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**Speakers:**

Ronan Swords, MD

Mingjiang Xu, PhD

Stephen D. Nimer, MD

Krishna V. Komanduri, MD

Jessica MacIntyre, ARNP

Vanessa Ruiz, LCSW

**Jessica MacIntyre:** So, it's my duty to give you a lecture while you're eating. So, I hope you don't fall asleep. Thank you for sticking around. My Name is Jessica MacIntyre. I'm a nurse practitioner here at Sylvester Cancer Center. I work with Dr. Nimer directly. I'm his nurse practitioner, but I also do a lot of other things - part administrative as well improving the patient experience at Sylvester. I also chair the Patient and Family Council which actually provides input at advisory to our leadership from the patient perspective. So, been in this role for about a year and a half with Dr. Nimer and I'm really honored to be here today. So, I want to thank the MDS Foundation and Dr. Nimer for inviting me to speak on the *Building Blocks of Hope, a Patient and Caregiver Guide for Living with MDS* and I know that you got your guides on the table. I won't be referring as much to it, but you can kind of skim through it while I go through some of the slides and I also want to thank Sandra Curtain who's one of our nurse leaders on the MDS Foundation for providing the slide deck for today.

So, as Dr. Nimer mentioned, the MDS Foundation is an international foundation and they also have an International Nurse Leadership Board and these are all the nurse leaders involved including this *Building Blocks of Hope* guide for you together.

So, just to start when we're in clinic there's a couple questions that come up. The first one is what MDS is and I know that you had a really nice detailed discussion with Dr. Swords about what MDS is. There's always some confusion when patients come in. So, we do take a lot of time in that arena to discuss what it is and it's always taking it down to the patient's perspective and the patient level and one of Dr. Nimer's favorite quotes is it's a funny looking bone marrow. So, it's nothing that your bone marrow is... it's not a normal bone marrow in general. It's just something that looks funny, but it's not really cancer yet. It's in the dysplastic form.

Another question that we get is when do we start treatment? Patients do get very anxious because they don't know if they should start treatment, if they should wait, if they should observe and a lot of patients in that observation period also get very anxious because they feel like they're not really doing anything for themselves. So, there's a lot of treatment triggers that let us know when is the time to start treatment and I know a lot of this is repetitive, but I just want to go through it a little bit quickly just as a refresher.

So, when do we start disease modifying treatment? So, when we see that there's a transfusion dependence. So, about 80 percent of our MDS patients have anemia and that's the major one that

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we see on diagnosis is a low hemoglobin level and most patients do come in already having received a blood transfusion. So, when we see that the dependency is getting more frequent then we start questioning whether or not we should start treatment.

Progressive or symptomatic cytopenias. As Dr. Swords explained, cytopenias are just low blood counts. So, a low white count, a low red count and low platelet count. So, if we see that the progression is starting to get worse then it kind of triggers us well maybe we have to perform another bone marrow to see what's going on. When we perform the bone marrow if we see that there's an increase in blasts then we know well maybe this is starting to transform to leukemia and we need to start treatment or the blasts are getting higher.

High risk disease we talked about the IPSS scoring system. So, patients that are high risk that does trigger us to start treatment on those patients versus those that are low risk, but again not just treatment triggers. These treatment triggers cause us to say oh we should start treatment, but definitely we do look at the patient as a whole. So, there are individualized factors that go into deciding whether or not we pursue with treatment.

Performance status. Does anyone know what performance status is? No. It's a medical term to kind of suggest how well is the patient clinically doing in activities of daily living. So, anything you're doing at the house. So, if you're in bed more than 50 percent of the time or in a chair or not active then that's a performance status of three and that's a poor performance status is what we call and those patients tend to do worse on treatment than do better on treatment. So, we like to optimize those patients until starting treatment. So, that's the other definition is fit versus frail.

Comorbidities, we have patients with comorbidities nowadays. We're living much longer. The life expectancy now in the United States is over the age of 80, around 83 – 84 for men and women. So, as we see more of the aging population we see more of other things coming to be. So, diabetes, heart disease, any pulmonary issues, people that have smoked in the past may have pulmonary function issues with COPD, liver issues coming from a long time or from previous medications. So, I love it when the construction goes on on the weekends. So, anyway, so comorbidities we have had a patient that has really poor renal disease, as an example, and to try to determine and he's high risk, to try to determine whether to start treatment on him or not is a decision because there's really no studies looking at renal function and patients with poor renal function with the hypomethylating agents like Azacitidine or Decitabine. So, those are things to consider and those are things you have to talk about with your doctor because there's a risk of toxicity that we may not know about with kidney function.

So, when we looked at IPSS risk category, we saw that the lower risk improves with hematopoiesis which improves quality of life. So in other words we pretty much use supportive care in this area. Higher risk we're looking at survival as a goal because know that these patients have a short life expectancy.



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Primary versus secondary MDS and what primary means is that it's a primary MDS that didn't come from something else as a factor giving them the MDS. The secondary MDS is due to chemo or previous radiation or something else causing the MDS and those patients tend to do more or poorly or poor than the primary patients.

The cytogenetic status. We talked about deletion 5Q. Those patients tend to be individualized to treatment with Lenalidomide.

And, of course, we tend to look at lifestyle because this does impair your routine. Coming into treatment or to get supportive care it is cumbersome to your routine and work or in just general your home routine. So, we have to consider so, for example, if a patient does not have transportation to bring them to be able to get transfusions very often we have to kind of figure out what are the other options for this patient and also personal choice. We do give the patient the choice to decide based on the information that we give them, but it's also your choice. So, you need to think about what it is that you want and what the ultimate goal of treatment is.

And you guys can stop me if you want to ask questions anytime I'm free. I'm very informal that way.

So, I know Dr. Komanduri touched a lot about allogeneic bone marrow transplantation. It remains the only potential cure. This is not an option for many patients as he mentioned. Age although, of course, we saw the increase in transplants with increase in age now, but we still have to take that into consideration. Some people may look 75, but some may not feel that age. So, maybe feel older. So, we have to take a look at how functional they are not just the age and the patient. As I mentioned, comorbidities if they have a history of an infectious process like HIV, hepatitis, those people are excluded from a transplant as well. Non-availability of a suitable related donor. As he mentioned, there's even though we have donor match programs a lot of times it's very difficult to find a donor that completely matches the patient. Sometimes they'll find a half match donor. So, that tends to be one of the issues that we find also with limitations with bone marrow transplant.

So, we talked about age alone should not exclude active therapies, but we do consider the performance status as well in transplant arena. All active therapies for MDS require time to work and we'll show you a little graph that shows you kind of visually because I like visual aides to kind of let me know how long it takes for these agents to work. So, it does say that four to six months of continued treatment is required to evaluate effectiveness and blood counts do get worse before they get better and that's something we need to make sure in the back of our minds we know because we do get a little anxious if we don't see a response right away. Unlike other cancers like lymphoma that we see a quick response when we see the lymph node decreasing in size or even in other solid tumors we see responses to chemotherapy much sooner, it's not the same disease and we have to kind of understand the disease process to be able to understand how much time we need to wait in order for things to get better. So again, plan ahead and we have to

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set expectations with the patient initially and for you to know that there is an expectation that we may not see anything right away and, of course, proactive management of side effects in the early phases of treatment are key to obtaining the best response. So, if we act right away on the side effects of your treatment, you'll be more likely to continue the treatment and more likely to adhere to it.

So, why is time required? So, we have to consider what's happening before the treatment begins. So, we do see blood counts drop as MDS progresses. So, this is what the main definition of MDS is. The normal blood cells are crowded out by abnormal stem cells in the bone marrow and the blood and you can see a little picture there of all the abnormal blood cells. There's some normal ones, there's some baby ones. So, there's a mixture of things in that little petri dish there and then we do see when the treatment is initiated that it cleans the marrow blood counts. They may drop further, patients experience hematological toxicities. Hematological means your blood counts may drop and you see that suit down there in your little graphic and also the graphic on the other side on the right hand side of me but the left hand side of you probably it's ANC which is the absolute neutrophil count and this is your total white count. So, your baby cells and your big cells of white count this is what the total is. So, we do see that when we start treatment you may have started at a 3.2 level initially there but then after six weeks you can see that bottoming of the white count but then as you see you progress up after 11 – 12 weeks you start stabilizing your counts and you start to go back up. So again, knowing that this does take time to work but then as patients begin to respond you still see that leveling off of counts, but you also see normal blood cells coming back into play in that little graphic on the bottom and then the response continues and then you'll see a continuous amount of blood cells that are normal blood cells continue to produce because of the treatment itself is responding. The challenge is getting through the first few cycles and that's where we tend to lose patients a lot. So, patients, of course, get discouraged that they don't see a change in their blood counts so we have to, again, make sure that we set expectations for them and that they know that this is not going to be something that's going to rapidly improve over one or two weeks after starting treatment.

So, the key principles of therapy for MDS is time is required for a best response. We talked about four to six months. Cytopenias often get worse before they get better. There are strategies for getting through the initial cycles. We do tend to dose modify sometimes we have to delay patients one or two weeks before starting the next treatment so that they can recover in a sense because sometimes you do need that little break in order to feel like you can go onto the next treatment and we understand that.

Supportive care. So, even though you're getting treatment you still may require blood transfusions, platelet transfusions. You may require growth factor support like Neupogen or Neulasta. So through that time you should have a caregiver that is supportive of you in that way and providing alternative treatments to help you get through your treatments and also we talked about setting expectations.

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So, this is just a graph of the trilineage response following four cycles of Azacitidine which is one of the agents we use in MDS. As you can see trilineage means just three lines of your blood cells which is your hemoglobin, the pink line; the platelets are your beige line and then the white blood cells are the blue line and as you can see after four cycles of Azacitidine with the hemoglobin you kind of see of an up and down influx. So, you'll have this up and down unstable blood count for a while and then you see the platelets they'll start to recover about to cycle three and you'll see that increase in the platelet count and then with the white blood cells you may not see the upwards movement until that actual fourth cycle. So again, it's sporadic of how your blood counts will respond and it's not going to be one trend versus another. You'll see various sporadic trends.

Yes?

**Q1:** (inaudible 14:00)

**Jessica MacIntyre:** So, here it's actually not elevated. These numbers are within the normal or actually a little bit below, some of them. So, if you have a white count it might be concerning for other things if it's too high. So, we may need to do a bone marrow to make sure that it's not transforming to leukemia at that point, but sometimes it can get super high. Yes, and it might just be because of the growth factors we're giving as well.

**Q1:** (inaudible 14:31) super high.

**Jessica MacIntyre:** I would say above 10. Anything above the normal, above 11, I mean, you have to consider where you start your white count and see your trends. If we see that you were always at a four and now you're 18 then that's a considerable increase that we need to kind of look into, but if we know that you are on a growth factor support like Neupogen or Neulasta we may contribute that high white count to that as well and that's a good response to that.

**Q1:** Procrit.

**Jessica MacIntyre:** Procrit is also for the hemoglobin. So, if we see an increase in the hemoglobin with Procrit, yes, we may think it's due to the Procrit and that's a good response. We want it to go up, but there's a certain level we have to stop with Procrit so that it doesn't get too high. So, we monitor that closely before we give you the next injections. No problem.

So, this is the other treatment that we can provide patients with MDS that have that deletion 5Q which is the Lenalidomide. So, as you can see with this patient this patient's been on treatment for over 10 years and that's what Dr. Nimer was mentioning is that we can have these patients living chronically with this disease continuously on treatment and you'll see that stabilization between the counts over that period of time. So, there are good responses with treatment and it

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may just be a stable response, but a stable response is good because that means your blood counts are normalized for you.

So, this is kind of leaning into the nursing part of things. We tend to be the ones that kind of sit down with patients and talk about a lot of the quality of life issues most of the time and I may be leading into Vanessa's talk a little bit, but I'll try to be as brief as possible not to move into her talk, but balanced diet. You did talk about a little bit about that with Dr. Xu from our research and reference to vitamin A, vitamin C, really a balanced diet for us is just eating as healthy as possible. Proteins are good source of healing for yourselves. So, we do recommend high protein depending on your if you have comorbidities or things like that then we have to kind of a nutritionist assess whether or not you can be on a high protein diet or not, but protein is a very good healing nutrient so that way you can have the healing process and be able to continue being active just trying to continue your healthy eating routine is important for us in general so if you're not eating then it's going to be kind of detrimental for your treatment because you're not going to have the energy to do the things that you want to do because your nutrition is not up to par. So, we do recommend is if you cannot eat and a lot of patients don't have an appetite, a lot of times it's because of the fact that there's so many multifactorial things going on. So, like anemia can contribute to a lot of things not necessarily just fatigue, but the fatigue can cause you to feel down, can cause you to feel not wanting to eat. So, it leads to like a domino effect. So, you don't eat, you get fatigued, you get depressed, you don't eat. So, the thing to maintain is a balanced diet. Continue eating as much as you can. A small frequent meals is always been what we have recommended. Yes, I heard about supplements. Supplements are recommended if you have them as a meal supplement. In other words if you don't want to eat breakfast, lunch or dinner you could have a supplement to replace that meal, but we do recommend at least you have some form of solid food throughout the day if possible because if you're only having supplements that's not really going to be good for your body just having supplements completely. It's not going to be a balanced diet for you. So, that's kind of my little thing on diet. If you have questions about that definitely I'll take those whenever you want because I know that's always kind of a hot topic with patients.

Daily activity and exercise. So, I always tell my patients I come from a Hispanic background. So, a lot of our Hispanic mothers always tell us, you're sick just stay in bed, don't move, you just got treatment, you got an antibiotic, just stay in bed, relax. No. For us, we want you to continue to be active because if you sit down in bed if you are laying down in bed too long your body gets used to that condition so when you try to do something it's going to be much harder for you to do it if you've been in that stagnant position for a very long time. So, keeping your activity level up to par is important even if it's just walking five minutes one day and then walking 10 minutes the next day. Just increasing your activity level per day will help you sustain the stamina to get through treatment as well and for us to be able to recommend treatment. If you want to receive some form of treatment we have to see that you're active.

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Avoiding infection. So, patients that do present with a low blood count or low white blood cell count has a risk for infection. So, the main thing to protect infection is by washing your hands. That's the number one rule. In hospitals, in your personal life, at home handwashing is the number one thing you can do to prevent infection. If your white count is too low you may be recommended the growth factor support with Neupogen and Neulasta. So, those two things may boost your white count and help you prevent infection, but again the major thing is to wash hands. Be avoided of people that are sick for sure is one thing. Protect yourself if your white count is low. They're having recommendations on foods to avoid if you have a low white blood count which is called a neutropenic diet. However, those neutropenic diets have never been proven to say if I do a neutropenic diet my risk of infection will be lower. It's just something that we've said for a very long time that makes us feel more comfortable as providers to know that we're doing something to add to your... to lower your risk of infection, but in reality there's nothing to prove that by eating fresh fruits or vegetables you're going to have a higher increase of infection rate, but we do tell patients at the first cycle of treatment to try to avoid it because we want to see how your counts are after the first treatment. So, you can choose if you want to not eat fresh fruits or vegetables for the first cycle. Everything has to be cooked. We do recommend cooking the meats, the fish, the poultry all very well so that there's no risk of E.coli for patients with a low white count. That's the major risk is having something that may be us that are not on treatment can tolerate and somebody that has a low white count cannot. The main reason why a lot of people don't recommend fresh fruits or vegetables is because they can grow from the ground and the ground has some bacteria that's normal bacteria, but we wash it off when we wash our fruits and vegetables. So, sometimes that can't really be cleansed completely when we wash our fruits and vegetables. So, some people do recommend to just eat peeled fruits and boil your vegetables or you can broil them or bake them. So, that's some of the recommendations that are also in your book as well if you want to look at those in the section of the diet and nutrition.

Avoid bleeding. So, a lot of us do have low platelet counts. So, having a safe environment at home is important and making sure that you're not bumping yourself in the middle of the night because you can also bruise very easily with a low platelet count. Don't play any contact sports. I know you guys want to play football and basketball and soccer, you know, but don't get hit by anybody. Sorry it was a joke, probably a bad joke. Right? And then try to make sure that you do use precautions when you cook. Make sure you don't burn yourself because your healing process can be slower as well.

And continue to enjoy the things you love. You have to live. This should not stop you from living your daily routine. You should try to make adjustments in your daily life, yes, to meet the treatment expectations, but at the same time you have to do something you love and somebody once taught me always introduce yourself to the patient, build a rapport, but at the same time find out what they like to do because they may like to play golf and you never really inquired about and that's something that you're missing out and they don't really think that they can do it, but you can. You can go out and play golf as much as you can. So, do the things you want because



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that does help mentally. Helps put you in a different perspective. Make you forget a little bit about what's going on and maybe give you the stamina to continue fighting through treatment.

And get enough rest. Definitely a lot of people tend to be insomniac at night and they don't get enough rest during the day so they come late to their appointments, they miss their appointments. A lot of times that's due to worry and anxiety which I know Vanessa will probably stress on a little bit, but we do have resources and there's a lot of resources. If you probably ask your provider we have support services everywhere now. That's the thing. We have psychosocial oncologists, we have nutritionists, we have social workers that can help you kind of with a lot of these things that you have to deal with on your day in and day out that may not really have an answer for when you leave the clinic. So, we have resources available. You just, as a patient, I always tell my patients ask because if you don't ask you'll never know and so be your own advocate is a major thing that we talk about during in our clinics.

Take advantages of available resources. So, explore the *Building Blocks of Hope* and it's a great resource. I mean, as a nurse I have seen many educational binders, many educational books, but this is very nicely put together by a group of nurses and it's to the level of the patient and they have so many nice resources in there that you can actually explore nationally and internationally that may be of help to you and ask for help when needed because a lot of times we're so used to not being dependent on other people, but when it comes time to needing maybe that extra car ride to the clinic or needing help from the chair to the bed, you need to ask. Don't feel like it's something that you're burdening somebody with. You need to ask for help.

And be an active participant in building hope. So you can actually be involved a lot more with the MDS Foundation. There's a lot of ways you can get involved with them and Audrey is here and to be able to provide some of that information. So again, becoming a partner in your care, building your MDS plan on the tab five of your book, there's a really nice MDS manager. If you look into the book, it kind of has in nice detail an organizer for you so you can write down your blood counts, you can write down if you have a treatment that day, you can keep track of things because believe it or not 40 to 80 percent of medical information provided by providers is forgotten immediately after you leave the clinic and half of that is remembered incorrectly. So, I always to make a point to meet with my patients after the first clinic visit because they tend to forget everything, everything. So, we like to recap and make sure you know exactly what we talked about, but writing things down is super important because it helps you remember what was discussed and also having an advocate with you during the visit either being a family member or friend.

So, the *Building Blocks of Hope* as you saw has a section about understanding the disease, knowing your IPSS and how to categorize the IPSS score. It has ask questions about treatment options. Definitely you need to know what the schedule is because that's going to impact your daily routine, possible side effects, how to manage them ahead of time. We're going to help you prevent that emergency room visit if you didn't know how to do that beforehand. Consider





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lifestyle and transportation. Definitely as we mentioned before it has some good tips of how to manage those areas within your treatment and ask for help, as I mentioned. Become a partner in MDS journey and build your MDS plan. You can track your progress with it as well and I mentioned in the tab five this is where the MDS plan is. They do recommend you make extra copies of it before you start writing in it, so that way you have more later on. As we mentioned, MDS patients are living longer now. So, you may need a lot more copies.

And then some things that are up and coming is the mobile application which I think is pretty cool. Smartphone and tablet capabilities with Apple iOS and Android. So, basically it can contact both professional and personal all in one. They can have the symptom tracker, medications with reminder capabilities especially if you're on Lenalidomide. It helps to remind you when you take your pills, tracks your labs, your transfusions, your treatments, it could help download reports to print, upload reports to track and it can sync with your calendar to management your appointments. So, I thought that was pretty interesting that a lot of people are leaning towards apps now to help them remember things and to track things. So, this is a nice new feature that they're using within the Foundation and then they also have the opportunity to participate in a virtual support network. So, Google free account is recommended to be able to do the support network and it's tailored information based on your IPSS score. So, you're basically put together with somebody within your same risk assessment and comorbidity score and there's updates on available clinical trials, personalized info management on that support network and live support through the MDS Foundation is available, sorry, live support.

So, you've all met Audrey Hassan which is the Patient Outreach and Advocacy Program patient lesson and that's her information there. I believe it's in the binders. If not, I'm sure she'll provide that to you at the end of the program.

So with that, I say thank you. If you have any questions, I know that was kind of brief, but want to make sure that I touched on a lot of topics in the little amount of time I had.

**Q2:** What's IPSS?

**Jessica MacIntyre:** IPSS is that International Prognostic Score that measures if you're high risk versus low risk.

**Q2:** Where do you get that?

**Jessica MacIntyre:** You can actually go on the MDS Foundation. They have a really nice way or kind of got calculator that you put in your levels, your hemoglobin level, your platelet count, all the things that are required to assess your score and you put calculate and it'll tell you what your score is and if you're intermediate, high or low. So, you can actually go online and do that. There's a lot of things that's taken to place and a lot of factors that make us understand what your score is.



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**Q2:** You mentioned a couple drugs that there (inaudible 29:47) are there ways (inaudible) program as far as (inaudible) follow up and how long you have to take it and all this stuff and also is most of this medication (inaudible)

**Jessica MacIntyre:** Even more.

**Q2:** (inaudible 30:07)

**Jessica MacIntyre:** Even more. So, oncology drugs are becoming much more expensive now and harder to authorize through insurance companies. So, as a nurse it's kind of put on us to kind of get the preauthorizations to kind of the paperwork. We're working also with utilization review which is our case management team to help us with those prior authorization, also get support for our patients that can't pay for it. So, there's a lot of foundations out there that actually support patients that can't afford the medications like copayment foundations and things like that. So, it has been difficult in this era because everything is now becoming oral, oral tablets that it's become a very high cost for insurance companies to cover. So, it's becoming difficult for patients to afford. So, that's why we have foundations like MDS and other advocacy groups that help us to help these patients cover their drug costs. I referenced the Lenalidomide treatment, response time and how much time you should take it. As long as you're responding is as long as you should be taking it. So, if you're on Lenalidomide for 10 years you're on 10 years.

**Q2:** (inaudible 31:19)

**Jessica MacIntyre:** Yes. Revlimid is the other name for it.

**Q2:** Other name for it (inaudible 31:26)

**Jessica MacIntyre:** You have a trade name which is the trade name is the one you see kind of on the commercials and then you have the generic name which is the Lenalidomide which is in lowercase letters. Any other questions? Well, thank you so much for your time.

I'm going to introduce Vanessa Ruiz who is our social worker who actually specializes in helping MDS patients here at Sylvester Cancer Center and she actually gave the talk last year, so I'm sure you'll enjoy her talk today. Oh, I'm sorry. Sir?

**Q3:** (Inaudible 32:03) I've been here for several years (inaudible) know about it.

**Jessica MacIntyre:** So, we do... we try to limit as much we can in reference to paper pamphlets and brochures because we've heard from our patients that it's kind of overwhelming the amount of information that they receive but our social workers have all that information. So, when they meet the patients now they're providing information on advocacy groups and everything as well,



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but thank you for the suggestion. I know Dr. Nimer's on it. We should promote it. Right? Thank you.

**Vanessa Ruiz:** Good afternoon, everyone. I will be your last presenter for today and hopefully then that means you get to go home. I know it's been a long day, but I wanted to discuss a couple things that between the physicians and Jessica have been addressed, but as a social worker like she said I'm the social worker at Sylvester in Miami that works leukemia, lymphoma, MDS and multiple myeloma patients. So, I specialize with the blood cancer patients. I see a lot of things or I deal with a lot of things as a social worker that aren't really medical in its nature because that is not my scope of practice. My scope of practice is to help patients overcome barriers to treatment and I do that in many different ways and in that time period and when I work with patients I see a lot of issues come up with patients repeatedly and so those are some of the things that I will be discussing today in my presentation.

So, this one is just some quick tips for patients. I split it up into quick tips for patients and quick tips for caregivers because they are specific to each one and then we'll just have some open discussion at the end.

So, in this first one is for patients that have five tips for patients.

The first one is about being informed. It's been addressed a lot, but I want to make sure that you guys remember this. You have to be informed about your medical first and foremost. This begins with your treatment plan. So, what is your treatment plan, what medications are you going to be on, what are the treatment plan goals, what is the doctor aiming to do with the medications? It can be different for everyone according to what types of medications they're on. So, it's very important to understand not just your treatment plan but the goal so that you understand what is your progress towards that goal in the way that your blood counts come back and the other tests that the doctors do come back. So, it gives you a better of what is the doctor trying to accomplish for your disease. You should also be aware of what are the side effects for the medications, what things you should be looking out for so you can discuss with your medical practitioner. Also be aware of what locations may be available to you for the different things. For instance if you are a Sylvester patient, most of the physicians that work with MDS will practice out of here out of Miami. However, if you live in Broward and you need lab tests maybe you can get your lab tests done in one of our Broward satellites to make it a little bit more convenient if that's the only thing that you're going to get done. So, sometimes it's very important to understand what are those other locations and what kind of services maybe you'll be able to receive at those locations that may be more convenient for you. Also it's important to know what services generally are available at the center or wherever it is that you're receiving treatment. We here at Sylvester have a cycle oncology department and that includes a lot of different professions beginning with our psychiatrists and psychologists, two nutritionists, exercise physiologist. We have our therapist, music therapist, chaplain. We have many different disciplines and services that are available. In addition, we have support groups that are available for patients and we have other



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support like we have, I believe, we started doing chair yoga at some of the different centers. Mindfulness. I think they're called like mindfulness meetings and they discuss a little bit about mindfulness and the impact that it can have on your everyday living. So, it's very important to be aware of what services may be available for you. Like Jessica says if you don't ask you won't know because as much as we do try to advertise some of these services, it may be hard because whether where you're in clinic like she was saying there's a lot of paper. You just received a whole booklet of paper and that can be very overwhelming to go through. So, ask. Always ask. Whether you ask your physician, you ask the nurse, you ask anyone they'll be able to help guide you or connect you to the appropriate place. Another very, very important thing is to know and understand your healthcare insurance benefits. Most patients because of the way the MDS is, most patients are older patients and many of them are on Medicare, but some are on private... their private commercial insurances whether it's because they were still working or they had decided to do so. So, know, understand what your insurance is, what it covers, how it covers. If you have a private plan that usually means deductibles. Understand what is your deductible, how it works, your copays for visits, your copays for medications. When it comes to Medicare, Medicare is a very tricky thing. As simple as they try to make it, it is not. It is actually very complicated and there are several parts to Medicare. One of the things that I find that most patients struggle is when the doctor recommends an oral therapy the medication will be coming from a Part D... your Medicare Part D. It rarely is able to come out of any other benefits, usually your Part D and Part D is a separate little difficult thing to navigate because there is something called that Medicare coverage gap donut hole and what happens is these medications are all usually so expensive that they push you into the donut hole. However, there are some different assistance available and there are different things that can be done to help patients with that. So, it's very important to understand your benefits, how they work, what are your rights as far as your benefits, what are you eligible for and be able to understand how that's going to impact you and your treatment.

Also, understand your rights as a patient. One of the things that Dr. Swords had made mention of is being able to make informed decisions and that is made by asking questions. Ask the physician as many questions or the nurse, nurse practitioner as many questions as you need to feel comfortable and that you understand what it is the doctors... what treatments the doctors are advising you and that way you can make a decision that you know is based off of the information that was given to you. If you feel the need to do private research that's also good, too. There are a lot of... there's a lot of research nowadays that's available on the Internet through reputable sites. For instance, MDS Foundation has a lot of information. The Leukemia and Lymphoma Society also is a very good resource and a lot of information on MDS, on the treatments available, how they work, trials that are being done at this time. So, it's very important for you to be informed so that when you make decisions you feel like that was the best decision you could make based on the information that you received. It's also important for you to know about your right to refuse treatment. Sometimes you get to a point where you say that's it. I don't want to do anything else. I just want to be. That's also your right. So, please do not feel bad for making that decision because that is a decision that you have as a human being to say I don't want to do this



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anymore. I want to step away and you don't need to feel that anyone can pressure you into making that decision. Also understand your rights for privacy as for as your medical information which is where HIPAA laws come into play and advanced directives which is something that I'll discuss a little further, but those are also a right that you have especially when you come into a medical facility is that the right to be able to get an advanced directive.

And the next one I talk about speaking up. So, this is important and I know that Jessica talked on a couple of these things, but whenever you go into visit the doctor usually asks you how things are going, what's going on, speak up. Don't keep quiet the tiniest little thing because it may be very important. Understand that there are many different side effects that you may experience such as fatigue, bruising, bleeding, night sweats, bone pain, fever, skin rash, weight loss. All of those things are things that your provider needs to know and understand so that they can see as a whole how the medication is working for you because it's not just what the numbers are doing, but if the numbers are going well, but you're having a slew of issues that is not giving you any sort of quality of life and if you're expected to live like that for a couple more years to 10 more years as they've been discussing on how MDS has been changing that's not the quality of life you want to have for five to 10 more years. So, it's very important to explain to your medical practitioner the issues that you're having and if you're having some of them and they usually let you know from the visit if you have a fever of over 100, I think it's 101, know who to contact, know what are the phone numbers that you need to contact because that can happen in the middle of the night and you're not sure what to do. Make sure that you have the contact information of where your physician would like you to call. Usually, you end up calling the... there's a phone number for the on-call and from there they can direct you, but during the day if you're a Sylvester patient we have triage nurses and there's a triage line where you call with any of these issues and those nurses are there to help you navigate as to what would be the next step. So, it's very important to be able to discuss these things as they come up.

Also, if you're having financial difficulties and this is one of the areas that I work with often let your provider know. Usually, if I've met you before I give you my information or if your social worker has met with you they give your information and that's a great person for you to call right away, but many times we have not met you. There's one of me and there are hundreds of patients that I'm available to service. I don't have the ability to meet each and every one of them at their first clinic visit. So, let your doctor know. Your doctor usually lets the nurse know, the nurse gives me a call and I usually come up in clinic or your social worker if you're not at a Sylvester facility. So, let us know that you're having financial difficulties and we will look to see what programs are available, what sort of services are available, what we could do help you out because you may have difficulties with the cost of your medication or treatment, you may have difficulties with your insurance and those are all things that we can try to help navigate for you and help you find the... and connect you to the appropriate resources to make this more viable and there are definitely programs that are available. Right now, I believe the Leukemia and Lymphoma Society has a grant for, I think, it's for \$5,000 for MDS patients and I believe it's the patient access network, I think it is or there are two that have very similar names. I believe they



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give up to \$10,000 for medication, for certain medication expenses. So, there are assistance programs available. Of course, they depend on availability and whether you qualify within their guidelines, but there are programs available so we can definitely help you connect to a program if you need to.

And the other one is about if you're having difficulties adjusting to your diagnosis. So, distress or what we often refer to as to distress is normal especially when you first were diagnosed. You can feel the shock of saying I really didn't feel bad. How did this happen? What does the future hold for me? Those are very normal questions and that is when we're feeling those worries, anxiety, fear, sadness, all of these things are normal and especially when you first diagnose and they can be normal through your process. It just depends on how you're coping with them and how they may be impacting you on your daily living and so it's very important that if you're having some of these difficulties to let your physician know, let your social worker know. We can help either connect you to the appropriate place according to what the issues are or we can help ourselves. I, as a licensed clinical social worker, I'm able to provide counseling to patients and sometimes I may sit even if it's once or twice with you and discuss where the issues that are going on and we can find a way to get some sort of either resolution or work through it a little bit. So, there is definitely assistance available and if you're having a difficulty such as that please let us know because we want to be able to help you through this process. It's not only medical issues that we're here for. We're here for the patient as a whole and we want to treat all the aspects of the patient.

So, the next slide is talking about getting help when needed and then Jessica, I think, said this like twice, but I'm going to touch on it a little bit more. MDS can often cause you to feel a loss of independence because between treatments and generally the way the blood counts are you may feel more fatigued, weakened and you feel like you're not you and you can't do what you are used to doing and some people are very... have been very independent whether it's because they lived by themselves for a very long time or they still working and they feel very independent and it's very hard for them. It is a very hard thing generally on our egos to feel like we need to depend on other people for help for different things, but this is definitely a time when you need to because you're not going to be able to do this alone. What we see is when patients don't have the support that they need they struggle even more through this process than when they do have the support whether the support is friends, family, church members or whoever else for them is a source of support. Some of the things that I see often and I'll be honest from our perspective is that children especially adult children are trying to help and the parents who are diagnosed with MDS have a very hard time allowing their children to help because as a parent you feel it's your job to help your children not for your children to help you although as the way that life has been historically people used to have a lot of children so that when they got old those children would take care of them, but we've become a society where we become so independent and we don't want to depend on others that we have a hard time and I see sometimes the children are definitely trying to become active and involved and the parents who are the MDS patient have a struggle a lot with allowing them to take over some things, but if



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you're just not feeling up to it or there's so many things going on you're definitely going to be needing some help. So, don't feel that you need to go at it alone. Another thing that I find very helpful is people may always say I heard about this, how can I help? And sometimes we don't now because we're not really thinking about it but it's very practical to make a list of things that you may need help with because if you're off in treatment maybe you need somebody, you know, your neighbor has offered to help. Maybe they can offer by watching the house or feeding your pets, picking up the mail. There are different things that are going on and people may be actually able to concretely help you by doing something for you, but if you don't make a list of things that you may need assistance with they don't know. They don't know what to do. They're trying to offer and they're trying to be really nice and it also makes you kind of hold it to them like you said you were going to help me because sometimes people and that in a sense helps you understand who's really there for you because if somebody says I want to help and you say well, can you do this errand for me and they do it and you see that that's definitely somebody is able to support you and is able to be there for you for what you need because you don't always need somebody to hold your hand while you're getting your treatment, but you may need somebody to be able to do some other practice things that you may not be able to given the fact that you in treatment.

Another important thing is to seek professional help when you're having difficulties and this goes back to the point about if you're having difficulties adjusting to your diagnosis. Most MDS patients are psychologically healthy before and during their treatment, but others struggle with the disease. This is a disease, a chronic disease that you may be living with for many years and it brings a lot of ups and downs when treatment is going well, when treatment is not going well, when your body is doing things that you don't understand. There's a lot of times when things are just a little difficult for you and you may be having some difficulty coping. Every person copes differently and not every coping strategy works for everyone and some people cope better than others. Usually, what worked for you in the past will work for you again. If you're a person, for instance, who likes to read and you find pleasure in reading go out there get a whole bunch of books and use your time to read if that's what brings you comfort. Some people like to golf. If the doctor says it's okay, go ahead and do golf. It not only keeps you active, but it gives you something to look forward to, to keep your mind off some of the difficulties that you're experiencing. So, find what it is that you've always liked and do it and if there are things that you are wanting to try that you always kind of put off because you said I didn't have time for that go ahead and try it as long as within the physician's permission that it's appropriate for you go ahead and try it because that's something that may be very helpful for you and I wanted to discuss two of the main things that we see with patients that can be depression and anxiety. Sometimes patients are like I'm depressed. It doesn't always mean because you're feeling sad that you are what we consider clinically depressed. Most patients who are clinically depressed had a depressed mood for more than two weeks which can include sleep disturbances, decreased interest in things that you like before, feelings of guilt, fatigue, impaired concentration, changes in your appetite and thoughts of death or suicide. That is somebody who can be very much so be depressed and should be seeing somebody for it. However, you can feel sad and that is normal.



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So, it's understanding what is normal where versus what is not normal. One of the things that we usually say is if something has interfered with your functioning then that's usually something that you need to talk about because if it's now impairing your ability to function day to day if these symptoms are starting to impair that ability to function and to feel well then that is definitely something that you want to speak to a physician about. Oftentimes the psychiatrist can help a lot with some of these things and some people feel that that's not the way for them. So, they might find a psychotherapist helpful. It really depends but it's very important to speak up and let people know that you're having these difficulties so that we can make the appropriate referrals. Like I said, social workers often provide a lot of counseling for patients and sometimes when we feel that what we're doing is not sufficient we will refer you to other places or we feel that other things may also be helpful we can also provide those referrals. So, it's very important to discuss that with your healthcare practitioner so that you're getting the help and the assistance that you need.

And so that moves us to being open to changes. With MDS, you're going to have to find your new normal because what was your normal before may not be your normal now. At some point you may return to the level where you were, but it may not necessarily be that way because between medications and their side effects, the disease itself you may find that certain things have changed for you. So, be open to what becomes your new normal and finding something that does work for you. Also be open to new ideas and treatments. These can include clinical trials like Dr. Swords was discussing this morning. There are different clinical trials that are being done by many different places and if you feel that that's something that you want to explore definitely discuss with your practitioner. Usually, what they do is they see if you are an appropriate candidate for those clinical trials, but if you don't talk to the doctors about that they're not going to know if that's necessarily something you're interested especially if it's not something that they're doing at that moment. So, it's very important to be open to the possibilities of new things. This can also include new activities in exercise. So, like I was saying there, for instance, here we have chair yoga and that is helpful for some patients because your mobility has been impaired to some degree, but it still allows you to be active. So, be open to these. Tai chi is another one that sometimes it's an exercise, but it's lower impact. So, be open to some of these new things. Also nutrition and you guys discussed that part a lot, but sometimes your nutritional habits need to change and sometimes there's a lot of things out there in nutrition that would be very helpful for you and for your disease. So, be open to discussing that. We have nutritionists here at Sylvester that you can meet with and they can create a nutrition plan for you according to what your medical needs are, what maybe your religious are and so they can do something that is sensitive to that and can be very helpful for you during your process and the other thing that I always say and it was there in your *Building Blocks* is to be open to your journey. This is your life. This is part of your journey and being open to what comes from it, understanding that this is something that now you are living with and that you can live with and so how are you going to live with it and being able to accept it and move from there and not sit and dwell on those things that are negative that you can't change because there are a lot of things that you won't be able to change that you won't be able to have control over, but you can have





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control over how you approach all these situations that are coming up and how can you approach you life as it goes.

And that kind of leads me to this last point which is set goals for yourself. Goals are not something that we just set when we're young. Goals can be set at any age and they can be all different sort of goals whether it's your goals for your healthcare. So, the physician works in that part in setting healthcare goals as to where they want to get you as far as treatment, but they can also be personal goals whether it's things that you've wanted to do that you never done or you have financial goals that you wanted in mind. Whatever sort of goal it is think about the short term which goals can be accomplished quickly and those are good because they give you a sense of satisfaction. You do them and you're like yes, that's a goal that I accomplished. It gives me a sense of pride and satisfaction, but also think about your long term goals and this I include something that can be oftentimes a little bit uncomfortable for patients, but it's also very realistic which is what we consider advanced care planning and this is what I discussed about advanced directives. So, when we talk about advanced care planning is what do I want from myself not just now that I'm living with MDS, but when things happen and I may no longer be living or close to, you know, life when we talk about end of life and those end of life issues are often very difficult for people to discuss, but they're very important. Advanced directives are a way to help. What advanced directives do is there are two primary ones. One is called the Living Will. It allows you to specify what treatments you would and would not want in the case that you cannot make decisions and you're in some sort of crucial end of life stage. Also there is a healthcare surrogate designation and that allows you to name the people who would make medical decisions for you in the case that you can't. In that case, there are by law the route in which we do that. So, for instance if you're married, your spouse is the first person who we'd look to if you don't have an advanced directive, but I think what advanced directives allow you to do is to have the conversation with your family, with your children as to what you want. Oftentimes when patients are in end of life situations and they may no longer be able to make their own decisions, the family is left with very difficult choices and if they didn't have the conversation they don't necessarily know what is it that the patient would have wanted and they're left having to make decisions on their own. So, it's very important as a patient not just because you have MDS, but because one day we're all going to pass because that is our reality. So, we have to come to terms with that and it's to be able to help those who you leave behind to help them to help them process your loss and be able to grieve appropriately. So, it's very important when we talk about that part is to have those goals and set those goals as to what it is that you want for yourself at that time.

So, now I move onto tips for caregivers and this is another area that I work with a lot. Caregivers are champions just as much as the patients. Caregivers are there with patients through their process and they're going through every curve on that road with you and as a caregiver it's also important to take care of yourself which is my first point.

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Take care of your physical health. One of the biggest things that I get is caregivers saying I haven't gone to the doctor and I have high blood pressure, I have high diabetes, I have all these issues and I haven't been able to see my doctor because I'm here three times a week. Well, if you don't take care of yourself you're not going to be able to take care of the patient. It's just like they tell you in the airplane that if the mask falls down, put it on yourself first before you go to help anyone else because if you can't take of yourself you're not going to be able to help the others. So, as a caregiver it's very important to take care of your physical health of your emotional health. Again like I said, you're going as a caregiver you're going through this with the patient and it can take a toll on your emotional health. So, it's very important for you to take care of yourself if you need to see somebody or if you want to talk to somebody, a social worker, there are support groups for caregivers whether in person, online, reach out to somebody because you need to be well enough to be able to help the patient and take care of your spiritual health, too. If that's something that's important for you then do whatever it is you need to do to take care of your spiritual health.

Like I said, get help when needed as a caregiver oftentimes what you're focusing is on the patient, but there's a lot of things that may be in your role as husband or wife you were doing and you may not be able to do, for instance, at home and ask others to help. Delegate the different chores to other people so that they can help you so that you can continue helping the patient whatever that relation is with the patient and also take some time for yourself. It's very important to take some time for yourself to be able to take care of yourself and sometimes just taking some time for yourself to relax and to take a moment for you to go and process this or even just to get disconnected because these being so much heavily involved in the healthcare can be very exhausting. The other tip that I have is to know your role. Know your role as the advocate for the patient because oftentimes that is what you become is you're trying to find out what are these medications, what are they going to do, what are we doing next and you become a member of the medical team in that sense because we always say that patients and caregivers are members of our medical team, so understand what is your right as an advocate for your patient and be the patient's support. So, understand how you can support the patient through this process and understand your rights because you do have some rights as caregivers, but also there are some limitations so you have to understand those which kind of brings me into respecting the patient. Oftentimes as a caregiver we kind of want do what we think is best for the patient and we may forget to ask the patient what they think is best for themselves. So, it's very important to respect the patient in their abilities to make decisions. This, again, happens oftentimes with children to their parents and they forget that their parents are still able to make their own decisions and they want to be gung ho and go out there and yeah, because we're going to get you the best treatments and all that, but we have to respect the patient and the patient wants and what their wishes are. We also have to respect the patient's privacy. Again, by law there are privacy laws and if the patient wishes to make certain things private we have to respect that. Many times that's not the case, but sometimes it is and we as a caregiver we have to respect that patient's right to privacy.

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And the last one is to communicate effectively and this would include with patients and healthcare providers. Of course, with the healthcare providers like Jessica was saying some of the very important things are to write everything down because there's so much information that you're receiving and so many things that happen at the visits that you forget. Another tip that I give sometimes to patients and caregivers is when you're home and you have a million questions that pop into your head, write them all down so you can them to your doctor's visit and then sit down and say these are my list of questions that I would lie answered. Many times those are answered as the doctor's talking, but sometimes they're not and so when the doctor is done and he's saying do you have any questions, you can say yup, here's my list, these are my questions so that you can feel that you are being supported through this process and that you know what's going on. So, sometimes as a caregiver you have a lot of questions and you want to be able to communicate that in a clear fashion to the healthcare providers. Also, I talk about communication as a unit between the patient and the caregiver. This can be a very stressful process and in that stress sometimes we tend to take it out on other people. So, we have to learn how to communicate effectively so that we continue to be supportive but at the same time we may be able to express what issues we're having because that's why I say using 'I' statements. You may be feeling a certain way that you want to be able to communicate to that person and even though that yes you're trying to be supportive, those are also your feelings and you want to be able to let them know that something bothered you, something made you upset or saddened you. So, use 'I' statements – I feel, I think because that helps release the burden off that person but rather you and how you're feeling and that also helps you to be able to maintain a good relationship with the patient because like I said this can be very stressful and when people are in highly stressful situations it can bring out the worst in them and so we want to reduce that and reduce those sort of tensions and the other thing that I always talk about is focusing on the present. So, sometimes you may get upset because something that happened five days ago, 20 days ago, 20 years ago is still bothering you. We have to let it go. We have to focus on the present, the here and now, what's going on now and how we can move forward because that which happened 20 years ago if you haven't been able to fix it yet you might not be able to, so how can we move forward and be able to continue through this process.

And so these are the things that I wanted to discuss with you. So, now I leave it open to everyone. Any questions whether about this or anything else?

**Q4:** How do you coordinate all the various (inaudible 1:05:55). They're getting you all kinds of medications. Who controls all that?

**Vanessa Ruiz:** So, one of the best things is and I always tell patients and we overlook this is have a primary care physician. Sometimes we forget about that primary care physician and it is very important. The primary care physician is kind of like your head it divides into the roots of all the different specializations. So...

**Q4:** (inaudible 1:06:21)

**Vanessa Ruiz:** That is the truth of our medical system and unfortunately our medical system is a little bit jaded in that sense. Sometimes when you're with a setting, for instance, if you're in a new health you have a primary care physician that's a U Health physician and most of your other specializations are here. Our medical records are all the same. So, your oncologist can see your labs from your primary care physician, your scan from your cardiologist or anything else and that can help although I know that it's not available to everyone, but for some people that is very helpful. Again, it's a matter of communication and being able to reach out to somebody else and say I need help with this and getting organized. That's why the *Building Blocks for Hope* binder is very helpful because it helps you to get organized and get your information organized because when you have multiple providers and maybe they're not within one large health system you can have your different appointments on there, your results and then you can share that information with your physicians, but also letting all your physicians know this and I'm seeing this doctor and I went to this doctor so that they understand and they can coordinate and discuss, too, because they can request records if needed, you should have a list of your medications and they should be updated every time you get new medications so that you can give that to each and every physician or discuss it at each appointment that you go. I know every time that patients see a physician here your medication list is updated but if you're getting medications from another doctor, it's not a UM doctor let our nurses know that way they have everything and when your doctor looks at your record they can see all the medications you're on and if they have any issues with any of those medications that somebody else is prescribing they can discuss with you and they can discuss with that doctor. It can be very complex that is part of our medical healthcare system that we're living in, but I think a little organization on your part can be helpful to be able to bridge the communication and if you do have a caregiver they can also be very helpful.

Any other questions here?

**Q5:** If you do receive your care here you said there's like a triage nurse. Is that someone that answers immediately because the University seems so large? I know at different clinics that I've gone to just mine the same it was always an issue getting either an early appointment or an answer or a callback.

**Vanessa Ruiz:** So, our triage nurses are kind of divided according to either physician or area. So, most of the patients that are under MDS treatment either see Dr. Swords or Dr. Watts and there is a triage nurse for there and they do are usually always available on the phone. If not when you leave a message they're pretty quick to answer because I call them all the time. They're my point of contact and they are... and they usually do pickup unless they're on the other line with another patient or like an insurance or something like that, but they... that was something that we implemented to be able to provide better service delivery for patients so that you would be able to reach somebody. So, usually, they are readily available to answer your questions. They help to coordinate sometimes the appointment or if you're having other issues they can help out. So, we are most of the time it's very... it functions unless that the clinic is



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short and the triage nurse is kind of helping out in clinic and that's usually only in that clinic them thinking of almost all the other doctors have triage nurses that's all they do. So, they just sit there and answer phones all day. I hope that answers your...

**Q6:** (inaudible 1:10:12) and they called back right away (inaudible).

**Vanessa Ruiz:** Yeah and especially you guys were in transplant.

**Q6:** It was part of the (inaudible 1:10:34). There was only one time the doctor when he called the triage nurse called him right back. (Inaudible) no, no, no. I don't like that (inaudible) she was very, very efficient in responding.

**Vanessa Ruiz:** Yeah and with transplant it is definitely a designated team especially if you're going the process of transplant and they usually do bring you here rather than the emergency room.

**Q6:** (inaudible 1:11:05)

**Vanessa Ruiz:** After hours and on weekends because don't... Triage is here during normal business hours to help during that normal business hour time. After hours and on weekends there is an on call number. It's usually as simple as 243-1000 and you can request the physician on call. You request a social worker on call and somebody is able to usually they either connect you through the system or they call you right back and they'll be available to answer your calls. So, there is usually a way according to what it is that you're needing to get an answer pretty quickly. I know for some other things like appointments when you call the physicians administrative assistants that can take a little longer because it's a different position but triage and on call is usually more rapid to respond.

Anyone else?

Well, thank you, guys.

**Audrey Hassan:** So, thank you Vanessa so much.

(Applause)

**Audrey Hassan:** I kind of wanted to echo Vanessa's sentiments about our *Building Blocks of Hope*. I don't want you to be discouraged by the volume of it. Some people... it's three hole punched. You've got the binder. Some people believe me, read it from front to back, but if it's overwhelming for you go to the section that you're interested at the time. Use it like a daily resource. I just want you to use it because it's been worked on by all the top thought leaders in MDS. So, it's up to date. There's a whole section on what's new on the horizon, questions to ask



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your doctors, everything we talked about today, a caregiver section. There's nothing missing from it. Nutrition. Can I exercise? Just an added note from especially from Vanessa's talk, we're starting to do coping and caring forums just like we did in educational program. We also realized through the foundation, the anxiety of living with a new normal. So, we're starting to do these same programs but instead from time to time I'll have a holistic nurse do a prayer circle or have a yoga expert, an oncology dietitian come. More with dealing with living with this new normal. So, I hope to bring it to Miami one day. So, you will definitely be invited when we do. So, thank you all for coming. I hope you found it helpful. I do. Nice meeting everybody. Oh, Janna would like to say one word. We won't keep you. Real quickly.

**Janna:** I just want to say so I started working for the MDS Foundation. My dad had MDS and I do social media and among a lot of different things, but if any of you have kids or grandkids that would like to get involved in the social media awareness realm of this, something I'm really passionate about and I don't know anything about anything about any of your individual social media habits, but MSD kind of affects a generation that's maybe not as active on social media. So, if you kids and grandkids that want to reach out, contact Audrey. She'll put them in touch with me and we have a really awesome awareness campaign coming up and we could use all of your help. So, that's it for me. Enjoy the rest of your Saturday. Thank you all.