

Melissa:

Thank you so much for joining us tonight. Welcome everyone. I am so excited that you are with us tonight for the kickoff of Sharsheret's annual Summit. We're so excited to start the summit by exploring the critically important topic of self-advocacy, and a special hello to all of those who registered and will actually be watching this when the recording becomes available early next week. This is our second Sharsheret Summit, an array of both national webinars and local programs that provide support to those impacted and to educate the greater community. During the fall, we've had or will have hundreds of programs across the country. But tonight, tonight is the first of three national webinars hosted by Sharsheret and generously supported by our summit sponsors. Thank you to the sponsors of this year's Summit, Eisai, GSK, Seagen, Daiichi Sankyo, Merck, Pfizer, Exact Sciences, and Lilly Oncology. Their generosity allows us to expand our reach, making life a bit better for those impacted by breast cancer or ovarian cancer or those living at higher diagnostic risk and educating people to be proactive about their personal health, ultimately saving lives.

And tonight's specific webinar is also supported by Bayer and ImmunoGen. Thank you to tonight's program partner, Astera Cancer Care, for working on this evening's program with Sharsheret. Before we begin, just a few housekeeping details. As a reminder, tonight's webinar is being recorded and will be posted on Sharsheret's website and the Sharsheret Summit website along with the transcript.

Participants' faces and names will not be in the recording. In terms of questions, we actually receive some great questions as part of the registration process, but I'm sure questions will arise tonight as we go through our speakers. Please use the chat box and we will address them during the Q&A session at the end of the webinar. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for over 20 years, because cancer is so much more than simply a physical experience. In addition to the many formal programs to help women and their families navigate different aspects of the cancer experience, I want to remind you that our clinical social workers and our genetic counselor are available every weekday, nine to five in each time zone for one-on-one support. They can answer questions, connect you to appropriate resources, allow you to vent on a difficult day and so much more.

As always, our support services are 100% confidential and 100% free. As we move into the webinar itself, I also want to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any specific medical advice or perform any medical procedures. The information provided by Sharsheret and our speakers tonight is not a substitute for medical advice or treatment for a specific medical condition. As always, you should seek the advice of a physician or qualified healthcare provider with any questions you have regarding your specific circumstances. Before we get to tonight's expert, we are so lucky to have two Sharsheret callers with us to share their very different experiences. So let's begin with Lisa who was from California. Lisa was diagnosed with breast cancer this year. Lisa, the floor is yours.

Lisa:

Hi. Okay, first of all, hello. If you're somebody who's recently been diagnosed, I feel for you, it's scary. I'm going to talk about the beginning of my journey, which was a little over a year ago. I was diagnosed with breast cancer. The hardest and scariest thing was that I had to figure out the whole cancer healthcare system with no experience while I was still absorbing and processing the feelings of being diagnosed and everything that came with that. But I shifted very quickly into pushing that away so that I could focus on research to find good treatment. The problem was I didn't know what good treatment would look like and I don't think I would even have recognized it if I stumbled on it. So in the end, I went with an oncological surgeon who was recommended to me by my gynecologist. But then I faced a six

week wait to get a first appointment with him, during which it was actually very hard to keep pushing my feelings down.

At that point, it was also I was dealing with a lot of anxiety. But I took that six week wait as a sign that he was the best doctor because everybody wanted to see him and I was patient. And then after six weeks I finally got 20 minutes with him and he sent me for more diagnostic procedures because he didn't yet understand the scope and the type of cancer that I had. That diagnostic procedure took a while to schedule and adding to the time. And then once I had it, it was hard to get in to see him again. This went on for months, for almost five months actually. And he wanted to use this very sophisticated cutting edge in surgery radiation machine on me but I had to qualify. I had to have a very specific set of conditions and lack certain other conditions in order to be eligible for it. What he was really trying to do I think, was to make sure that I was an appropriate patient for the use of this machine. The machine itself wasn't even going to be available because it had to go through some big recalibration process. But over the course of five months, I became practically unhinged because I thought I should be getting treated and not just being diagnosed.

But my nature is to keep things to myself when I'm stressed out and I didn't really want to talk about having cancer because I felt like it would make it more real. So I didn't share what I was going through with most people. And I have kids, I didn't want them to worry. I mean, the whole thing felt like it had to be sort of kept contained, and I think that was a big mistake. Because on a very casual visit to see the dentist just to get my teeth cleaned, he asked me how I was doing. And for some reason I said, "Not great. I have breast cancer." I don't know why. It just came out. And he said, "Oh, you know what? My mother just went through breast cancer and I know the best doctor. And she's actually a patient here, so I'm going to recommend that you see her and you can use my name. And my mother is done with treatment and she had very positive outcome." He wrote down the number for me and I called this doctor. I used my dentist's name. Within a week I was in surgery.

I think what I wanted to share about this story is that because of your maybe ignorance and fear and lack of connection to other people who are going through the same thing, you just accept what is presented to you and you assume that the doctor knows best. And the fact that this doctor was in no rush was alternately like reassuring and frightening for me. And really, if I had been with somebody who was more attentive and more available, I could have spared myself many months of anxiety and worrying. I'm good now. I'm at the end of it. I had lumpectomies and radiation and now I'm on tamoxifen. I have a long standing relationship with this oncological surgeon who is a lovely person and a woman I might add. I recommend that you not keep it to yourself if you're going through this and just make sure that you talk to your community because you never know where help will find you.

Melissa:

Thank you so much for sharing that. I love that you were able, over the course of time to learn from your experience and do what needed to be done for yourself. That's amazing. Thank you.

Lisa:

Thank you.

Melissa:

Next, we actually have another caller. We have Joanne who is from Michigan. Joanne was diagnosed with breast cancer just under three years ago and she had a very different experience that she's going to share with us tonight. Joanne, the floor is yours.

Joanne:

Hi. First of all, I want to thank Sharsheret for the opportunity to speak. This is just a wonderful organization and I don't think I could have made it through those beginning weeks without the support that they gave me. Okay, so you've been diagnosed with breast cancer, your thoughts are flying around in a thousand directions, multiple appointments are being scheduled. I think it's time to give a little bit of thought to the sort of patient that you'd like to be. It's really important to cultivate a relationship with your care team right from the first meeting, so this is what I would suggest. When you start to go to your appointments, see who you'd like to bring with you. I would really suggest bringing two people with you. One person can be a spouse, a significant other, a good friend, someone that's going to come and just listen and absorb everything, take it all in with you, ask whatever questions come to mind, help you cover all the bases. The other person will be someone that will take notes. They won't focus on asking questions. All they'll do is try and document everything that comes up, whatever the doctor says, the questions that are asked, the responses given.

And then when you come home from the appointment, they should send you those notes, email them, send them over to you, and then you should sit down and read through them. Make sure that what they wrote is what you heard and that you understand everything that was said. If there's anything that you have any questions about, make sure to write down your questions right away before they fly out of your head, and that way you can email them to your care team or you can save them for the next appointment. Okay, so my next thing is that you need to really work hard on expressing gratitude for everyone's time, patience and sensitivity with their exam and all their explanations. And when I say everyone, I mean everyone. From the schedulers to the people at the front desk, to the nurse practitioners, to the doctors, to the medical assistants. They'll appreciate you as much as you appreciate them. Another thing that somebody taught me early on because they had been through their own medical journey is that it really is helpful to make yourself stand out in your care team's mind. I know it sounds a little self-serving, but at the end of the day it will just make you happy and them happy.

And what I mean by this is that it's important to do something specific. What I did was that every appointment I bake cookies, I just grab my container, threw them in, and I would just bring a container of cookies to every appointment. I would tell everybody, "Thank you so much, I really appreciate your help." I know people that have bought a bag of Hershey's Miniatures or Hershey's Kisses. I know people that have brought little thank you notes every time. But the important thing is that you want them to remember you and you want to cultivate these relationships so they'll be there when you need them. Because during your treatment course you're going to speak to lots of people and you're going to hear a lot of different opinions. But ultimately the only opinion that really matters is your own. You're going to need to listen to your own voice, but you're going to need to do it in a way that you can take in all the opinions so you can get all that information and do all that research. There's going to be times when situations arise that you need to advocate for yourself. It will be uncomfortable, but the more positive your relationship is with your care team, the easier it will be.

I had two such times that I want to talk about. One of them is that towards the beginning of my treatment plan, my Oncotype test came back and I was exactly on the border for age and number for whether I should have chemo or not. The doctor that I was seeing, she told me that she does not believe in giving chemo under these circumstances. No chemo, that's the end. I'm not having chemo. When I left the appointment, my husband and I felt very off balance. I went into it feeling like I wanted to do everything positive. And because I was borderline, I wasn't sure if that was everything positive that I could be doing. So at that point, we spoke to a lot of different people on our care team. I spoke to nurses, I spoke to receptionist, I spoke to doctors, I spoke to whoever I could find that was within that group to say to them, Do you like this doctor? Do you respect this doctor? How do they come to this

decision? What should I be doing? What should I be looking at? Is there someone that you can recommend to me that I could go to for a second opinion? Will they be angry at me if I go for a second opinion?

But everybody told me no. Any doctor that's a good doctor is not going to be upset if you get a second opinion. Know they respect your right to make that decision. Ultimately, I did get a second opinion. I ended up switching doctors to a doctor that told me, "If you were my mother, I would tell you to have chemo and do everything possible." And that was what I needed to hear and that helped me make my decision. Another time that I advocated for myself was that I got a very serious infection in my expander after I had a mastectomy and I had to go right into the hospital and have it removed. While I was in the hospital, the doctors came in and they said to me, "Listen, we know this is a lot and you're overwhelmed, but you need to make an immediate decision here. Either you need to leave the expander out and just go flat and then between six and 12 months we can put an implant in, or we can do a surgery today to put an implant in but you're going to run the risk that the implant could get reinfected or you could have issues from radiation. What do you want to do?"

So as you can imagine, I was tremendously overwhelmed. I had just had surgery. They're talking about doing more surgery within hours. I didn't know the answer. But because I had cultivated the relationships with my care team and they knew me and they cared about me, I was able to reach out to them. Several have had given me their personal phone numbers that I could text them by that point and said, "If you have any problems, just get in touch with me." I was able to reach out to the oncology nurse and to some of the doctors and I said, "Help, I don't know what to do." They were able to put together a Zoom call with some of them in person in my room within an hour that we could all get together and talk about what was the right decision. And they gave me the information and they said to me, "Ultimately this is your choice. You need to sit and think what you want to do, but here is all the information." Afterwards they told me that this was the only time they had ever done something like that.

Of course, you can imagine the next week I followed up by bringing everybody cookies. But the bottom line is that I can't stress enough the importance of creating a positive relationship with your care team. It's just going to lay the groundwork for many future positive interactions. Like I said, to reiterate, as much as you care about them, they will care back about you. So thank you again, Sharsheret.

Melissa:

Thank you so much to both of you. What's clear to me is that both of you, through your experiences, learned how to advocate for yourselves and developed good relationships ultimately with your healthcare team, which is so important. So thank you. We are especially fortunate to welcome our speaker with us today, Neshama Marcus, LMSW, is the Director of Social Work at Astera Cancer Care in New Jersey. She's been tasked with building a social work department for Astera's multi-site oncology hematology practice. Neshama received her bachelor's degree from Rutgers University and her master's degree in social work from Rutgers University School of Social Work with a concentration in non-profit and public management. She also has her post-graduate certificate in gerontology from Rutgers University as well as postgraduate certificate in grief counseling. She has so much to share with us tonight. Neshama, the floor is yours.

Neshama Marcus:

Hi, thank you so much. What a beautiful introduction. It's amazing to follow all the speakers and hear your story so thank you for that. We will hopefully cover some of the questions that are in the chat filtering in. I'm going to temporarily ignore the questions. I'm hoping to get to them and I will have a

Q&A at the end. For the purpose of today's presentation, the topic is, Ask and Advocate: Creating a Positive Relationship with your Treatment Team.

Melissa already gave me my introduction. I don't need to do another one, but I will have my contact information at the end so that way if you need to reach me or if you have any questions after, I'm happy to answer them offline if you prefer. So I know you mentioned Astera Cancer Care. I'm not going to talk too much about it, but yes, we are a multi-specialty community oncology practice that's physician owned. We deliver high quality, coordinated, and patient-centered cancer care in New Jersey, specifically Central Jersey. We service as high as Rutherford and Jersey City and as south as Robbinsville, which is close to Trenton. We're part of the OneOncology Network for those who are providers in this space. Our services include medical oncology. I heard radiation. I heard breast care and surgery. We do non-malignant hematology. We have social work. We also have palliative medicine and supportive care. We have onsite infusion services. We have a specialty pharmacy. We participate and lead actively in clinical trials.

So our agenda for tonight, what is a cancer advocate? We heard advocacy, advocacy, advocacy. So what does that even mean? In order to communicate with your oncologist and your care team, it's important to understand who the care team members are. Significant factors in fostering your relationship with your care team, how to understand your own anxieties that come with disease. And finally, how to communicate with your care team. And then we'll play some games and pull you guys in some scenario. Okay, so what is a cancer advocate? It's a person who wants to help anyone who is diagnosed with cancer, navigate the medical system and community resources that accompany in. Cancer advocates can directly improve quality of cancer care. So they can be providers, they can be patients or family members who support individuals living with cancer. They can be interested in raising awareness. You may just be like a neighbor or a friend. They can be actively participating in cancer research, whether it's as a provider or the patient who's participating in clinical trials. They can participate in policy, whether at the local or federal levels. Really in order to be a cancer advocate, all you need is passion and willingness to be part of it. So I hope by the end of today you realize that you yourself are an advocate.

So first we're going to go into proactive options. Before we get into reactive, how can we be proactive? And we heard some examples earlier. As you can see, there are a lot of members of your care team. So when I say care team, I'm going to list all the different people that go into the formal aspects of a care team and then we'll talk about your informal care team. In terms of the formal care team, your medical oncologist is the person who oversees all aspects of the diagnosis throughout the course of the disease. From the moment you come into the office, oftentimes for many, many years after. Your team can include the radiation oncologist, I heard. It might include a surgeon or surgical oncologist. A lot of times people ask me about advanced practice providers. Those are your nurse practitioners or physician assistants. They work hand in hand with your medical oncologist. Sometimes patients will ask me, what's the difference between the two?

Your medical oncologist is your lead and your NP or PA is your support. They can do most aspects of your care. They can do exams, they can order or interpret any labs or diagnostic test results. They can do diagnosing, whether it's cancer or other illnesses. They can prescribe medication or order any alternative therapies. They can provide education and counseling for patients and family members. They can perform biopsies, oftentimes that happens in the office, sometimes it's offsite. They can discuss advanced care planning and discuss personal care wishes. They can perform aspects of the clinical trial as well. Folks often ask me the difference between advanced practice providers and registered nurses. The nurses are the ones that are usually in the infusion suite. They're not able to prescribe any type of medications. They're not able to do any type of diagnosing. They are able to administer. They typically give chemotherapy or other medications in the infusion suites. They can identify medical needs.

So if you're in the infusion suite and you're noticing some type of symptom or some type of side effect, they can identify it and refer to the nurse practitioner or physician assistant or medical oncologist and they can perform aspects of the clinical trial. You might have the phlebotomist on your team. That's the person who's responsible for doing all the lab work. You might have medical assistants on your team. Those are the folks when you first come into the office who do the vitals, they might update your chart. They might gather your medical information like your provider roster or medications that you're taking. And the reason why I go into such detail is because oftentimes patients will come in and start talking to their medical assistant as if they're the RN or as if they're the nurse practitioner. It's important to know who does what and what information you should be providing.

The medical assistant might say, "Are you still taking this medication?" And you might want to go off about all the reasons why you like it or you don't like it. That's not the person to talk to. The person to talk to that is your providers. Your front desk and reception are on your care team. Those are folks who typically do the paperwork. So you might, for example, hand the front desk disability forms that should go into your chart or that have to be completed by the doctor. They can do the clerical aspect of the application, but you're not going to talk to them about why you're on disability and what the benefits are and how much money you're going to get. That would typically go to either social work or a patient navigator, depending on the practice and their workflow. There's the authorization team. Those are the folks who check to make sure that before you come in for any type of infusion or any type of treatment that has to be had, they're responsible for making sure that insurance is ready to cover it. That's very important for it to be authorized before it's scheduled.

You have a treatment scheduler. They're responsible for making sure that a chair is ready for you and available to you. They typically coordinate with the front desk who does the booking of the appointments for the provider or handles the scheduling of the labs. These three roles are often confused. I'm going to go into a little bit of detail about the social worker, the palliative and supportive care specialist, and the patient navigator. The social worker is responsible for helping patients and families and maybe informal or formal caregivers cope with cancer and address any challenges that come with having a cancer diagnosis. I usually put social work into two buckets. There's the case management component, which is handling the barriers. It might be financial resources, it might be home care, transportation. It could be what I consider the second bucket is mental health. It could be individual or family counseling, it could be support groups, but those are typically the roles of the social worker.

For palliative and supportive care, sometimes this can be a misnomer. Palliative care does not mean hospice. Palliative care means that the person is responsible for handling pain and symptom management typically during treatment or if treatment is no longer viable. So sometimes the reason why I say there's a difference between palliative and supportive care and hospice is hospice means that a patient is no longer participating in curative treatment. Palliative and supportive care can happen when the patient is continuing with treatment. Their focus is on pain and symptom management. Sometimes the palliative and supportive care can help make important decisions about future healthcare and help you complete documentations that support your long-term wishes. The patient navigator is like the glue from a medical aspect. They're responsible for working with a medical oncologist to ensure that there's continuity of care. They help make sure that all the labs are in when they're supposed to be in the clinical trials.

Paperwork is in any procedures or any type of treatment that you may have, gets followed up with and is in the chart and is ready by the time your provider is meeting you for your exam. So they really gather from all the different doctors, tie it together and give it to your provider in a nice package with a bow. So if you have any questions in terms of, did my lab work come in? When's my doctor going to connect with

me? That's usually your patient navigator. Then you have your pharmacist or pharmacy technician. They're responsible for usually oral medications. It can include anything from drug interactions, making sure that adjustments are made to dosages, that they're taking into consideration side effects. Some folks have rehab therapists. They're usually responsible for helping patients return to their highest level of functioning. So ideally it's to the way that they felt before a diagnosis. They can help patients do anything from regaining speech, help with mobility and doing tasks of everyday life.

Rehab therapists can include physical therapy, occupational therapy, speech therapists, and recreational therapists. There's usually a whole team. A lot of folks ask me about nutrition. So the formal name for a nutritionist is registered dietician or an RD. They typically help patients cope with nutrition obviously, but any aspect that includes like weight changes, any loss of appetite or change in appetite and other side effects of treatment. Some folks don't know, but mouth sores is a common side effect of chemotherapy. So mouth sores impacts appetite and impacts weight change and they help with that as well. You have a pathologist. Sometimes the pathologist can be your primary medical oncologist and sometimes it can be an outside provider. They're responsible for providing the final diagnosis of cancer or stage of cancer. But the goal is to make sure that that person works very closely with your medical oncologist if it is an outside provider. You might have a genetic counselor. They're responsible for helping you to understand cancer genetics and your family's cancer risk.

You might have a diagnostic radiologist. They're responsible for reviewing and interpreting any imaging. You might have one or many mental health professionals that can include your social worker that's on staff, but it can include an independent or onsite psychiatrist, psychologist, licensed mental health counselor. You might see a creative arts therapist. You might also have a chaplain, whether it's onsite or off. Their focus is on usually spiritual counseling, helping you to contend with some existential questions you have in terms of purpose and goals for the future. Sometimes people will ask me, and it's already come up in the chat a couple times, some people ask me privately, what do I do if I don't have anybody to come with me? So I want to make sure that you know that there's always helpers. This is one of my favorite quotes, "Anytime something bad is happening, you can always find a helper. You just have to look for them." So an informal care team can mean anything from family members to friends, to neighbors. It can be a clergy member.

It can be people in your faith-based community or a place of worship. It can be anyone in your school or your children's school community. It could be someone in your prayer circle. Sometimes there's local community help groups. You might have to put some effort in to find them. But usually most communities have some type of helping community. You might have a relationship with a cancer related organization. You might have a not-for-profit organization like Sharsheret that can provide you with additional resources. They can link you with various aspects of your medical team and they can provide psychosocial support. So it's important that now that you know your formal and informal care team that you know that we're all on the same team, even though we might have some different goals. So I thought it would be helpful to delineate what a provider's goal usually is. So provider's goal is typically to be prepared for their appointment, to demonstrate empathy and sympathy. To use welcoming body language, verbal and nonverbal language. To not appear rushed, right?

Everyone I heard mentioned that you have maybe 15 to 20 minutes with your provider. You want that time to be quality time and you don't want to feel like you're being moved along. The provider aims to speak with patients directly. Sometimes there's other family members in the room or caretakers and they may be tempted to look and try to engage everybody. But the goal is to speak with the patient directly and make sure the patient understands. The provider asks the patient how they prefer to hear information. There are some folks who prefer to hear very direct, positive, negative, all of it, the down and dirty. There are some folks that prefer to hear only curative treatment options, only positive. So it's

important that the provider asks what's the best way to communicate with you. It's important that the provider listens. The provider should focus on the positive and not just the negative. They should practice shared decision making.

It's important that the provider, this is what they do all day, they handle cancer all day every day. So yes, they're the expert, but they're not the expert on you. You're the expert on you, so it's a partnership. Their job is to explain the care plan and its entirety to make sure that the patient understands. They recognize differences and they acknowledge them. So they might say to you, is there anything important that you would need for me to know? It might be anything from, I'm not available on certain holidays. It could be like a history of trauma, something that might impact. It actually came up the other day, I had a patient with a history of sexual trauma who had asked me what the process was for biopsy. So I had to ask several different doctors how they do it because I wanted to make sure I wasn't missing anything. I was told that some patients do biopsies on their side and there are some patients who do biopsies face down.

So for somebody who experienced a sexual trauma, being face down, that wasn't comfortable. She asked if she can go on her side. So that's an example of something that you would want to communicate with your provider. The provider has to follow workflow for communication. In terms of the patient goals, most of it is similar. The patient should be on time for their appointment. They should prioritize relevant health issues. Sometimes when you walk in, you might have not slept well and you want to talk about sleep. You can definitely talk about sleep, it's important, but you want to prioritize what's most relevant. You want to follow health and safety protocol. I heard a few folks mentioned to bring a companion or two with you. Yes, that's very important. Be honest in your communication. Sometimes people don't want to complain. So if something's not working, please complain. Please say something's not working. If the doctor says, "How are you?" And you're not feeling well, don't say, "I'm feeling great. Thanks for asking. How are you doing?" Share if you're struggling.

It is up to the patient to explain how you prefer to hear information. Be sure that you understand your care plan. You might think you understand. Take a moment. No one's rushing you out the door. Ask the doctors to sit for a moment, digest everything, communicate it back to them. Make sure you understand. Practice shared decision making. Same thing. Follow your care plan. Sometimes you might have a really great care plan but you're lacking the motivation. It's important that you follow your care plan. If you're meant to get a lab or a biopsy or some type of diagnostic test done, have it done. Have it done at the time that you and your provider discussed because you're both on the same page, you're both moving forward. And the last thing you want to do is show up to your appointment without having the results in hand. It's important that you use the practices website or patient portal before you ask questions. So sometimes patients will ask their doctor something that's very easily found on the patient portal or website.

Take the time to explore common questions. It's important that patients follow the workflow for communication same as the provider. If you're meant to ask the patient navigator something, ask the patient navigator. If you're meant to ask the provider, ask the provider. If it's a front desk issue, ask the front desk. Don't ask the doctor if they can do your scheduling. That's something that the scheduler or the front desk can do. Like I said, communicate anything that would be helpful for the provider to know. So that was how to communicate with your formal care team. I know it's very loaded slide, but this is how you communicate with your informal care team. So all those folks, your family, your friends, et cetera. So at the top is assess for commitment. The first thing somebody says to you is, "I really want to help. Thank you for sharing that you have cancer or diagnosis or that you have something pending or that you're not sure. I really want to help. How can I help?"



So it's important to assess for commitment. You're not going to like a drill sergeant, ask them, "Okay, well, what are you doing? When are you doing it?" Like that. But you are going to ask them what are they looking to help with. Some folks that want to help might offer rides. Some might offer to provide meals. So ask them what they're looking to help with. Ask them for how many hours they want to commit to or how much time they actually have to help. Not only the type of task but also their availability. So somebody might want to drive. Like I work nine to five, I might really want to help a friend with transportation. But if I'm working nine to five and the office hours for their practice is nine to five, it's not going to work. So I might be available six to 9:00 PM to help. It might be more of an evening shift type of responsibility. Once you have who's on board, how many hours, what they're interested in doing, their availability, you start delineating roles and responsibilities. It's important to know that you can choose to delegate this.

So you might have somebody who's really good at organizing, they might not have the time commitment to actually complete tasks, but they're a great organizer. So their goal is to figure out who's doing what, when they're doing it, how they're doing it, where they're doing it. And most importantly, what is the backup plan? So I have somebody really great who's scheduled to help me with transportation to my appointments every Monday. What happens if they're not available? What happens if something goes wrong? They get a flat tire. Who's filling in for them? Overcommunicate to your team. What do you want to have happen? When do you want it? When do you need it? Make sure that your team understands the plan. Make sure that they confirm that they understand and that they agree. So typically you might have someone that's like, "Yes, I'm all in. I'm all in. I'm all in." And you say, "Okay, what are you doing?"

And they don't really understand the plan or they don't realize the level of commitment that they signed up for. So they might have thought that they were offering a ride on Tuesday, but really they offered weekly drives on Tuesday. You need to be on the same page. Reinforce trust. You want to make sure that you thank the folks that are helping you and make sure that you know that it's about trust. So I typically will say something like, "I'm grateful that I can rely on you to do this task," which means that I honor your level of commitment and I appreciate your dedication and your reliability. Review accountability looks scary. What it really means is, are you comfortable doing it again? Did this work out? How can we adjust for next time? It's kind of assessing. Share the results and the impact. This is helpful for folks to know that what they did helped you and it mattered. So because you helped me, I'll use transportation as an example because it's easy, it alleviated my anxiety. I didn't have to worry. I got to my appointment on time because you cooked for me or were able to get me to the appointment early, I was settled in so my heart rate was stable. Because you cooked for me, I wasn't panicking about nutrition. My weight was stabilized.

Share the results and the impact. It's helpful for folks to know how they contributed. Okay, so that's all proactive. That's if in an ideal world you're thinking into the future about how you can set this up for success. Now we're going to go into reactive. In order to understand how to deal with issues that might arise, it's helpful to understand what are triggers, what are normal triggers, and then what are disease related triggers. For patients who have anxiety before diagnosis, these are normal triggers. Typical medical issues. I stub my toe. I bent my finger back. My stomach is bothering me. That makes anyone anxious. Relationship issues can make people anxious. Financial concerns. That could be employment, that can be income, that can be timeliness of bills. Finances can be a trigger. Family stress can be a trigger. Anything from relationship like divorce to caregiving, maybe grieving the loss of somebody. Those are common triggers. Work triggers, school triggers. Change is a trigger for most people.

Most people are creatures of habit. They like their routine, they like their network of support, they like their plans and their order. Changes frustrates people and it causes disruption. Change in routine can be

a flat tire, meeting a new person or adding a new person into the mix, changing plans. Like you're supposed to have an appointment on Monday and then you have to change the plan and rearrange and handle transportation, those are all common triggers. Manmade or natural disasters are considered change. It's a disruption from what we're used to. Any weight loss, weight gain, that's a normal trigger. Socializing can be a trigger. People that have social anxiety, interacting with other people can be triggering. Some people get performance anxiety, like giving presentations like this. Some people feel like they have to perform when they have to meet expectations at work or at school or maybe from their partner or from their parents or from their children. Normal triggers.

Isolation is a normal trigger. I'll use COVID as an example. That could be geographic isolation where you're physically distanced from other people. It could be social isolation like you're left out of a group interaction. It could be technology. Some folks that don't know how to use Zoom or how to operate the phone or connect with people using technology can feel isolated. Some folks don't have social media or don't know how to use it can feel isolated. Some people feel marginalized by peers or their coworkers, that can be isolating as well. So those are all considered normal triggers. Some people are claustrophobic, they don't like tight spaces or crowds like normal elevators, so that can be a trigger. Most people that have that feeling of being unprepared is a normal trigger and fear of the unknown like what's going to happen next, those are all normal triggers. I'm going to share the next slide. It's a little scary, but I'll explain that.

Melissa:

Before you go into that next slide, and we talked earlier that I think this is such an important slide, but I want to just make you aware of the time and I want to make sure we get to questions. Everything is so important on these slides, but I just want to make sure that we get to all of them.

Neshama Marcus:

Yes, I'll move along. Just the add-on disease related triggers. If you typically have issues, anxiety with medical issues, now do you have the whole disease and appointments and schedule? If you typically have relationship issues, anxiety can add strain to the relationship. If you typically have anxiety about financial concerns, there's disease related treatments and copays. There could be loss of work, there could be loss of income. If there's family stress to begin with, you can add fear of loss. There could be changes in the family structure. Some folks that are working might not be working. Some folks that weren't working might be going to work. For some folks, there's pressure to retire or to go on disability. For some folks who already have anxiety about change, you can add the disease related change. So changes to routine, changes to body and appetite.

For the folks who have difficulty socializing, I just gave you a whole list of 30 to 60 medical professionals who you're now interacting with. If you have issues with performing, some folks have an added pressure to improve or get better. That you have this whole team of 30 to 60 people who are there to support you. There might be that pressure to get better. For folks that were isolating or have a fear of isolation or anxiety related to it, during COVID particularly, you might be isolating for medical necessity. For folks that have anxiety about being in tight spaces, you have your exam rooms, you might be sharing transportation with other folks, you're in elevators, you're in hospitals with a lot of people, so that might be triggering. For folks who have difficulty making decisions, well, now adding new really important healthcare decisions might be triggering. For folks that typically feel unprepared, you now have the variability of treatment, right? Treatments can change, they can move. Something's working, something's not working. There might be a side effect. You might have a new condition, change in prognosis. That can make anyone super anxious.

And then there's the fear of the unknown. Patients will often ask me, well, what can I expect next week? What can I expect next month? Do you think that I can go on vacation next year? So that fear of the unknown is very scary for a patient who has cancer. So to me, the most important piece is that your doctor knows that you have all this anxiety. Every patient comes with all of that anxiety, so it's important to know that you need to know how to communicate with them and they need to know how to communicate with you. So this is a slide that I like to share. You're probably wondering what's a woman holding a baby in the middle. When I happened to be pregnant with my first child, I attended a birthing class. In the class they taught you and there was also baby care, they taught you how to hold a baby. The first thing that the woman said to me, and I've used this a million times in session is when you're passing a baby, you pass it to the person and you say, "Do you have the baby?" And that person has to say, "Yes, I have the baby."

That's what communication or effective communication is supposed to look like. One person shares the information, the other person receives the information and confirms receipt. Here are some dos and don'ts about how to communicate with your oncologist. Do ask for the best way to communicate with your provider. Don't email, text them and call them until they respond. Do ask your provider for a realistic timeline like when can you expect to reach back out, don't reach out several times within one workday. Do learn your provider's schedule. Know if they're making rounds in the hospital, because that usually means that they're not available. If they're in surgery, know their schedule. If they're on vacation, know who's supporting them and backing them up, who's on call. Don't expect your provider to return what I'm considering to be non-urgent calls between patients or while on vacation because it's very difficult for the provider. They're going back to back for the duration of the day. They have to start field and decide what's urgent and what's not urgent, what can wait until later.

Don't expect your provider to return non-urgent calls. Do provide any updates related to your diagnosis and treatment. Don't focus on unrelated information because you want to make sure you're maximizing those 15 to 20 minutes with your provider. Do leverage your time. Come prepared. Don't come disorganized. Some people come with like stacks and stacks of papers and they're shuffling through and they're trying to figure out where they wrote every question. Come prepared. Do let your provider know specifically if they're not meeting your expectations or how they're not meeting your expectations. Don't leave the appointment disappointed. That would just lead you to more anxiety and ruminating. It also doesn't give an opportunity for your provider to address any of your concerns. Do let your provider know if you're unclear about next steps. Don't leave the appointment if you're not clear, if you're not sure who to contact or what your follow-up looks like. Okay, so I think that you're going to want me to put a hold on the poll because I want to make sure I leave time for questions.

Melissa:

Yeah, although I think it's very interesting when we talked about this, or even earlier today, there were some quick questions. Can you just go through to the next one? Let's just talk about it, right?

Neshama Marcus:

Sure.

Melissa:

I think that if we just give people a second to look at them, we won't have time to talk about it. But it's interesting, when we went through this I thought, well, I could do several of those things. I see the one I shouldn't do, but there might be more than one option.

Neshama Marcus:

I'll go through it quickly.

Melissa:

Okay.

Neshama Marcus:

So the first scenario is on poor communication. So you're concerned that your test result came in, no one's returning your calls, you're feeling anxious. You can either call the office repeatedly until someone answers. You cannot do anything. Oftentimes patients are worried that for some reason that if they get squeaky, it's going to impact their care. Some people try to show up unannounced at the office and make demands to the front desk. The most important piece to walk away from from this slide is anything related to test results or the continuity of care, call your patient navigator. If they're not available, you can always leave a message. They typically respond back within 24 hours. If you feel anxious, you can always try them again.

Melissa:

And for people who don't necessarily have an assigned patient navigator in their practice, there is someone that you can call, whether it's the nurse triage desk or whoever handles that role in your particular team.

Neshama Marcus:

Absolutely. It happens to be in our practice, the nurse triage line serves as a symptom hotline. So if you're having any side effects, they typically call the triage. But yes, check with your practice, see who plays that patient navigator role.

Melissa:

I see Jen just said, "Use the portal. For some, the results get uploaded directly to the patient portal."

Neshama Marcus:

Sure. Usually patient portals, you can have full access to any of your results. Some patients don't know how to interpret that information. So typically a patient navigator can interpret the information as long as it's assigned by their provider. So the lab results might be in the patient portal. If you contact the navigator, they might say, "Let me get back to you, I'm going to check with the provider." So oftentimes the provider wants to speak with the patient directly if there's any negative issues or next steps or things that they have to do. And if not, everything's good to go. I'll see you next visit. That's usually when the patient navigator will return the call.

Melissa:

You know what, we have some questions that are actually related to some of these things. We're getting very close to nine in the Eastern time and I want to make sure. We referenced this in this last slide. So I saw a lot of questions come in and we even got some questions ahead of time about what do I do if I don't have a social worker that's part of my practice or if there isn't a patient navigator? And so we talked a little bit about, then you have to know what role the professionals in your particular practice play. But do you have any other quick advice for-

Neshama Marcus:

Sure. It's super important to get a list of all the staff and who plays what role in the office. If there is no social worker, you're going to ask the office who they typically refer to. Usually there is some type of either not-for-profit or community partner that plays that role.

Melissa:

Absolutely. Okay, here's another one and this is a big one. How do we get all of our doctors to work together for treatment? We could have an oncologist, a primary care physician, we might have a pulmonologist or neurologist to deal with some of the symptoms that treatment or disease is causing. And even when you've asked for them to work together, it doesn't seem to be happening. What are the next steps there?

Neshama Marcus:

Sure. I'd say rule number one is your medical oncologist is leading the oncology journey, the cancer journey. Really you should make sure that your primary care serves as, I call them like the quarterback. So the quarterback is responsible for making the plays for gathering information. Think of your normal like before cancer specialists. If you're having an issue with your feet, you go to the podiatrist. You're having issue with bone and functionality, you go to orthopedist. The primary care is responsible for holding all that information. Your oncologist is meant to be communicating with your primary care. Your primary care is meant to be communicating with your oncologist.

Melissa:

Yeah, perfect. Okay. You are in a happy relationship, a productive relationship with your healthcare team, and you're halfway through treatment. Unless something very shocking happens, you're not changing doctors because you're happy where you are. But it turns out that some of the side effects of some of your treatment are being poo-pooed, and the doctor says, "No, that's not that. It's not this drug. It must be something else going on. It's not related." But it's new and you're frustrated. What do you do in a situation like that?

Neshama Marcus:

Sure. So as a social worker, confrontation is super healthy and it's very important. Sometimes people don't want to get confrontational with their provider. They think that the provider is going to be upset with them, they're going to be disappointed in them, they're going to scold them, they're going to yell at them, whatever. So it's important that you're able to have difficult conversations. You should be able to say, "I heard what you're saying, I understand the care plan that you delineated. I'm not super comfortable with that. Can you explain it to me again? Do you think I should go for a second opinion? What are the other options?" Being able to say I'm not comfortable, I know that that's setting a super clear boundary, but boundaries are healthy.

Melissa:

That's good. They're healthy and sometimes difficult, but worth it. Last question. So a couple people mentioned that their relationship with their healthcare team changed after COVID and it hasn't resumed the normal what the patients have considered healthy relationships beforehand. Now we've heard a lot about healthcare professionals being burned out over the last couple of years, but do you have any thoughts, last thoughts you can share on this particular issue?

Neshama Marcus:

Yes, I do think that this comes up a lot. I wouldn't say that they feel that their providers are burnt out, but I have heard that because policy changes that don't necessarily foster that warm and fuzzy, people feel a little bit disconnected. So I think that informal ways of connecting are helpful. Being able to say, "I so appreciate what you've done for me. I'm with you. We're with you, you're still my team." I haven't heard too much about burnout from a provider. Most people that go into oncology go in because they have the ability to help manage people with chronic and terminal illness. So I've heard that happen in other fields of healthcare, but I haven't heard that happen specifically with oncology. I'm sorry to hear that that's happening.

Melissa:

Well, you know, you say personal touches. Maybe this is the time to bring those cookies in or some pre-wrapped goodies or something.

Neshama Marcus:

Yeah, I mean, the policies don't necessarily allow for warm and fuzzy. Folks who are getting treatments for the first time who are now no longer able to bring someone with them into the infusion suite, that could be scary. So being able to say to the nurse, "Look, this is my first time, can you sit with me for a couple minutes?" They're willing and able and excited to do that, but you definitely have to speak up because they might not necessarily realize the impact that COVID has on, or policies have on implementation.

Melissa:

I think it makes sense that you have to think about what your own needs are. You know you're anxious, but maybe you don't realize necessarily that just having the nurse sit there and hold your hand for the two minutes as the medicine begins to flow and you realize it's not going to hurt or there isn't an infiltration or something like that could be the answer to calming your nerves. I wish we had more time, but we have to start wrapping things up. So I do want to thank our two callers, Lisa and Joanne who shared their personal experiences. It's always helpful to hear from someone who's been there and that's part of the reason our peer support program, our Lincoln caller program works so well. So if you're interested in that, please reach out. And of course, Neshama, we want to thank you for sharing your expertise. It isn't always easy to speak up on behalf of herself, but I found your presentation informative and really empowering, and I hope everyone here did as well.

I did see a comment that I want to address in the chat box, which is that somebody, and maybe more than somebody, but somebody expressed that the information felt overwhelming. It was just a lot of information and they weren't used to, like they didn't have all those people so they weren't sure what they were supposed to do now. So I do want to say that, please, if you want to help process this, definitely reach out to our social work team. There's Neshama's contact information if anybody has a specific question. But can we put our clinical team contact information in there? I also want to share with you some upcoming Sharsheret Summit programming. I'm going to try and switch the slide. There we go. Okay. Before I do, you'll also notice, before I talk about this slide, you'll also notice there's a brief link to an evaluation survey in the chat box right now. You can actually click that link and still listen to me share about upcoming programs. It won't take you away from the webinar. You've heard me speak about how excited we are about this year's Sharsheret Summit.

We have several national webinars and hundreds of programs across the country as we commit to raising awareness and helping people get through their experiences. There is a link to our special summit website in the chat box right now. You go to not our regular website, but this, there's information on national programs and registration information. On local programs divided by geography, there's an amazing digital resource kit you can download for educational information and so much more. And I do want to say the website is constantly being updated with additional programming so check back definitely. You know what? I want to show, these are the two programs I talked about. We said there were three major webinars. So Monday night, the 24th, next Monday, A Girlfriend's Guide To Breast Cancer. Appropriate for not only people who have been diagnosed, but women who are looking to be proactive about their care. And then on Tuesday, November 1st, Navigating Insurance: A Conversation About Coverage.

Anyone who has health insurance knows that it's not always easy to deal with, especially when you're dealing with something like a cancer diagnosis that's very difficult and takes a lot of time. So this is going to be a great conversation about how to manage that. As we conclude this evening, the evaluation link is back in the chat box. I want to take one more opportunity to thank Neshama for all of her information and insights. Once again, to thank Astera Cancer Care for working on this. Tonight's webinar specific sponsors Bayer and ImmunoGen. And of course, to share our deep gratitude to the sponsors of this year's Sharsheret Summit, Pink, Teal, and You, Eisai, GSK, Seagen, Daiichi Sankyo, Merck, Pfizer, Exact Sciences, and Lilly Oncology. Remember that Sharsheret social workers and our genetic counselor are there for you to answer questions, connect you to resources, and provide support.

You can reach our team through the contact information that is in the chat box right now. All registrants for tonight's program will be receiving a follow up email very early next week with our calling tour recording, a transcript, and some other resources. Have a wonderful evening. Thank you for joining us and we hope to see you at next week's Sharsheret Summit webinar. Have a great night.