

Forum Presenters:

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**Moderator:** Okay. Well, thank you, everybody for coming back. I'm so happy to be here this afternoon to be moderating the next set of experts that we have. We called this the patient and caregiver survivor panel, but after we just heard from our expert physicians who are experts on diagnosing and treating MDS these are patients and caregivers who are experts at living with MDS. So, I'm going to start. We have three patients here and two caregivers, (Attendee 1) and (Attendee 2) and (Attendee 3) and (Attendee 4) and (Attendee 5). So, I think to begin I'm going to ask each of the patients that are on the panel to tell us a little bit about your MDS experience. Just a few minutes to tell us about your diagnosis, how long you've been living with MDS, what type of therapies you've received so far and generally how it went for you and how life has been since then. So, (Attendee 5) if you want to start for us.

**Attendee 5:** Hi. If you don't have any wings, you're not going to get any answer for me. Anyways, my name is (Attendee 5) and I'm from Vermont. It'll be four years January 16, 2017, post bone marrow transplant from here.

(Applause)

I'm not sure when I was diagnosed. I think Lynn or Dr. Lowrey could probably figure that out. I don't remember, but my thing is how I got started and it was by accident. I was cutting my grass and I was getting a little short of breath from each up and down and as I was having some abdominal pain. So, my wiser half which is I call (wife). She's my wiser half. Finally convinced me to go to my primary care physician. Took a blood test. He didn't say anything. He told me to come back the next day. Took another one. Went back the afternoon, took another one. Sent me to the Foley Cancer Center down in Rutland which in turn I met with Dr. Eisemann and he sent me up here with I think my first appointment was with Lynn and Dr. Hill. So when there's two people in the office you know you're in trouble. So, that's when they dropped the bombshell that I had MDS and he was explaining all the remedies that I would go through and my first reaction was well can we just skip all the chemo and just go right to the transplant and Dr. Hill said, "No, (Attendee 5). We don't do it like that." So, I spent a lot of time here as a patient, twice. I

survived the transplant really well. I had a lot of fun on One West, a lot of great care I got a lot of great nurses, great docs. How has it changed me? It has, it will and it's just that way. Transplant people are a different breed. I do get exhausted/fatigued a lot. I'm very much a go getter, but I have to take naps in the afternoon and then I'm okay. I have good days and bad days. Mentally, I do have a couple meltdowns once in a while. I had a great caregiver, my other half, (wife). She was absolutely phenomenal. With her working 40 hours a week and taking care of me and we have four dogs. She did great. I did do a lot. I didn't have any really adverse reactions to the chemo or radiation or anything. The only thing is I lost a little bit hair and I never really had any to begin with. So, I didn't really care. So, I told (wife) just to shave it off and we did. Now, I'm pretty good. I can't complain. I still have a great staff taking care of me. I have a great other half and that's it. Next.

**Attendee 3:** Hi. I'm (Attendee 3) from Maine. I guess mine is 2009. Mine was a surprise to me. I was working construction and I had both hands done for carpal tunnel. Eight weeks later I went in and had my neck done and had four, five and six fused together. Eight weeks later I went right back to work in construction and I kept seeing my regular doctor and he says, "Jeez. You look awful tired. How do you feel?" I said, "I feel alright. I mean, I'm working 12 hour days. What do you expect?" So, they checked the blood and said I was low on iron. So, he kept taking iron pills and nothing would change. So, he sent me to see another doctor and I went to Augusta to Alfonse Center and I drove in. I see cancer. It's like whoa! What is this? Why am I here? I'm low on iron, but it turns out that I have MDS which I just didn't realize I had until tonight, today actually. It was a preleukemia (inaudible 5:36), refractory anemia with ring sideroblasts is what it's called. So, basically my red blood cells takes the iron and they hoard it and makes a ringlet around it and it affects my breathing. I get tired pretty easy. I get cold. That's why I wear my jacket right now and I said it was quite a surprise to me. My life really didn't change much because I had to give up so much because of all things my arm's going numb and stuff like that. I had already given up hunting, fishing, swimming or anything like that. The biggest change in me now is I'm very fussy at what I eat, where I go. I don't make a lot of contact with people because I don't want to get germs or anything like that, but besides that I've been pretty lucky with what I got. I feel pretty thankful. It's been six years and mine has not moved a bit. I've had a couple blood transfusions and that's it and we're talking about the injection to help boost my red blood cells is going to be the next thing instead of keep doing blood infusions, so I don't build up the iron and besides that it's been a great time for me. I mean, I guess I got the best one there is. If there's going to have one, I have the best. It's very slow moving and I don't know what else I could say about it. It's pretty straightforward here with me.

**Q1:** So, (Attendee 3), is there only therapy to date just the blood transfusion?

**Attendee 3:** Just blood's all I ever had. Three times I had three infusions so far. Nothing else besides that and I'm always in between... I'm between like eight and nine on the red blood cells. My whites are great. I cut myself all the time. I heal great. So, I have no problem and the whites are alright, too.

**Q1:** How long where you diagnosed?

**Attendee 3:** Probably 2009. It hasn't changed very much since then. I said I've had three infusions since then.

**Q1:** How often do you see your hematologist?

**Attendee 3:** I go once a month to see my doctor and all we do is we check my blood work and it's like, "Well, I don't know what you're going to do... What are doing? How come you don't change?" I take vitamin D, vitamin B, pretty much even (inaudible 7:40).

**Q2:** Every six months here and nothing's changing.

**Attendee 3:** I'm a pretty boring guy. That's good for me. I mean, I'm happy with it. I just got to watch what I do. I get tired pretty easy like I said if I don't do myself.

**Attendee 4:** He naps, too.

**Attendee 3:** I'm more worried about... I have degenerative bone disease I'll probably go from that from anything else. More and more I lose the feelings in my arms, my legs more and more all the time. That's affected me more than anything else.

**Moderator:** (Attendee 1), do you want to...?

**Attendee 1:** I'm (Attendee 1) and I live here in New Hampshire. Mine was found in 2014 just from a routine CBC. I had all three blood levels were low and my primary care thought I had (inaudible 8:33) after a couple bone marrow biopsies they determined that I had MDS. So, I went on Vidaza and a study drug. I can't remember what (inaudible 8:45) and I think I went five or six cycles and my bone marrow biopsy came back (inaudible 8:52). So, Dr. Lowrey said, "Well, it's not supposed to do that." So, we progressed to a bone marrow transplant which I had last August (inaudible 9:03) and today is day 277 post-transplant and so I'm doing real, real well. I have good days, bad days for the most part all of my days are great. I went back to work fulltime. I went back to work part-time in February. I'm back to work full time now. Walk the dogs and spending my time with my wife and probably the biggest change that it's made in my life is I tend to be a workaholic. I like to work (inaudible 9:38) I like being able to work and everything and now it's time to take (inaudible 9:47) and enjoy life instead of working it all away. I still enjoy working, but (inaudible 9:55). So, that's it for me.

**Moderator:** Thank you. So for the caregivers on the panel, (Attendee 2) and (Attendee 4), could you take a few minutes to tell us about your experience as a caregiver? You could even expand a

little bit to tell us about your support network and people who have helped you along the way and how did they help? Was it hard to rely on people or delegate things?

**Attendee 4:** Well, because of the form that (Attendee 3) has, of course, he hasn't needed an awful lot of care from me, but of course initially when the diagnosis came through we're going through the steps. It was really a shock to get that diagnosis and then to think okay, where do we go from here? What's going to change in our life? What do I need to do to support him through it and I'm like the organizer of us. So, I like to organize everything beforehand so then I kind of go into overdrive, too, of thinking that everything in the house needs to be pretty sterile. I'm a preschool teacher, too. I am bringing home all these germs with me every day, but I got some great tips too. They just said like everybody does get into comfortable clothes once you get home. So, doing that. Kind of like I said I kind of go into overdrive a little bit with this, but through talking with... We have Dr. (inaudible 11:22) in Augusta as well as Dr. Hill here and the team that goes with that. So, just talking with them and learning more information about it. With us I just know (Attendee 3) gets tired quicker. He's a lot of times he goes to bed a lot earlier than I do, but then he's like this morning he's up at 5:00 and I'm sleeping in till 7:00, but so that kind of changes where I know he's not one to want to go anywhere later at night. He also is if somebody's in the hospital he doesn't go in to visit them. It's not a risk that he needs to take with it. So, we just try to take some of those precautions. Family members know, too, if you got the flu please don't come to the house. Cold, anything like that. Our house is usually pretty warm because he's cold. So, he's really cold. I'm really warm. And then he does have bad days, too, where he's down and sometimes it's hard for him to realize that it's okay. He just needs to take that day and lay down. I work fulltime, too, plus. So, at times I feel like I'm leaving him home alone a lot, but he does pretty good with it and he's able to keep himself busy around the house and make it so he can still enjoy things and for support, we are very blessed. We have three wonderful children that are a great support to us, too. So, it might be that if I can't get the day off to go with him to appointment that one of them can. We have two that are in the area. One's overseas, but two that are... so, they chip in and help out a lot and his mom lives right next door to us, too. So, I always know, too, that there's somebody else around the house and things like that around the area and stuff. He has pretty much family here. So, our family's there for the long (inaudible 13:27) and that helps a lot.

**Attendee 2:** Hi. I'm (Attendee). (Attendee 1) and I went to high school together and we had just gotten back together 2014 in August and then October of that year we found out that he had MDS and I was in the process of leaving family in Maine and I was going to be coming down to be with him in January, but I came down like three months sooner than I had planned because he was ill and so there was a lot of stress in my life. So, becoming his caretaker was like a 24/7 job for me. I wasn't working at the time, but before his transplant I took a job over at APD for a little while and then I came over to work for Dartmouth and so the only support I had was my new coworkers at the hospital and doctor... (Attendee 1)'s doctor's a nurse, too, of course. My family is still back in Maine and so I didn't really have any close friends here yet. So, support I did use the social worker that was appointed to us and I did talk to her a few times and met with her

once, but I was under a lot of stress so... I don't know if I was the best caretaker for him or not, but...

**Moderator:** I'm pretty sure you were. How did you take care of yourself emotionally and physically during that time of high stress?

**Attendee 2:** Oh, wow. That was very difficult. I'm a very emotional person and I guess the only release I got was from all the crying that I did. That's kind of person I am, but I tried to be positive and for him basically especially after his transplant. He could barely take a shower then he'd have to lay down and go back to bed. He was so tired. That was all part of it. He did have some graft versus host. Nothing severe, but I still put up his medications every week for him because he's still on a lot of medications, but I do anything and everything that I can for him still that if needs, but it was difficult. It's kind of a blur for me now. I can't remember everything because it was such a stressful time in our lives and then in the middle of all that I went through a divorce, left a child back in Maine and all that. And then we got married... We got married before the transplant in last June.

**Q3:** And then you were also transitioning from the trailer to the new house.

**Attendee 2:** Yes, yes, we were living in a camper, mmm hmm. So before he came home because after transplant you don't have hardly an immune system, so I had a professional person come in and help me clean it from top to bottom. If there was any mold it was clean and what not and then we were trying to transition to a new home which we finally did and we've been in it since December. Anyway, it's been quite an adventure to say the least, but he's doing quite well as you can see and we're hoping that will continue.

**Moderator:** When they talk about life events that are most likely to cause stress, I think you hit almost every single one of them – divorce, marriage, a move, leaving support system and then a health diagnosis. Congratulations on getting through the other side in your marriage. Can anybody else kind of comment on the question that I asked (Attendee 2) in terms of ways that they found to help themselves through this process emotionally or physically or a physical benefit that helps them emotionally or vice versa?

**Attendee 1:** I mean, I had plenty of support because I had (Attendee 2) was there all the time, every minute she could be. At work... I work for the State of New Hampshire so everyone at work was way, way supportive of me. I didn't have to worry about losing my job. I didn't have to worry about those kind of things. So, that type of support, the nurses at One West are fantastic. They really, really are. Probably my biggest problem was I retained water. So, at eight o'clock at night they'd give me something so that I'd get rid of the water, so I was up all night. I didn't know that sleep deprivation was part of the treatment or not, but if it was it worked great.



**Moderator 2:** (Attendee 5), would you kind of share how (wife) got through for you through the transplant and post?

**Attendee 5:** (Wife) is... when we first got diagnosed, we got home and as probably as Dr. Lowrey and Lynn and Dr. Hill know, (wife)'s like a dog on a bone. If she wants to find out something, she's on that computer and I'll tell you what, she'll know more than the two doctors and Lynn and she'll have 9,000 questions. So, that was her piece of mind. She did do my meds in the beginning and she had a lot of support from her family. Her sisters were always there and I was... Well, my good days I would tell her, "Look, just take the car and just go visit somebody, go do somebody." She had a lot of friends in other places. I would say that made me feel good. As for me, my support system other than her is there were a lot of times that I didn't want to talk to her because I felt that I was burdening her. So, I went to through the VA to see a social worker and everything like that and that helped, but there's one thing I got to say that I never, never, never from day one asked why me. When we were on 89, after our appointment with Lynn and Dr. Hill, (wife) says to me, "Okay, you can cry now." I'm Italian. Italians don't cry in front of anybody anyway and I said, "What for?" It's part of life. That's what it is. There's nothing I can do about it. We can't change it. We just do what Dr. Hill and Dr. Lowrey and Lynn and everybody else say to do. We just go along with the system. So, every morning I'd wake up and I'd put a smile on my face and I'd say, "Damn, I screwed the world again. I'm still here," but I got through it. Four years January 16<sup>th</sup>. The best day that I had at Dartmouth I had an appointment with Dr. Lowrey. He walked in the office and he said, "Congratulations. You're at 100 percent your donor." I didn't know what to say. So, when I get on Facebook and my friends and January 16 comes around, I tell them it's my birthday and I make sure that the staff up here remembers. I tell them it's my birthday and then the real day comes, but really I kept a great attitude. I was negative. (Wife) was a great caregiver and had a lot of friends that came over and (wife) went in the office on the computer or something like that and we just chit chat. Thank God I didn't smoke anymore. Boy, that would have been really bad, but hey, I had a positive attitude. That's all you can say and I think there was only one time when I came up here when I was really, really crappy and I think Dr. Lowrey remembers that time. I just wanted out of here so bad. I was so cold and I can relate to being cold because I still am cold, but good attitude. That's all I can say. Thanks, Lynn.

**Moderator:** That's great advice. You touched on a question, actually, I was going to ask in terms of what are the highs and lows, what have the highs and lows been in terms of your treatment, diagnosis, transplant if you'd had a transplant. (Attendee 5), I think you kind of answered that question. Could the rest of the patients and caregivers for the same... along the same lines comment on that? Highs and lows?

**Attendee 3:** I met some awful nice people but Dr. (inaudible 23:44) in Augusta, she's awesome. She's amazing. I'm a different person. She talks to me quite different than you would to any other person. I'm pretty frank. I'm the type of person who bites the nose off my face to spite myself. So, I get along pretty good with her. It's been a good experience and Dr. Hill and this

place here is awesome. I couldn't think of a better place if I had to go somewhere this is where I want to be. If it does every progress, this is where I want to go and I've been to both places. I've been to Boston, too, but if I have a choice this is the place I will choose to go. I won't go anywhere.

**Attendee 4:** I think the hardest part was actually for us is the initial diagnosis. It was just... and I know we got a lot of information then, but it surely didn't retain any at that point in time. Digesting the diagnosis, what (inaudible 24:43) would be.

**Attendee 3:** I said why me, but I think I said isn't it enough after both my hands, my neck, everything I've had has been done at work. I was running a machine, a guys messed with it and had my hand sucked in and got my hand crushed. I've had another guy messed with piece of pipe was (inaudible 25:03) split my rib open, broken my ribs. Everything has happened at work. So after I had all that and all them operations then I come down with leukemia or with this MDS. I said isn't this enough? Haven't I had enough in my life at 49. Do I need any more? That's my biggest woe is there what else and degenerative bone disease, I keep losing more and more bone, so I have more and more losses in my hand and in my leg and my hips. Actually, I'm going for an MRI Monday to see about my lower back to see if I got pinched nerves down there.

**Moderator:** Highs and lows.

**Attendee 1:** My high is every day I get out of bed.

(Applause)

**Attendee 1:** I love every day because every day now is a gift that's been given to me. The low probably the lowest point was when I was in the hospital and the doctors are making their rounds and the nurse gives me a barf bag in the middle of retching and the doctor couldn't talk to me. I had to inform her I needed new sheets, too. You kind of lose all of your... It's all out there and the LNAs and the nurses down in One West, they're just the best. Smiles every day and just pleasant and whatever needed to be done they took care of it and off we went and luckily I had a humming bird feeder outside of my room, so I could watch the humming birds and that stuff.

**Attendee 3:** (inaudible)

**Attendee 1:** You did?

**Attendee 2:** I just wanted to add that I think one of the worst days for us together was, well, before the transplant the prep of course, prior to transplant is pretty rough on the body and the one night that I didn't stay in the hospital room with him was the night... Well, I think it was the first night he went into pulmonary edema because of all the fluid that they were giving him and he was so scared that he was going to die and the nurse said let us call your wife to come in and

he wouldn't let them. So, I didn't even know about it until a few days later and then the other bad night was the night of the transplant. He spiked a fever of almost 105 and the nurses packed him in ice and asked me to help. So, we put... We'd pack in his groin and under his arms and he pulled the one out from his groin. He didn't like that one and we tucked it right back in. He says, "What are you doing?" It was pretty scary to see my husband like that and so transplant is not easy. It's pretty hard on the body and you have to be fairly healthy to even be considered to go through it. We were very, very lucky that came out on the other side and is doing very well and I cannot thank the nurses and the doctors of this hospital enough. They are the best. They saved his life.

**Moderator:** My next question has to do with communicating your diagnosis to your friends and family members. Can any of you offer some advice or maybe what worked and what didn't work in terms of communicating and explaining your new diagnosis and your treatment to your friends and family because that can be a really tough thing.

**Attendee 5:** I know this is tacky, but I said Google it. I couldn't really explain it. I just said MDS and it has to do with bone marrow disease and if you want to know more that's what Google is there for and that's all I did.

**Attendee 4:** It kind of gave a little bit of information that we had that it was a blood disorder that he had that was preleukemia. We didn't know it would advance from there. In fact, some people don't understand. He looks okay. So, why's he get tired?

**Moderator:** Right and especially if there isn't treatment. You still have your hair and maybe you're not even receiving treatment. So, how do you explain to your friends and family that you need to be more careful about infection and that may be some of the things that aren't readily apparent or a change.

**Attendee 4:** Or if there was family functions and he wasn't up to it that day, too, to have family understand why he wasn't the day. It's not that he didn't want to be. It's just he was not up to going that day. The next day he could be fine, but...

**Moderator:** (Attendee 1).

**Attendee 1:** The most difficult thing is because most people don't know what MDS is. You say MDS and they look at you with deer in the headlight look. So, you just revert back to the preleukemia and everyone knows what leukemia is and you could explain it's a disorder and I don't make enough blood cells and with me I had pancytopenia. So, I was bruising, I was tired and the whole thing. So, it's pretty easy when you see bruises all over somebody that something's up. You know what I mean? At work, they tried to wrap their head around it, but they knew that I was getting tired because I'd work right up until the day before my transplant and I probably shouldn't have been because I was out and about doing inspections throughout



the state and I had severe neutropenia at the time, but luckily what little bit of immune system I had sure did a good job during that time because I didn't get any infections before my transplant, but it's hard when you try to explain to someone when you're not a medical person what MDS is and they don't know. They don't even have a clue what it is because now I've invited everyone at work to come here today and hopefully people will get to know more about what it is and we're all different. The disease is such a big wide range of disorder that there's no definitive thing. Breast cancer, everyone knows what that is or lung cancer or something like that, but because MDS is so wide in its scope that it's tough to relay that to people.

**Moderator:** Along the lines in terms of communication. I think we've heard all day today the different themes in terms of working with patients and families as a team and a lot of you have mentioned good experiences that you've had with doctors and nurses as a part of your team. Can you offer any advice in terms of communication or things that have worked well or have been challenges in terms of working with your healthcare team wither it be doctors, nurses or other multidisciplinary members?

**Attendee 1:** I think they do a great job myself. I'm sorry. I didn't mean to interrupt.

**Attendee 5:** That's okay.

**Attendee 1:** I know I've fired many a primary care because they don't listen and everybody here listens. I mean, they do. They look you straight in the eye. They listen to what you say. They laugh at your stupid jokes. They really care.

**Attendee 5:** My thing was communication is one of the biggest part of everyday life and ask questions and if you don't, I mean like I had (wife). I mean, I didn't have to ask any questions. She had them all, all 150 of them. Right, Dr. Lowrey? So, just ask questions. Don't hold anything back. There have been a couple times when I was afraid to say a couple things and Lynn knows that and I don't know how many times I've called her to ask a stupid question, but communication. If you don't have the communication with your medical team then you've lost it. So, there you go. Right there. Okay. I'm done.

**Moderator:** How about you, Attendee 3 or Attendee 4?

**Attendee 3:** They've always been very clear with me. Anything I need, I'd call up any time. I've had problems before with other places but not here.

**Attendee 4:** I think one of the biggest changes with (Attendee 3), too, was his original PCP that kind of started him on the path of this. He's moved on to more administrative and, so we've lost him. So, (Attendee 3)'s getting used to a new PCP and there are different people and because I do work I don't get to go to all the appointments with him where I would ask more questions

than he does. Sometimes I just want to give him a list because he's also not one that gives a lot of details.

**Attendee 3:** Don't need a lot of details.

**Attendee 4:** So, I have more questions than he does, but so that parts a little challenging too so then I try to do it where every once in a while I'd get to go with him to the appointment and ask my questions, but the team's always like it's really good.

**Attendee 3:** I have trust, so I don't ask a lot of questions. I trust you guys. You guys know what's best for me. I'm not worried.

**Moderator:** Dr. Hill?

**Dr. John Hill, Jr.:** The question is I don't know if I speak for the other providers or not, but in talking with perspective transplant patients we describe what we think is the scenario, but we have to be quick to admit that we've never been through a transplant and sometimes offer that there are patients that have said if anyone ever wants to ask me about a transplant I'd be happy to do that. So, I would ask (Attendee 5) and (Attendee 1) just for the benefit of the folks here. Looking back on things is there anything that you would do differently and certainly would you do it again if you had the opportunity? Specifically, what would you do differently? Would there be any advice you could give to someone that may be thinking about this process?

**Moderator:** So, to repeat the question which was actually the next one on my list. If you knew then what you know now would you do anything differently?

**Attendee 1:** Me? No. I don't think I'd do anything differently. Maybe walk more before the transplant. I think there were times that I just couldn't do it afterwards and then once I finally got walking the more I walked, the more I did that the better I felt and my appetite came back sooner and everything like that. So, I guess that would be the only thing that I would do is getting ready for a transplant is get on a walking schedule or a light/low impact exercise schedule, walk the dog or whatever, but would I do it again? Absolutely. I would. I mean, there were times... I mean, (Attendee 2) described a couple of times during my stay in the hospital that were extremely difficult for me, but I feel better now than I did before I had the transplant. I was raised to put up and shut up and so when I was bruising, when I was feeling really exhausted and I just chalked it up to getting older or whatever and I didn't say anything. So, it was probably coming on before my primary care found it with a CBC. So, yeah. I would definitely do it again.

**Attendee 5:** I wouldn't change anything. People ask me you should get a second opinion. Well, I had two or three. I had Dr. Eisemann which really never told me what I was up against. Dr. Hill did. Dr. Lowrey. Dr. Meehan. So, I had three, but would I change anything? No. I mean, yes, I have bad days and I have good days. Would I talk to somebody about it? I already have. You

meet people on Facebook and, “Well, I heard you had this. Can you give my brother a call?” or something like that and we’ve talked on the phone for hours about it and I still have that... that’s an open invitation for all the staff here. I would do it. I wouldn’t change it for the world. Nothing. There’s a lot of things that I can’t do or I don’t feel energetic. My poor yard is gone to pot, but and I don’t mean that literally, Lynn, because I heard that laugh, but no, I had a great staff and, again, One West was the best. I can’t say anything more about it and I wouldn’t change anything.

**Moderator:** A new diagnosis of MDS or going through a transplant can be a strange experience in terms of really forcing you to slow down and retreat from the world a little bit. How was your lifestyle changed since your diagnosis? Did you resume your old routine or create a new one? Have you developed a new normal? Do you think your life is different now?

**Attendee 3:** I have a different lifestyle. I mean, I was working construction. I’d eat anywhere, anything. Well, now I’m very fussy where I eat, where I go, what I go into. Very fussy on a lot of things. Just to be safe (inaudible 40:34). I don’t want to get sick.

**Moderator:** So now, you don’t even think about it? Those things are incorporated into your daily routine. (Attendee 1), (Attendee 2)?

**Attendee:** Well, I’m still pretty early in my recovery and so as far as creating a new normal it’s kind of an evolving thing at this point. (Attendee 2) and I got married, what was it? Nine days before my transplant or something like that... No, a month and nine days before... and we got a new house and all of that and my stepdaughter’s coming to live with us. So, everything is kind of evolving right now, but it will not be what the way I was living before because like I said, family is family and that’s the most important thing whereas most of my life I’ve been a workaholic and I’ve worked 60, 70, 80 hours a week and now I work 40 hours and that’s it and I come home and I spend weekends at home, holidays at home and I don’t give up that time because all of that time that you give up you never get back. You can never get it on the other end because you don’t know when that other end is going to be there.

**Moderator:** That’s certainly a theme that we hear a lot with our patients is a diagnosis of whatever it may be, cancer or MDs and looking ahead forces you to slow down and appreciate the little things, appreciate the things that are important to you in a way that you weren’t able to appreciate before your diagnosis. (Attendee 5), do you want to comment on kind of your lifestyle now, a new normal?

**Attendee 5:** It has changed after my transplant. I slowed down a lot, considerably. Things that I used to do I don’t do anymore. I was big into photography and since my transplant I didn’t do it. I just finally got packed my camera stuff in the car and took off. In Vermont there’s all kind of old buildings ready to fall. I like to take pictures of that. I’m more of my donor. We’ve talked, a young guy, but you do change. Your life does change. I still eat like a pig. I’m Italian. What

more do you want? I could sit eating pasta 24 hours a day. It doesn't bother me, but it's the attitude. If you have a great attitude and you're very, very positive, you can conquer anything.

**Moderator:** Thank you. I'd like to give the opportunity to open up questions to anybody in the audience who has something that they would like to add.

**Q4:** I'm divorced living by myself and my daughter just graduated college. She's on her own and the family's far away. How do you go about doing all this if there is no caregiver?

**Attendee 2:** I was under the impression that you couldn't... I don't know if you need a transplant or not, but we were under the assumption that you can't have a transplant unless you have a caregiver. They don't have to live in the home per se, but you got to be pretty close in case they need something pretty quick. So, you have to find someone, a friend or adult child or something like that and if he had still been alone, I don't know what he would have done.

**Attendee 1:** All your senior centers. We have one in town, too, that I've talked to a lot of times and though they're not medically trained or they don't know the terminology, I just say that's good they're sitting there talking to you. That's one option.

**Dr. John Hill, Jr.:** This is an issue that isn't completely unique to you and so it's come up periodically and the way we've dealt with it is we try to be as creative and flexible as possible. In the few cases where it's occurred, the individuals generally had a circle of friends that on a rotating basis were willing to say, "Gee, I'll be the caregiver for Tuesday," or maybe Tuesday, Friday, whatever. Three, four, five friends that agreed that they would on a certain day they would be the one to kind of look in on you and so the main thing we kind of think about, a couple things. One is having someone to come to the appointments with you is really helpful. Often it's overwhelming. You're already fatigued after a transplant or you're overwhelmed at the prospect of a transplant. So, you may get about 50 percent of what's said. Hopefully the other person gets the other 50 percent and on the way home you can say, "Well, what did they say about this, or... So, that's important and then post-transplant, you're fatigued and having someone with you, again, two ears is better than one, help with the medication list, that sort of thing. Someone that also can check in on you. Let's say you wake up one morning and you're ill. You have a fever. You're not feeling well. There's always that tendency to roll over and say oh, I'll be better in a couple hours unless there's someone that's either there with you in the home saying, "Hey, you don't look so hot. Maybe we should check your temperature and call the clinic," or someone that calls and says, "Hey, today's my day to check up on you. How are you hanging in?" and then you say, "I'm not feeling well," and then one thing leads to another and that way an intervention can be made fairly quickly, but basically that's the issue. Friends or family that while they don't live you are willing to be a caregiver in shared way. We've also toyed with the idea of do we have supports in place amongst our staff that we could sort of have surrogate caregiver team approach where we do the calling and to be honest it's tough. We haven't quite come up with the scenario where if someone had no caregiver prospect whatsoever

that it was necessarily going to work, but we're working on stuff like that because we want everybody to go to a transplant that is eligible and for whom that would be the best treatment.

**Q5:** Actually, I have two questions. One is touching on what Dr. Hill just said. Is there a service through local VNAs that provide any of that post-transplant care for patients? Do we know that?

**Moderator:** So certainly, we have transplant patients who go home and need additional VNA support whether it's just somebody checking the accuracy of a medication list or checking vital signs. More frequently than the clinic visits, but they're not necessarily in tune in the same way that the transplant team would be. In those situations, we hope to work with the VNA nurses as providers and nurses to kind of be another source of support on the other end of the phone.

Any additional questions from the audience for our panel?

**Q6:** I work in a facility with patients like yourselves and your caregivers. I would ask if either the patients or the caregivers have any advice for me as a nurse that I can forward onto my patients and caregivers. I know one of the things that I might struggle with the most is reassuring and trying to support the caregivers to take care of themselves because they're not really any good to their patient or family member if they themselves are worn out. Do you have any suggestions on how I could be of better service to my caregivers that I'm dealing with on a daily basis?

**Dr. John Hill, Jr.:** I know I'm not a patient or a caregiver, but I think what we found is just acknowledging because we forget to do this a lot. We're so focused on our patients. Every now and then we just take a step back and acknowledge that the caregiver really has a tough job that it's probably as hard as the patients, it's just different because the patient gets the attention and the focus and the caregiver is the bad cop at home. We say you need to make sure the call is made if the patient's not feeling well and sometimes the patient isn't... You know how men are. It's often the scenarios that the man says I feel fine, honey and then later on it comes out and then sometimes we holler at the spouse because we say, "Well, you're the caregiver you should know." That's probably unfair but the bottom line is when we stop and say, "Boy, you have a tough job and you're doing a great job here." You're really keeping this person going. I think it means a lot just to acknowledge it.

**Attendee 1:** With a smile on your face.

**Attendee 3:** I think any words of comfort for him.

**Attendee 1:** Yup.

**Attendee 3:** They got the harder job.

**Moderator 2:** I definitely think that it's an area where we as nurses have not done a lot of what is the role of the caregiver and, I mean, I really feel that that's probably one of the weaknesses in our program and it's kind of an issue that's really dear to my heart. So, we do have a social worker student who's really looking at caregiver burden and then is there a way to help. We have implemented the distress tool to try to identify what our patients are experiencing because we know when you're very stressed you can't be as compliant with the plan of care and interestingly most of the time my caregivers are sitting with their husband and it's very, very apparent that the patient kind of feels he is here and the wife is like here because she is taking that caregiver role. So, we're just really kind of struggling. Do we need to kind of have a caregiver class that caregivers come before the actual transplant to kind of guide them through that? Do we need to kind of have a caregiver support group? We do have one for anybody who is in the caregiver role, but I think the cancers that we deal with and transplant really are different than when you're really kind of responsible for someone doing a really specific episodic part of their care and the MDS journey can be over many, many, many, many years and our panel has really kind of stressed that. So, how do you kind of stay in that role for that time.

**Moderator:** The few things that I tell patients and caregivers when I'm doing education and I don't know if it helps or not, but I do it anyway is to remind the caregivers to drink, exercise, do something every day that makes them feel good whether it's just a little extra time reading a book, an exercise class, manicure or something like that and not forgetting to just take care of themselves every single day.

Anybody else from our provider team have questions or comments? No. Okay. Well, at this point we'll offer Sue some time. Did you want to have some time to talk about your program and the patient education materials?

**Sue Hogan:** I really didn't have anything prepared, but we did want you to when you have chance you haven't already looked at our *Building Blocks of Hope*. That's a great, great piece of... it has so much information in it. It was put together by Sandy Curtain in our Nurse Leadership Board. It took a long time to get together and it's always evolving. That's why we have it in little separate chapters because it doesn't pay to print up a whole book and every month something new happens and something new is changing. So, it's the most up to date piece of information that we give out and we even translate it. We have it translated because we're international. So, please if you haven't had a moment to look at that do when you go back take your time. It might take a while to go through, but it's really valuable. It's also on our website. That being said, please visit our website. We have other resources on there. If you get back if you have any questions we have Audrey Hassan at our office. She's our patient liaison. You may have spoken to her already. I'm not sure. She's really, really great and she has other resources she can give you. If you have questions she can send them on to our Nurse Leadership Board or our doctors. So, we try to keep everything alive and I'm trying to think of what else in... Oh, if you could fill out the evaluation form for us that Dee gave out, too. That's very helpful, too, because as I said I absolutely... I don't know how you feel about this panel. We never really had



a patient panel at one of our patient forums, but I do like this and I'm thinking maybe going forward we're going to use it in future patient forums. So, I hope that was helpful to you, too. In any case, just call the Foundation if you have any questions and we have different... We're very resourceful. We have ways to find answers for you. So anyway, thank you for coming today.

**Moderator:** So, just to kind of close out and summarize for our audience here one final question. This is your chance to tell the audience any words of wisdom if you're a patient or if you're a caregiver kind of how to support the next generation of patients and caregivers with MDS. I'll start with you, (Attendee 5).

**Attendee 5:** The next generation of MDS patients. Wow. I guess what I've been saying all the time. Keep a positive attitude and communicate with your medical team and I don't know... I guess that's pretty much it and keep a smile on your face. I'm big on that. Your turn.

**Attendee 4:** I think more forums like this in different areas would be fantastic because it gives us all a chance to connect and because it's such a wide range diagnosis that I'll get more information on it.

**Attendee 3:** I guess as a patient just tell your caregiver how much you appreciate what they do for you and if you can do anything at all, I mean, a load of laundry, you do dishes, anything like that to help them out while they're away and you're at home it really helps them. Make sure you tell them how much you appreciate them.

**Attendee 2:** I guess I would say to have faith in your physicians, nurses and all the support people. They really do care and they really have your best interest at heart and I'm so glad we didn't decide to go to Boston. I'm glad we stayed here and I think the caregiver instruction class whatever you want to call it, I think that would be awesome. I mean, just because I'm a nurse doesn't make me any better of a caregiver than anybody else. So, I mean, I'm his wife first and foremost. So, I think that would be awesome.

**Attendee 1:** From what I watched my wife go through while I was going through the worse part of the transplant my advice would be when you start out have a caregiver for your caregiver and someone that can say, "Hey, you know? You're way too tired. Let me go visit him tonight. You go take a bath or something, take him out for a coffee or whatever. Poor (Attendee 2) with everything she had going on in the background, there was no one there to help and I wasn't really in a condition where I could help from a hospital bed as much as I wanted to and then there were days that I was just... I was intolerant of everything, but yeah, they talk about the patient and a caregiver. I would think that the caregiver needs to have as much support if not more than we do because we have the doctors, the nurses, the LNAs and everyone that's here and the caregiver comes and she's the caregiver here and then she goes home. She has laundry to do. She has all this stuff to do. Take the dogs for a walk and the whole thing. I think that would

really increase the effectiveness of the caregiver because they do get worn out and (Attendee 2) got worn out about half way through.

**Attendee 5:** Back to graft versus host. I'm sorry. Is there an organization like the MDS Foundation for graft versus host? Don't tell me to look on the Facebook because I have and I read some horror stories, but I've also saw some good ones, too, but is there an organization for specifically for that? And the answer is no.

**Attendee 1:** You could be the founding president.

**Attendee 5:** Nope. I'm going to call Audrey next week and tell her to do it.

**Sue Hogan:** I'll tell her you said that.

**Moderator:** The BMT InfoNet does have... I don't know if you've checked out their website and the information that they have and they have a lot of information about quality of life after transplant, graft versus host being a huge portion of that. BMT InfoNet and they have a symposium every 18 months for... it's symposium that's held in different places in the United States and they have one coming up, I think, this month. I don't know where it is this year. It might be in Florida.

**Attendee 1:** I believe it's in Chicago.

**Moderator:** It's in Chicago? Okay. And all of their seminars are posted on the Internet. So, they always have a big component in terms of quality of life and living with graft versus host disease.

**Attendee 1:** I think we should do one here. I'm serious. And (Attendee 5), Susan Stewart, the founder of that, is very open. I think her phone number is even on the info that comes out. If you don't find something about GVHD that's helpful, you can certainly call and this is going on for 15 or 20 years that she's done it.

**Attendee 5:** What's her name? Stewart.

**Moderator 2:** She's the author of the allogeneic book. If you don't have it, I'll give it to you.

**Moderator:** She's a patient and survivor of, I think, she had Hodgkin's disease or non-Hodgkin's disease, but...

**Attendee 1:** (inaudible 1:02:39)

**Moderator:** She develops this Foundation and it has developed patient materials because when she went through transplant she found that there was a gap in terms of education that written

from the perspective of the patient. So really, that's what her organization is centered around is making things accessible to the patients and the caregivers.

**Attendee 5:** (inaudible 1:03:03).

**Attendee 1:** We'll write up a proposal together.

**Moderator:** One more question?

**Q7:** You talked about caregivers as being women. What do you do for male caregivers? I think that's quite a different issue from a female caregiver. Their challenges, I think, probably are different.

**Dr. John Hill, Jr.:** It's a great comment and I was thinking about that. I sort of made an unfair generalization. We joke a little bit because men often are stoic and don't want to discuss their symptoms because they want to protect their spouse and maybe some women are the same way, absolutely, but certainly we have many, many female patients and male caregivers. I think the same comment holds true that we need to support our caregivers more than we're doing and we need to acknowledge the challenges that the caregivers face whether they're... irrespective of gender and I love the idea of a caregiver for caregiver, (Attendee 1). Maybe we can work on that, pilot that or something. It's just great because it really doesn't matter, the gender. It's a tough, tough job and...

**Q8:** I got a comment. As the male caregiver, I want to jump in here. I don't want to sound selfish, but sometimes I get so tired and the first thing somebody says when they meet you is how's your wife? I wish they would ask me how I'm doing first. I don't want to be selfish, but sometimes I love her, I want her to get better, but at the same time it's like I don't exist and I'm not trying to be selfish. That's just the way it is.

**Attendee?:** How are you?

**Q8:** I'll tell you what. We had an experience Monday. I might want to back up just a little bit. A year ago when we first got the diagnosis, she had started out in December by having a majority of her teeth out to get dentures and her gums and jaws would not heal. It was actually the dentist that told her to get another blood test and then two weeks ago she come down with a macular degeneration in the one eye. Monday, we were going from... We're from Michigan. We were going from Belleview to Lansing for her first injection into her eyeball for the macular degeneration. As we rounded the curve on I-69, there was a body laying in the road. We kind of forgot what our problems where. As it turned out we found out after we got out here it was a 16 year old boy jumped off a bridge to commit suicide and we were like 30 seconds behind it happening. So, you kind of get a sense that things are bad, but maybe they're not as bad as you

think they are. So, we enjoy traveling together. We have a lot of fun together. Most of the time life is good.

**Q9:** I have a question. For like you're traveling quite a long distance. We are four to five hours away from about and I've always thought if he comes to this point of having a transplant am I going to relocate down here for a while because I can't imagine and maybe you could answer that, too, right after the transplant he's going to up the traveling four or five hours for appointment or if we're going to have to relocate for a while.

**Q10:** I'm not going to come down with it though. Mine's not going to progress.

**Q9:** I thought do we get an apartment down her for a while for so many months or something like that because I just can't imagine him wanting to take that trip back and forth.

**Attendee 2:** (inaudible 1:07:35) back and forth to see my daughter (inaudible) so I wouldn't put him through that.

**Dr. John Hill, Jr.:** I'm happy to defer to colleagues who may want to comment and we have to make the point that no two patients are alike, but in general our patients when they come in for a transplant there are certain criteria before they're discharged that they're ambulating on the ward, their activities of daily living essentially would be intact. They're eating and drinking enough. No active infections. They're not overly dependent on transfusions. All of those criteria have to be met before they leave the hospital and for the most part our patients that come down from Maine, we make sure that they're able to travel back home and when discharge is done and there is a relatively quick follow up, but we also have a good follow up coordination with the doctors in Augusta so that it's usually rather than bringing you back every week it's usually alternating. So, the doctors and nurses in Augusta are empowered based on discussions we've had with them to kind of know what to look for and we have a very close relationship. So, maybe with an occasional exception, I'm not aware of too many Maine folks having to set up temporary residences down here and that sort of thing. So hopefully since that's one more thing on top of everything else that you're going through, hopefully our patients are pretty much back on their feet by the time they go home even though, obviously, it's a case by case basis.

**Attendee 4:** I know if it got to a point where you can't travel there is a place in Maine where you can get a hold of these pilots that will fly you for free to these hospitals.

**Moderator:** Okay. Well, thank you for so much... everybody for coming. Thank you so much to our panel and our patient and caregivers.

(Applause)

