in the hospital." The hospital was right next door to the doctor's office. Dave said, "No. I don't want to go." He said that a few times about things and he said... the doctor said, "Well, I can just put you right into a room. You don't have to go through the ER if you go now." "No, I don't want to go. I don't need to go." So on Sunday afternoon, I took him home and Sunday afternoon he said, "Sandy, I need to go to the hospital." Okay. Dave had... after the Procrit stopped working, he went into transfusions and those were very helpful for quite a while, but eventually they stopped working, too, where it was two weeks with... he'd have a two unit transfusion and two weeks later he'd be back for more, but I have to say he did this all without complaining. He was a good patient in that respect even though he wasn't interested.

I covered the relationship with doctors. I think the other thing was rest. It's exhausting. It does get exhausting. I was lifting wheelchairs and walkers and that's something you just do and I didn't realize till some time later how exhausted I became. So every once in a while, I would call in the troops, family and so forth and take a weekend. That did so much to help me. When I got back I had the patience, I had the endurance, I had more pep and vitality. So, that's another thing that I strongly would urge you to do to take time from caregiving to take time for yourself. It's very, very important. I didn't belong to a support group. I had a neighbor who had her husband was having some difficulties. We would get together with a couple glasses of wine and we would be our own support group. That works, too.

I don't know what else to tell you because it's all available in this book about being a caregiver. I didn't think I was going to be a good one because my mother had already told me I was never going to be a nurse and that wasn't going to work, but I would tell Dave he was dealing with Nurse Ratchet now and he knew who she was and he would laugh or smile and we would carry on and I did the best that I could and I think that worked out in the end of us. That's all... We're doing the best you can. You don't have to be a nurse. You just have to love the one you're with.

Do you have any questions? If Dave... There's a thing about actors that you don't tell anyone you're sick because you might not ever get another job. So whenever anyone would ask him how he was and his voice was always strong and he did a lot of tele(inaudible 19:38). "I'm fine. I'm fine." So, he would be... I think he would like me to share the experience, but not with him here. Yeah?

Q11: I have a question about the... You said the Procrit shots stopped working. How did that play out? How did you know that they weren't working anymore?

Sandra Madden: Because of the... It seemed like sometimes we were at the... our oncologist office two or three times a week and if it wasn't showing any improvement he increased the dosages but you get to a certain point where you can't do that anymore and Dave's heart also came into play here. We're not sure when the afib started. So, it could have been after or it could have been before, but during this process he had to have a pacemaker put in also.

Q11: How often was he getting the Procrit shots? Do you remember?

Sandra Madden: Well, first it started out maybe once every two or three months and it just increased over the years. Now, he was... when he passed away, he was 82 years old. So, he was beyond bone marrow. That was never discussed to do a transplant and although chemo did come up, he didn't want to do that and I don't think the doctors wanted to do it either at that point because of his heart had a lot of strain on it.

Q12: Did he ever try Aranesp? That's Procrit on steroids.

Sandra Madden: Well, he had Aranesp and he had Procrit. Yes. Both.

Q12: (inaudible 21:24)

Sandra Madden: Not at the same time, but he had two different doctors. We came back to South Florida for a bit and I think that's where he had the Aranesp, Procrit up in Jacksonville. Yeah?

Q13: How long did he (inaudible 21:41)?

Sandra Madden: That's another thing we're not sure because the weakness started maybe seven years ago, but being treated was about a four year period. So, and it was... we had a joke that... I don't know like maybe we were weird and had a sense of humor, but one of the things that the immune system was down. So one of the things that the doctor suggested was it's lupus. So, we'd be in hospital waiting rooms and it's lupus. It's lupus. It wasn't lupus, of course, and the doctor here in South Florida said, "Don't let anyone tell you it's lupus," but there's so many diseases out there that have similar reactions that it was difficult to get to the final diagnosis. Okay, this is what it is and this is how we'll treat it.

Q14: Was he in a wheelchair because of the weakness?

Sandra Madden: Yeah and he had neuropathy in his feet from the diabetes before this happened, but he would get very weak and it was the same thing and I don't know if this is a man thing. I'd

have both things in the car and, “Do you want the wheelchair?” “No, I can do the walker.” I said, “Well, it’s the hospital and the doctor’s office.” “It’s alright. I can do it. Sandy, I think I need the wheelchair.” So...

Q15: Do you think being (inaudible 23:18)?

Sandra Madden: That’s a good question. I always wanted to know what was happening and I can look at the records. I still have some of those records I can look back on and say, “Oh, my God. Oh, my God.” I wish I had known this then with those records, but having the records showed a progression and I guess that was helpful to me, but yeah, maybe not, maybe just ignore it.

Q16: We are having (inaudible 23:58) and I’m very interested in the Jacksonville experience versus South Florida. Did you move out here to get better (inaudible 24:06)?

Sandra Madden: No. No. That was a psychological move. We had a lot of friends here because we’ve gone to the University and I thought, “Okay. We’ll go down there. He’ll have his lunch. There’s a Hollywood luncheon every week with former... even Vaudeville comedians that are still here and they get together once a week and I was hoping that that would help him psychologically, which I think it did for some time. So, that’s why we came down, but after a point it was well, I can’t even go there anymore. So, but Jacksonville has become quite an area. We have the Mayo Clinic. MD Anderson is opening in September. MD Anderson which is... very prominent. It’s opening in September there and I guess one of the things that our oncologist was in an office called Cancer Specialists of Northeast Florida which is right beside the Baptist hospital there which is not the same system as here. He said to the doctor one day, “Well, I don’t like your sign out there.” “It wasn’t my choice,” but it was just Dave was not into being sick. He didn’t even like to have... We went to dinner with our friends often and if one of the friends started talking about their illness, he, “I don’t want to hear that. Let’s talk about the Lakers,” or, “the heat. We’ll talk about that.” So, I have done a blog site. Dave and I wrote a book about his career about eight years ago and it... now it has another chapter that I’m doing on blog. I have some cards here. It’s [www.davemaddenepilogtoruebenonrye.com](http://www.davemaddenepilogtoruebenonrye.com). (sp?) It not only talks about Dave’s journey with MDS, it also talks about MDS. I’m trying to keep up with that and I’m changing about once every two weeks adding material. So if you’d like to take a card here, please do and if you have any other questions I’d be glad to answer them.

Q17: (inaudible 26:40)

Sandra Madden: Everyone addressed him as Mr. Kincaid. I don’t think many people knew his real name.

Q18: I have a question. My father has MDS. He’s pretty much transfusion dependent every week to two weeks and he’s waiting now to have the transplant here. (inaudible 27:01) BY the end of the month, but right now my dad is very frustrated that he’s so tired he can’t do anything and



doesn't want anyone (inaudible 27:15) and it sounds a lot like your husband and so now we're trying to... we're here to learn about it. We learned a lot (inaudible 27:25), but we want to know now at this stage how to care for him (inaudible 27:34) he's very down and frustrated that my husband there most of the (inaudible 27:38) he can't do it. He's a doer and always very talkative, but we don't know how to help him (inaudible 27:47) we're all working, how to stay positive and not (inaudible 27:53) with the disease.

Sandra Madden: Dave wasn't a doer. So, I didn't have that. He loved his movies. So, that's about what he did to entertain himself or on the phone. We had people calling him from Los Angeles and wherever. So, that kept him engaged also.

Q18: Also (inaudible 28:20)

Sandra Madden: That worked. If Dave knew the wheelchair was in the car and he gave out while he was walking he'd say, "I give up." It's macho... I shouldn't say that.

Q19: How old is your dad?

Q18: Fifty-six.

Sandra Madden: Dave was a smoker for... He stopped when he was 40 years old. He did cold turkey. He was doing the "Partridge Family" at the time and he and Danny made a bet with each other. His was to stop smoking, but that was a long time ago.

Thank you very much. I wish I could have been more helpful.

Q20: Where do you get that book?

Sandra Madden: Reuben on Rye? That's on Amazon. Which book?

Q20: (inaudible 29:48)

Sandra Madden: Alright. Well, thank you very much. Next time I'll have a PowerPoint.

(Applause)

Q21: (inaudible 29:58) when you and your friend get together to have a couple glasses of wine (inaudible)

Sandra Madden: Okay. I'll remember that.

Vanessa Ruiz: Good afternoon everyone. I'm the last presenter and I'm kind of going to wrap up to some degree everything that we've been listening. You guys have had a lot of the medical information from the physicians. You've had Eliz Smith present on the *Building Blocks of Hope* which is the big binders that you guys have and those resources and of course you got the caregiver perspective and what I'll discuss a little bit more about is my area. I'm a social worker. I'm actually a social worker here at Sylvester Cancer Center that works with MDS patients. So, I do work closely with Dr. Watts and a few other physicians who work with the MDS patients. I work with patients prior to transplant. If a patient is going to have a transplant, they do have a transplant social worker that will resume the care, but I work with the patients with all these other sort of issues and things that come up and so they asked me to give some quick tips for patients and caregivers and I compiled a short list of what I call my top five based on a lot of the things that we commonly see, a lot of the common threads that we see with patients and issues that come up and I do work for the Cortala (sp?) Center for Supportive Cycle Oncology Services. So that is our... a lot of the other services that we have including our psychiatrists, psychologists, integrative medicine, acupuncture, massage therapy, nutrition, music therapy. So, we are all these support services here at Sylvester.

So, these are the top five for patients and the first one that I always tell patients is be informed. So, it's kind of interesting because Sandra was talking about how her husband didn't want to be part of that and there are some patients that will be like that. They don't really want to have that much information. I do see it, but I always tell patients you have to be your best advocate and in order to be your advocate you have to be informed. You have to understand your medical care. You have to understand your treatments, your disease, what are the treatment symptoms, what are the symptoms that you should expect. Everything that you want to know about your disease and similar to what you guys are doing here is coming to this forum to get more information, you as a patient, you want to understand what your medical care and treatment is and I think it's great that the *Building Blocks of Hope* binder that you have has this kind of booklet where you can track all your symptoms and all this other information. We tell it to patients even the ones that don't have that will have similar to like Sandra said a little notebook to put down maybe questions. Sometimes patients have questions while they're at home and when they come to the doctor's office they completely forget their questions. They kind of go blank because there's so much going on at the doctor's office. So, you want to write down these questions. Write down any symptoms that you had that were maybe you weren't really sure about and it's between this time and the time you're going to go see your doctor it happened and you don't want to forget about it because maybe it might be relevant for the physician in order to make a good determination as far as you medical care. The other thing I tell patients is to know and understand your health insurance and how it works. Of course, many patients who are older have Medicare, maybe you have Medicaid or a supplemental insurance and that in of itself is a very complex system. There's Medicare Part D which is your prescription drug coverage and there's so many details involved that you want to understand how it works, how your deductibles work, how any coinsurance or copayments work. You want to better understand it because sometimes when treatment options come about, which I often help patients with a lot of the oral agents and

establishing them getting the treatment is that their copays come up and they don't understand how the coverage gap, for instance, works for Medicare and why now they're having to pay thousands of dollars out of their pocket in order to get their treatment medication. So, it's important to understand how it works and to be informed about it and there's a lot of information, of course, that you can get online or calling directly your insurance providers and you want to understand your rights as a patient. You'll hear back and forth your HIPAA, HIPAA, HIPAA anywhere you go. Of course, those are your privacy rights as a patient, but you also want to understand your right as a patient to be able to access healthcare, to make determinations as to your care that you're the one who's guiding whatever happens to you.

My next tip is to speak up. Don't keep it quiet. Oftentimes people will downplay maybe some of the things that they're going through. One of the first ones, of course, is any medical issues, any symptoms, anything that's coming up that you don't feel that it's in your normal, in what we call your baseline. Don't keep it quiet. Let your physician know because it might be something that can help to save your life because you just never know what might be the thing is a key piece of information for your physician or your treatment team. You also don't want to keep quiet if you're having financial difficulties. You can always speak to usually a social worker, a case manager, depending where you're getting treated who can help see if there's any assistance programs, any financial assistance program for medication costs. Depending on what your situation is you'll want to be able to reach out to some if you're having difficulties. Even if it means you're having difficulties paying your insurance bills... I mean, the bills that are coming from your treatment center. If you reach out to somebody, you might at least get some sort of guidance, but if you keep it quiet, you're just going to maybe having more a problem created for you and then by the time you try to reach out to somebody it's too much and the help that can be provided may not be as useful and, of course, speak up if you're having difficulties adjusting and what I mean by this is being given the diagnosis is very difficult and you will have a period of adjusting of coping and that is very normal and there will be anxiety, there will be some feelings of depression, some sadness, because you do go through kind of an up and down and some days will be better and some days will be worse, but if you're seeing that some of these things are interfering with your activities of daily life that they're making you so that you are not able to live like how you used and not just because of your MDS now because maybe you're worrying constantly about something and you just can't get it off your mind of some of the symptoms, for instance, of depression are you're not having pleasure in things that you used to do. Now, they're no longer pleasurable. You're having difficulty sleeping. You're in an irritable mood or in a depressed mood and those are symptoms that if you're seeing them more frequently you want to talk to your doctors because your doctors could always recommend treatments or recommend you to a specialist, of course, to get some sort of treatment to help you because as they've discussed, the time that you could be living with MDS can vary. So, it could be a short time and it can be a long time and you don't want to live a long time with poor quality of life. You want to have some good quality of life for whatever time that you have.

My next tip is get help when needed. Many times we want to say I'm going to do this alone, I can do this, I can handle it, but you don't have to do this alone. That's, of course, where caregivers come into play and caregivers have a large part in helping patients, but you also have friends or other family members that might not be your primary caregiver, but may be helpful for you and it's okay to have them help you out and do things for you and you don't have to feel that it makes you any less of a person or it somehow makes your self-worth less because now you're needing to get some assistance and that goes, of course, with professional help. I see a lot of the taboo of getting psychiatric or psychological treatment and it is not something negative. You're going through a very difficult time in your life and you need some professional intervention. The same way you're going to your physicians to get treated for your MDS, you may need to go to a physician to be treated for a depression or anxiety or if you've had a previous mental health history and you have something that was prior to MDS, you want to continue to have it managed. Of course, it could be anything from bipolar disorder, schizophrenia or anything similar to that and something that we always think that it helps is people will ask you, "Well, what can I do for you?" and sometimes you don't know and you don't know because you haven't really sat down to think about it. So, make a list. Make a list of things that maybe you need help with. They can be things around the house that maybe you're no longer able to get to or just something else that you think that you might need assistance with and that way when somebody approaches you and says... I mean, "I would like to help you," you can say, "Well, would you be able to do this for me? Is this something that you can help me out with?" because that makes it something very concrete and it doesn't make it just something that somebody is saying, "Oh, I'm going to help you out." It actually makes so there's some action behind them.

The fourth tip is to be open. So, being open is to a lot of things. One of them is new ideas and treatments. Of course, you're being open to new medical treatments such as clinical trials. People who are seeking clinical trials or other sort of treatment that are still in the process of being validated completely for MDS and that's great, but it is also being open to other sort of treatment. Again like we say, seeking professional help, but I had a patient recently who is not on the bone marrow floor. On our second floor in-patient unit who had pet therapy come in and so he had a huge beautiful poodle come in and sit with him and they did their pet therapy and he is actually a counselor. He said to me, "Sometimes we forget because I've been in this for a while, but those 15 minutes with that dog was so helpful for me. It helped me feel better," and so sometimes you close yourself off to hearing about new things to try or things... or something new that you might feel uncomfortable with and try to be open and step outside of your comfort zone as much as possible and also be open to trying again. So, somebody was talking... you were talking about your father in that he's a doer. So, maybe it's how can he do something or feel like he can cooperate at the level where he's at. So, I had a patient who liked to garden and he liked to have like a vegetable garden. I said, "Why don't you have a raised garden?" So maybe you're having difficulty bending over, but having something raised or something where you could sit down and do your gardening right there. At least you feel like you are doing something like somehow you're cooperating or at least gives you something to do because oftentimes the thing is when you're not feeling very well you have nothing to do. So, I always

tell patients find something that you like. I have patients who like music who used to be drummers in their young age and now with our music therapy program while they're in the inpatient unit they realize how much they enjoyed that and even if it wasn't doing at the levels that they did maybe 20 – 30 years ago that they still enjoy it and they can still partake in it somewhere and other... So try things that you used to like before. Sometimes people do like reading, painting, knitting, sewing, whatever level that you can try because that oftentimes helps you to feel better, but also gives you something to do. It helps to keep you going and those are very important things that I always tell people to be open to your journey. This is a journey. Everybody has a journey and everybody's journey's different and some of it includes medical issues that will affect your journey. Some of it is other emotional, family issues. So, everybody has a journey, everybody has difficulties that they come up that they will confront in their lives and this is your journey. So, be open to it, accept it and learn to work with it and learn to live with it because the more you fight it, the more you're fighting everything else and if you say I have MDS and now I'm going to do what I want to do at least battle it and whatever else that you need to do that becomes you accepting it and you taking control over it. I think one of the most difficult things is people often feel that they don't have control over things which you don't, many times you don't have a lot of control over your treatments or how the treatments will affect you. So, you'll want to have something that you feel you have control over.

And the last one is setting goals and, again, Sandra talked about this. You want to have short term and long term goals. What can you do in the next few days or the next few weeks and can you do maybe in the next few months or the next few years and make them realistic and attainable. Make them things you can do, but it helps you to feel like you are accomplishing something. It helps you to also have something to look forward to like a trip or a dinner with friends, anything like that where you say, "I'm going to hopefully feel better today and this is what I want to do for today," or, "this is what I want to do for this week," and those little goals you may think at first are kind of silly, but then you start to realize that that's how you will continue to live doing these little goals and little goals and then when you realize you start to see all the things that you have done and you're like, "Wow. Look at all the things that I've already accomplished," in a timeframe where you maybe wouldn't have thought of it before.

And so now I'm going to go into five tips for caregivers. So, I also lead the caregiver support group here at Sylvester. So, I do work often with caregivers and see a lot of the issues. A lot of them often relate to burnout because caregivers don't take care of themselves. One of the analogies that we always talk about is when you're in the airplane they tell you if the airplane is going to go down, put on your mask first before you put on the mask of the person next to you and that's because if you can't breathe you can't now help the person next to you. So, you have to always take care of yourself first as a caregiver and that, of course, is physically, emotionally and spiritually. Physically - eat well, exercise, go to your doctor's appointments. I have patients where like I'm so busy with his appointments that I haven't gone to my appointments. You have to go to your doctor's appointments because if you're not doing well, how can you help the person who's probably a little sicker than you are? You have to take care of yourself.

Emotionally - have friends, join a support group, look for assistance. Have a glass of wine. Do something that emotionally helps you kind of manage the stress because it is stressful. It's not just physically exhausting but it's mentally exhausting to take care of somebody who's sick, to almost feel like you have to take on their burden even though you shouldn't, but to feel that way it can be very stressful and very exhausting and you want to take care of yourself in that sense even if it's doing something that you'd like to do or relieving yourself for some time. That is always going to be helpful for you and spiritually if you're into meditation or into prayer or into any other sort of religious activity that you enjoy doing, look for the way where you feel balanced spiritually because that will also help you be a better caregiver and, of course, a better person.

Get help when needed. You can't do everything alone. You as... You cannot be a single caregiver because there's just way too much going to happen that you can't do it alone. So, accept that other people help you even if it means taking that weekend off and saying, "Hey, can you come in and take care of my family member while I take a weekend," or, "while I go and get a massage," or, "while I go..." and just have a cup of coffee somewhere else. I need to step out. Sometimes you need that relief to kind of get, again, get your energy, get your pep back in to be able to then come back and approach your family member and be able to continue taking care of them. Delegate to others certain things. We were actually talking about this with my colleagues and it was sometimes it can be very overwhelming when everyone's asking you, "How's it going? What's going on? What's this? What's that?" We thought about having an information gatekeeper. So, delegating it somebody who's also close in the family and letting that person be the one who contacts everybody or people will contact and let that person kind of give the report as needed because then it becomes overwhelming when you're trying to be at the doctor's office, listening to the physician, trying to understand the lab work, trying to understand the treatment and then having to tell everybody else what's going on. It's exhausting, so have somebody to be that point person and the same thing goes with other tasks even if it means tasks around the house, even if it means when you're going to go... if you have to go away for treatment or you're here for transplant that somebody's taking care of the house or if you have pets delegate things to other people and, of course, it goes back to taking time for yourself and taking time off if you need to in order to get that help, that extra energy that you need to continue.

The third step... I mean, the third tips are is to know your role. Understand your role as a caregiver in that you are the patient's advocate and team member. You're part of that patient's team and we often talk about treatment team and we say that because it's not just your physician. Many times your treatment team is composed of what we call multidisciplinary where you'll have the physician, his nurse practitioner, the nurses in the clinic, the social worker. If you have any other sort of physician as part of your team and so you as a caregiver are part of that patient's team and you're a very important part because you're the one who sees all the things that the physician doesn't see. For instance, if the patient forgets to tell the physician that he was having a low grade fever, you can be the one to say, "Yeah. On such and such date, or he had a few days with a little bit of a fever," you want to be able to be a part of your family member or

whoever it is that you're taking care of his care and you want to be the patient's support and understanding what it means to be the patient support. You don't always have to be their cheerleader. It's okay sometimes for them to feel a little down and it's okay for you to let them feel a little bit down. Keep an eye on it. You don't want it to go past a certain point, but you don't always to feel like you have to be telling them, "It's okay. It's going to be okay," because you don't know that first and foremost and it's not always going to help the patient. Sometimes they need to be where they're at and need to have a moment to kind of look at things and regroup and take some time before they can get to the next step. So, understand that being support doesn't always mean that you're right there doing counseling or just trying to help them out. Sometimes it just means listening, sometimes it just means taking a step back and letting them be. You can tell them, "Hey, you have to eat well," but you don't need to spoon them. You don't need to force feed them. If they want to eat, they eat. If they don't, they don't. That is ultimately their decision. So, you want to understand what it means to be supportive as a caregiver and understand your rights as a caregiver. So again, this kind of goes into a little about privacy rights. There are some limitations within a patient's privacy right and the patient has the right to limit some information that you receive, but you do still have some rights as the caregiver to be involved in the patient's care.

And the fourth one that I'll touch on is respecting the patient and what this means and it's very difficult sometimes is respecting the patient's ability to make decisions. So, many times I see this oftentimes with families who it's an elderly parent and their younger children and they kind of want to make that decision. "Okay, mom. This is the treatment that you're going to do and yes, this where we're going to do." What if that patient doesn't want to make that treatment? What if that patient decides, you know what? This is not for me. You have to respect the patient's ability to make the decision. They're ultimately the one who are going through this. They're ultimately the ones who have to make the decisions as far as their care and what they would like to see in their care. Again, privacy. There are things that they don't necessarily need to share with you. It's up to them and you have respect the right to their privacy. We're always very conscious when we're talking to family members about the information that we provide them because we oftentimes ask the patient is it okay? Sometimes they'll tell you full disclosure. Let them know anything, but there are other patients who say, "No, there are some things that I want to keep to myself," and lastly you want to respect the patient's wishes and there are several things that come into play. Oftentimes I deal with what are called advance directives, living wills, healthcare surrogate forms and patients have the right to decide what they will like to happen or not happen in the event that there's an emergency and you have to respect those wishes especially if you're a healthcare surrogate. If that's what they want whether they don't want resuscitation, intubation, anything like that, you have to respect that wish. At the same time you have to respect their wish to maybe discontinue any treatment and say, "Hey, I'm done. I'm stepping away and I'm going to let nature take its course and do what it's going to do," and that sometimes is very hard as a caregiver to accept that sometimes patients say, "I'm done. That's it. This has been exhausting. I can't do this anymore. I just want to be left alone," and it's hard as a

caregiver because you want to continue to fight for them, but that's their choice and you have to respect that wish of the patient.

And lastly, I put communicate effectively and this is across the board, to the patient, to the treatment team, even to your family members. Respect your feelings and the patient's feelings. Understanding that what you feel is valid as a caregiver and that's why I say use "I" statements. So if you're communicating with a patient which can be very frustrating if you're having some difficulty, use "I." I feel this way, I think this so that you don't put the burden on them but rather on you and you can express to them how you're feeling and if you're having any difficulty and that way you respect both your feelings and the patient's feelings.

Focus on the present. Don't drag all the things that happen in the past that now you're upset and now you're at a moment where you're on your low and you bring up something that happened 10 – 15 years ago and it's just not going to come and help anything whether they didn't do something or they did do something. It's not going to help the situation. So, focus on the present, focus on the now. Part of this is I always talked about patients about quality of life and the quality of life is what you're living, what you're living day to day and every day that you have is another day more and that's for everybody because the person may have MDS and the caregiver may die of something before that person who has MDS because that's life. You don't know when your end day is, but you want to focus on the day to day and taking it day by day because every day is going to have its betters and its worse, but all you can do is take it day by day. Don't worry about what's going to happen in five – ten years. Try to focus with what's going on right now and how you can affect the change that you want at the time.

And so now the second part is just an open support group discussion, whatever questions you guys have, anything that maybe you guys would like to ask. I know the physicians have left, so I don't have a lot of medical answers for you, but anything else I'd like to try to assist in answering. Yes?

Q22: If you (inaudible 55:47) kind of quit when you said about (inaudible). Under let's say drugs do the boost to your red blood cells, are they administered through Medicare down at (inaudible 56:07)?

Vanessa Ruiz: It depends if they're administered at home or if they're administered at the facility. So if they're administered at home, it will go under your Part D and there you could fall into a coverage gap within some time. If it's administrated in a facility, it goes under Part B. So, that's what understanding how things work as far as your insurance.

Q22: And does that also include transfusions?

Vanessa Ruiz: Transfusions are always under Part B because usually they're done at a facility. They're rarely done at home because they have to monitor you very well.



Q23: How many transfusions will Medicare cover?

Vanessa Ruiz: Medicare covers for things that are medically necessary. So, they don't necessarily have a cap. Now, you do have to know if you have an Advantage plan whatever limitations an Advantage plan may have, but Medicare usually will cover anything that's medically necessary that they deem medically necessary and that the treatment facility can prove it was medically necessary. So, they'll cover it. I don't think necessarily they have a cap and don't quote me on it but there's many things that don't necessarily have a cap in that regard as long as a patient continues to need it.

Q23: Question, the Medicare folks said that they only cover two blood transfusions.

Vanessa Ruiz: Per week? Per... I know it's just two. I have patients that get a lot more transfusions. It may have a limitation of a per day or even a per week that may be something along the lines of that, but definitely not just two because people would be dropping left and right and they need... sometimes people are transfusion dependent and they need to do it on a weekly basis or several times a week. So, it might be a per day or a per week sort of situation. Anybody else? Any other questions?

Q23: I had 13 of them.

Vanessa Ruiz: Anybody else? Any other questions? Anything else anybody want...?

Q23: Nobody talks about progression. What happens with the end of life scenario and is there effectively hospice referral?

Vanessa Ruiz: So, that's a point that I'll say... I'll be very honest and the physicians don't always feel very comfortable with. Death. Not everybody's comfortable with death and we're kind of used to it as social workers because we're the ones who deal with the hospice and talking to the patient about hospice, but a hospice is initiated when the physician and the family members determine that there's no other treatment options or the patient does not want to continue any treatment and the next best referral for the patient is hospice. Sometimes there's something called palliative care which is different from hospice and it can... Palliative care can go in along with your treatment. Palliative care is more into manage symptoms whether they be pain or any other sort of symptoms that are coming due to your disease and that can happen in congruence with your treatment. Hospice, however, it's by itself. So, once you're in hospice, Medicare covers hospice and they cover what's called a set amount. They give them a per day rate to the hospice company and some hospices work a little differently as far as what they do and they don't accept and their limitations but usually hospice is for a patient who has about a six month period of time left and they do provide different services. The physician will make the referral. We usually go in. We speak to the family about what hospice agency they would like to

use because they have the freedom to choose the agency and then once they choose an agency, what will happen is we call up the agency or if they choose two or three that they want to look into and they will send a nurse and the nurse will come in, explain to you their services and you decide whether to sign up or not into that hospice agency. Once the hospice agency takes you in, now they're the ones responsible for your care and so there'll be a physician. They have a physician that does an evaluation. I think their evaluations about monthly. They have nurses that come in and depending how much care you need, it can be what they call 24 hours and it can be a 24 hour care if you're on a critical point or it can be several times a week depending on how much of assistance the patient needs and they also provide medical equipment, beds, oxygen, all of that goes under hospice. Hospice is definitely... We always tell patients that hospice is a good option because it's your time you rather go comfortably. So, the hospice physician will make sure that you have medications that you need so that you're comfortable that you're not in pain and that you are generally doing well and hospice can be at home as well as it can be in an inpatient unit depending on that hospice company and what they have available and that's definitely a question to ask your physician. Some physicians kind of want to give you as much treatment as possible, but it ultimately is your decision. If you say that's it, I don't want any more treatment. What's kind of my prognosis? What's my possibility? And if it's not all that well then maybe that hospice is the way you'd want to go and live whatever time you have left. Any other question? Anybody who want to give any other remarks? Anybody that they had anything that they wanted to share?

Q24: I'd like to ask anyone that's already had a transplant here (inaudible 1:01) caregiver. Do you have any suggestions (inaudible 1:01:46)?

Q25: (inaudible 1:01:50)

Vanessa Ruiz: And it's very important. Like I said, since we do have a transplant social worker, she's actually the one that sits next to me. So, a lot of our patients end up kind of being both of our patients because I deal with all the hematological cancers and those are usually the ones that get stem cell transplants. It's very important for a patient to have a caregiver because they can feel very weak, tired, fatigued, are not able to do their activities, the daily living. So, it's kind of what you're doing now probably to the tenth degree, a little bit more intense especially for the beginning part of that patient's transplant while they're recuperating. You got to remember that their immune system is pretty much wiped out and that it will leave them pretty tired. So, you're going to do a lot of the basic care and so you have to make sure you have a lot of support for yourself and actually probably people to maybe help. It's good to have maybe one or two caregivers rather than just one person to kind of switch off and it all depends, every patient's transplant experience is different. I've seen it... I've worked a little bit with some of the transplant patients when I have to cover and some of them recuperate remarkably and other ones have a harder time adjusting to it and their bodies take a little longer. So, everybody's transplant experience is different and you really won't know 100 percent until you get there and it happens. That's unfortunately how that goes, but be prepared and have a lot of good support for it.



Q25: (inaudible 1:03:27)

Q26: I was going to ask, do you have lots of (inaudible 1:03:36 – general chat)

Vanessa Ruiz: Well, you all have a good afternoon. Pleasure.

(Applause)

?: (inaudible) going around for the...