

Can We Talk? Tips For Communicating With Your Health Care Team

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I. Introduction

Shera Dubitsky: I want to welcome all of you to Sharsheret's National Teleconference: Can We Talk? Tips for Communicating with Your Health Care Team. We are excited that so many of you have joined us tonight, and you are representing many states from across the country. My name is Shera Dubitsky, and I am the Director of Navigation and Support Services at Sharsheret.

Before we begin, I want to do a couple of shout outs. We'd like to thank Merck for their ongoing support and for sponsoring tonight's program. We'd also like to thank our partners in collaboration for this event, Cancer Support Community, John Hopkins, and Dana Farber.

Who are we? Sharsheret supports young Jewish women and their families facing breast cancer. Our mission is to offer a community of support to women of all Jewish backgrounds diagnosed with breast cancer or at an increased genetic risk by fostering culturally relevant individualized connection with networks of peers, and health professionals, and related resources. Our expertise is in Jewish women and young women, but we offer support to anybody who reaches out to us.

We receive many calls every day that have recurring themes that focus on communicating with your treatment team. Here are some of the questions that we typically get: How do I make the most of my time with my doctor? When do I speak with the doctor versus, let's say, the physician assistant or a nurse? Another question we get is, when is it appropriate for me to call the doctor? Here's another big thing that we get: I don't want to be labeled a difficult patient, but I'm told to advocate for myself.

Communicating with your treatment team is critical before, during, and after treatment. Whether you were diagnosed 10 weeks ago, 10 months ago, or 10 years ago, tracking your medical history and emotional experience is helpful in capturing your cancer journey and also in terms of using it as a springboard to conversations with your treatment team.

If you look to the right of your screen you'll see a handouts tab. Why don't you go ahead and click on that and you can download a care plan. This care plan is also included in a survivorship kit that you can customize based on your personal needs. Go ahead, reach out to Sharsheret. You can order your full kit. It's a free resource that also includes a cookbook and a pedometer.

I imagine that many of you on tonight's call have spoken with your doctors about participating in a clinical trial. I want to encourage you to visit Sharsheret's website and access the transcript or audio of an earlier

teleconference that we did that addresses the facts and myths of clinical trials. I also would like to introduce our new clinical trial brochure, that you can see here up on the screen, which is now available to be ordered. This resource can help guide you in your discussions with your treatment team about clinical trials.

One last thing before I introduce our speakers for the evening. You can go ahead and ask questions throughout the teleconference by typing your questions in the question box on your dashboard on the right side of the screen. I'm just going to ask if you can keep your questions broad in nature so that everyone on the call can benefit from the discussion. We will try to get to as many questions as we can after the presentation, and for those of you who are not joining us on the computer, please know that you can call Sharsheret any time with your questions and we will certainly address your concerns.

It is now my pleasure to introduce our first speaker, Dr. Noam Drazin. Dr. Drazin is a physician in the Cedars-Sinai Medical Group. He specializes in the treatment of a wide range of solid tumors, cancers of the blood and lymphatic system, and blood disorders that are not related to cancer. After earning his medical degree from Albert Einstein College of Medicine in New York City, he completed an internship and a residency at Cedars-Sinai Medical Center. He received his hematology oncology fellowship training in the combined programs of Cedars-Sinai and Olive View University of California at UCLA Medical Center.

Dr. Drazin has special interest in education and communication, having completed intensive training in promoting effective communication with cancer patients and their families. He encourages patients to enroll in clinical trials as a way to receive the most advanced care, and he makes community presentations on the latest therapies and research in cancer care. We are also fortunate to have Dr. Drazin as an active member of our California Community Advisory Committee and as a Team Sharsheret athlete who will be running the LA Half Marathon with his wife, Cindy. Dr. Drazin, I'd both like to welcome you and cheer you on. Go ahead, the conference is yours.

II. Communicating With Your Health Care Team

Dr. Noam Drazin: Thank you so much, and I appreciate the wonderful welcome and introduction. I'm hoping that this presentation that I put together today will be helpful in a wide variety of reasons. Sharsheret is a wonderful organization and I've had the absolute pleasure of being able to refer patients to Sharsheret, as well as now participating more directly with the organization as they've opened up an office in the Los Angeles area, a local office with a wonderful regional director. Obviously I really enjoy teaching both patients and medical students and residents, so I'd really

love the opportunity today to discuss communication with the audience. Why don't we move on to the slide, if we can.

The topic of the discussion tonight is going to be all about communication and communicating with your healthcare team, and with your doctor. I thought it would be very important to define doctor/patient communication and talk about benefits, and then we'll go into specifics with regard to different aspects of care, which we'll get through. Obviously, the question and answer session at the end is for you to ask any questions that come up during this talk, so please feel free to write those down, because I'm not sure we're going to be taking questions during the talk itself.

If you look at my first slide regarding doctor/patient communication. It's been found in many studies that effective communication is absolutely essential for patients to get high quality medical care. Studies have shown better outcomes have been linked to better communication between healthcare providers and their patients. One particular study that I'm not referencing but I made sure to look at is a study on blood pressure. Obviously not a cancer-related diagnosis, but blood pressure management always improves with better patient/doctor communication. The opposite is true, when you have bad communication there are severe limitations in the care that is provided to patients, and there have been noticed significant gaps between what the doctor or caregiver wants to intend to give to that patient and what the patient actually takes from that. That's clearly well-known as well.

Part of the problem with communication, that is actually thankfully improving as we get into these years is that formal training, is currently now occurring in medical school, and it definitely wasn't happening when I was in school back in the 1990s. I would say that doctors in their early to late 40s at this time, or older, may be more paternalistic in their styles, and I'm going to go ahead and define that at the next slide. Younger doctors who may have undergone actual official and professional training in communication may be more apt to advocate for patient autonomy and more mutual approaches to care, as I mentioned, which we're going to talk about, as well.

We really want a two-way street between patients and doctors, and for the most part I think that's what most people want. The days of Marcus Welby and doctor knows best are long gone, and I don't say unfortunately long gone, because I really believe, truly believe that to have an excellent patient/doctor relationship is one that is mutual in the understanding. If you could move to the next slide, please?

I think what's best is to really define as a patient what works best for you, and what do you want in your doctor? Do you prefer a doctor in boss role, or what's known as the paternalistic role for physicians and patient/doctor relationships? I think that is kind of on the minority side these days. I

wouldn't say it's completely absent, but I would say I don't see much of it anymore. It tends to be desired by patients and families when the patients are particularly ill at times, and it also provides some relief from the burden of worrying about your own care.

I will tell you that there are a few patients that I've come across in 20 years of practice that like that approach, but I would say the more common approaches are the ones below, which we're going to talk about, such as the mutuality approach to healthcare, which is where physicians and patients both are standing in front of their care. It provides more patient understanding of the disease and the treatment, and there's shared decision making and a partnership between the physician and the patient with regard to their care. It also includes upfront discussion regarding the goals of therapy and wishes. I don't want to give this short shrift. The issue of goals of therapy and goals of care is extremely important these days in understanding how to proceed when it comes to patients with advanced disease and patients with poor outcomes. It's really important to feel comfortable discussing those goals of therapy, and actually to find a physician that is willing to discuss those with you, because that may not be always the case.

Then the last type of communication, which is also not so common, probably as common as paternalistic roles, is a consumerism approach to healthcare, where the patient themselves calls the shots and the physicians are passive in this relationship. I'm not sure in what situation that actually works, because as much as patients want to take control of their care, they don't necessarily know what the best thing for them or their family is. I'm not sure that a consumerism type approach works. A lot of how we see consumer directed marketing by pharmaceutical companies kind of pushes that consumerism approach, but I also see it as helping with the shared decision making approach where pretty are well informed. Next slide, please.

Good or bad doctor/patient communication or different styles can impact the ability for patients to obtain the information they want or need. We're going to go through a couple things tonight. We're going to talk about screening for cancer, we're going to talk about fertility concerns, issues related to the diagnosis of breast and ovarian cancer. We'll touch on some advances in treatments, but again, the major focus of tonight is going to be on communication. Then well also look at clinical trial availability and access. Next slide.

Let's start with screening, and I think it's important to so everyone has the right jargon, that's why I wanted to talk about this first. Let's look at breast cancer first. Just from a definition standpoint, primary screening versus secondary screening. Primary screening is screening before you're diagnosed with a malignancy, before you're diagnosed with the cancer

itself. Secondary screening is post-treatment screening for the recurrence of cancer and if there is a need for secondary screening.

Let's start with the first, breast cancer and primary screening. I think it's important for patients to understand the roles for both mammography or ultrasound and, at times, MRI. I think that you may or may not be someone who gets annual mammography. Some women out there are getting both combined mammography and ultrasound, depending on the density of breast tissue. Then a whole new level of screening goes to MRI, or magnetic resonance imaging, for patients who are not great candidates for mammograms for one reason or another, or have a genetic mutation, such as BRCA, BRCA1 or BRCA2, where MRI screening is now the more appropriate way of screening. Those are the methods for screening for breast cancer. There are other non-western methods, like thermoscans and thermogenic type of screening, but it's not something that is actually approved for screening use in this country.

It's important to understand what primary screening is to communicate your needs to the primary doctor, and understanding when and where you should be getting the screening. Is it at age 40? Is it at age 50? Some new data has recently come out, you may or may not have read, trying to push that age of screening up to age 50. I think there's been a lot of pushback in the community, medical community across the country, especially nationally, trying to get back to that or to stay at the 40 year old mark for starting of primary screening. Everything changes when it comes to a strong family history or prior breast biopsies, and that's really a case by case basis, but from a standpoint of primary screening for just the general woman walking down the street, it's starting mammography or any type of screening at age 40. Being able to communicate whether insurance coverage is an issue, because there are people out there, and there are insurance carriers out there, depending on the location, where they're not going to pay for screening until a certain age. If patients want a screening before that particular age they're going to have to come out of pocket, and that may be an issue for one or another.

Some ovarian cancer primary screening, as we all know, or maybe we don't know, there really isn't a role currently, or a mechanism for primary screening for ovarian cancer. There have been some clinical studies out there looking at a combination of pelvic ultrasounds and a CA125 serum test, and those are particularly in the BRCA1 and 2 carrier trial, but there is not a current standard when it comes to screening for ovarian cancer. As we know, we sometimes see a diagnosis of ovarian cancer already at advanced stages.

I'm going to move now to the next slide, which is breast and ovarian cancer both in secondary screening. When you have a prior diagnosis is it mammography for breast cancer? After having been treated and after having received chemotherapy, is it a screening mammogram or is it a

diagnostic mammogram? I think it's important to note that you should feel comfortable saying, "Doc, I need a diagnostic mammogram, not a screening mammogram now that I've had a diagnosis of breast cancer." That's something that you need to feel comfortable communicating to your doctor.

Do you need an MRI? If the original cancer was not detected with regular x-rays or mammography, then MRI probably is that next step in secondary screening in that patient population. When it comes to ovarian cancer, do we repeat CT scans on a regular basis after original treatment? There are guidelines from the GYN oncology world with regard to that. Those are your secondary screening methods. The most important is communicating effectively with your oncologist or your care provider, whoever that may be, and be in charge of that aspect of your care. Knowing what you should be getting at that time is extremely important. Next slide, please.

I also think it's extremely important when we're talking about screening for cancer, what do we mean when we're diagnosed? There's a very big difference between being diagnosed with advanced disease, or metastatic disease, or localized disease. Let's talk about localized disease to begin with, in breasts, for example. That's with or without lymph node involvement. Usually stages you at anywhere between stage one, two, or three. I think the most important thing that gets conveyed by your physician, or you should know going in, is that with localized disease, both stage one, two, and three, number one is that this is curable.

It's really most important that that time for your doctor to tell you that you are free from disease, and that is probably the first sentence that comes out of my mouth when I see a patient newly diagnosed with breast cancer, at least localized breast cancer. Should be the first sentence out of a mouth, because as you know, if you have been a patient, or if you have had a friend who has been a patient before, sitting in that waiting room after being diagnosed and coming to see that oncologist for the first time is an extremely anxiety provoking event. Being able to kind of take that down a notch when you hear from a clinician that you're in the curative mode of therapy is extremely important. You should know that going in.

You should also know that the term "adjuvant," or the treatment provided called adjuvant treatment, is chemotherapy or hormonal therapy that's given to someone to reduce the risk of recurrence. It is not to treat active cancer. It is to treat the potential risk for recurrence, so it's preventative treatment, and it's really important that at least that it's understood, or you feel comfortable asking your doctor to explain that, because it's a totally different mindset than actually treating a cancer that's currently in the body. This is post-surgical. There's a whole aspect that I'm not talking

about which is neoadjuvant or pre-operative chemotherapy, which happens in certain cases where patients are treated with chemotherapy before surgery, but in this case, I wanted to talk more about the adjuvant therapy or preventative treatment. I can answer questions regarding pre-operative chemotherapy after in the question session.

My practice experience has been over the past 14 to 20 years that surgeons don't usually communicate the issue of curable disease, or the fact that everything's been removed. Again, from an oncology standpoint, that should be the first sentence out of my mouth when I see patients. Next slide.

When it comes to recurrence, I mentioned it a little bit before in the adjuvant therapy component, is that there is a risk, and there's always a risk. Chemotherapy done in the adjuvant setting or the preventative setting reduces that risk. It isn't a guarantee, but it takes the risk, whatever that may be, down from 30% to 10%, from 50% to 30%. Whatever that may be, it's an improvement in the outcomes or an improvement in the odds of recurrence, but the truth, and the most common thing, is that anxiety and the fear of recurrence is extremely common. Patients, when they come to see me, regardless of how long it's been since their treatment, whether it's been two years, three years, five years, ten years, they're always worried about disease recurrence.

We try to ignore these stories, and I think the internet is a great resource for patients, but it's also a great anxiety provoker. The internet is a great place for -- I've always said this -- great place for miracle stories and nightmares, and it is not much in between. We tend to concentrate on looking at worst case scenarios when we search on the internet, and we always try to avoid the information about stories of cancer coming back after five to ten years, but they do occur. We do want to identify the fact, and I try to identify the fact that patients have anxiety, and they may be a good candidate for either an anti-anxiety drug or an anti-depressant. I think as a patient you need to feel comfortable asking for that medication, or at least verbalizing that you are anxious and you're nervous and you're worried about this. There is a role for pharmacologic benefit when it comes to that. Next slide, please.

We're going to move on to metastatic disease for a second. Whether it's advanced breast disease, stage four, or advanced ovarian disease, such as stage three or four. We either diagnose someone with metastatic disease or advanced disease at diagnosis, so sometimes, unfortunately, patients are diagnosed with advanced disease upfront, or at recurrence. It's important to know when patients recur it's always, almost always a systemic recurrence, not a local recurrence. When we talk about chemotherapy to prevent recurrence, we're talking about chemotherapy to prevent someone from developing stage four or advanced disease.

Metastatic disease, however, is not curable, but extremely treatable. The possibility of turning advanced breast cancer into a chronic illness because of the many advances in this field, and patients need to know this information prior to making their shared decisions regarding their care. I am not a fan of sugar coating prognostic information when patients present with metastatic disease, whether they present initially with metastatic advanced disease or at recurrence. All my patients know that their disease is not curable, but they always leave my office with a plan. Whether that plan is for continued treatment or advanced treatment, then that's great, if the plan is to do nothing, then whatever they're comfortable with doing. The important thing is having that discussion and not coming out of a visit with a physician with undue expectations which may or may not be realistic. We can talk about those further. Next slide, please.

I was asked to touch a little bit on fertility, because I think fertility is a big issue. It's an issue that is sometimes ignored by clinicians and ignored by doctors and caregivers, and thought about almost constantly by the patients themselves. It's a really important topic to be discussed. It should be mentioned by the physician, or at least by you if you are suffering from a disease or are newly diagnosed. It doesn't matter whether you're either diagnosed with localized disease or advanced disease, you should be bringing it up if you can, if you feel comfortable doing that.

The question is, if you're a young woman without prior child bearing history, is there a risk for future child bearing? Without getting into significant detail, patients who've had breast cancer, if they have hormone receptor positive disease and they're on hormone blocking agents, they may not be a good candidate for having a pregnancy. The question then goes, is there going to be a situation, is there an opportunity for egg or embryo harvesting prior to starting chemotherapy? Even if it's someone who's not going to ever be able to carry a child? Do we want the opportunity to exist to have those harvested for use at a later date?

The important thing is, it's not always possible, and part of that has to do with the acuteness of the illness. Someone has advanced disease or has a lot of disease that needs chemotherapy almost immediately, or has a very high risk of recurrence and needs chemotherapy, there may not be enough time to undergo the proliferation and the harvesting of eggs and embryos for this purpose, but it's definitely something that needs to be discussed. There are also fertility implications from the BRCA gene issues, and I encourage you all to discuss that with your clinicians. Now there's actually technology from a fertility sampling of selecting out embryos, or eggs, actually, that do not carry the BRCA mutation that you may carry. The technology has progressed to that point, which is amazing and it's fantastic.

I think it's important to note that not all chemotherapy make women sterile. The previous, very aggressive chemotherapy that you used to give

to patients with breast cancer almost always led to significant ovarian failure, but that may not be the case. Again, there are no guarantees in life, so having that discussion and getting your options out in the open before you start therapy is extremely important. Next slide, please.

I was asked to talk a little bit about treatment advances. I'm going to spend just this one slide just so that you feel comfortable maybe understanding what those therapies are. What you should feel very pleased and comfortable about is that there is a large armamentarium of drugs for treatment of both breast and ovarian cancer. This is the new age of oncology. There's less toxic standard chemotherapy, which translates into fewer cycles of chemotherapy, so less time down. We're no longer using the red devil, for any of you in the audience who received doxorubicin or adriamycin in the past, that's not really used very much anymore. There are certain situations in which we do, but it's not a very commonly used drug anymore in the treatment of adjuvant breast cancer.

There's a whole new age as I mentioned, new age of oncology, based on molecular-based therapy. There's Her2 based therapies in breast, so that's herceptin and other type of Her2 based directed therapy. There's this whole class of drugs, palbociclib, ribociclib, abemaciclib, which is not yet out, but those three types of drugs, Ibrance is one of the trade names, used in advanced breast cancer. This is a new and amazing therapy which have greatly increased quality and quantity of life in patients with advanced disease. Then the PARP inhibitors, this type of molecular therapy specifically useful in patients with BRCA mutations in ovarian cancer, has been extremely effective in the treatment of advanced disease, and there's constantly studies going on looking at utilizing those earlier in therapy in ovarian cancer.

Then there's who whole aspect of immunotherapy. You've seen lots of commercials out there on TV, in periodicals of magazines. Keytruda, for example, an immunotherapy by Merck, who's one of our sponsors tonight, is a PDL1 inhibitor. Both PD1 and PDL1 inhibitors are out there and currently approved for use in multiple cancers. Not yet breast and not yet ovarian, but I'm sure there are clinical trials ongoing looking at those cancers, but already approved in melanoma, and lung, and head and neck cancer, and very effective in those cancers. There's lots of ongoing clinical trials in many different diseases. I do represent this. It gives me optimism looking forward to be able to practice in an age where we're saying goodbye to the more toxic chemotherapies and welcoming the more molecular based therapies. Next slide, please.

I think when you've been able to have or generate a good patient/doctor relationship, I think it's important to at least address the issue of second opinions and the ease of obtaining second opinions. A lot of the issue and the ease of obtaining second opinions is dependent upon the communication style. Someone who's paternalistic, doctor knows best

type of communication style, you're probably, if you're the patient of that type of doctor, you're unlikely to really obtain second opinions, or at least feel comfortable obtaining second opinions, because your access is very much dependent upon that doctor making that choice. When you have more of a mutualistic or shared decision making, there's less of an ego dependent care from the physicians side, a much more cooperative care towards clinical trials and other colleagues in the community.

Just from my personal experience, patients are always asking about clinical trials and opinions, and I am fully supportive of patients seeking second opinions and potential instructions regarding clinical trials and clinical trial access. Part of that is related to the fact that you need to somehow as a clinician, and I try, and I think I've successfully tried, successfully been able to do this, is leave my ego at home. Say that you feel comfortable sending a patient elsewhere when you aren't the expert in that particular field, or if there's a clinical trial that may be the best option for that patient, then you feel comfortable sending that patient away. Which may mean you never see that patients again, or they're out of your care, they're out of your hospital system, out of your practice. That should be okay. It is worth discussing how your physicians feel regarding second opinions, and I would say that in my experience, my contemporaries feel very comfortable, because it only strengthens that confidence in the great care that you're currently getting. Next slide, please.

From a tips standpoint, how can I help you kind of navigate through this and through communication? I think probably the most important thing to hopefully be able to accomplish is correspondence. How comfortable are you as a patient communicating with your doctor? Do you feel more comfortable speaking to that person directly in a doctor's visit? Do you feel more comfortable sending that doctor an email message? Or is it a directed communication through the electronic medical record, which we all have access to now? It really depends on how you feel and how the physician feels.

I will tell you, in my own experience, my email address is on my card. I give patients the opportunity, obviously, because it's available to them, to email me. I find it very helpful to communicate in between doctors visits when the problems occur or when the questions occur, as opposed to waiting for that next doctor visit, which may be a month later, might be six weeks later, to discuss something that's on a patients mind. Again, you have to feel out what type of physician communication you have. Physicians have potentially more time to respond when out of the office than when in person sometimes, and that depends on your particular doctor.

I think a big tip is to really be honest with your desires for care. First of all, be very open in what type of communication you prefer, and if that doctor

can't satisfy that, then maybe it's time to seek some care somewhere else if that's even possible. Also, be very open about what your goals of treatment are. I think that's incredibly important.

I think to finish, this is my last slide. I had an opportunity, if you can see on the handout section of the webinar, there is an actual Communication Tips handout which I had a chance to look at prior to starting the webinar. It's really great. It talks about some of the stuff that we've talked about today, but it also has some other things that we didn't talk about and might be helpful.

Thank you very much for the opportunity to address you all tonight. I look forward to working with Sharsheret in the future. Thank you so much.

Shera Dubitsky:

Thank you so much, Dr. Drazin. I'm glad I have a mute button because at one point I laughed out loud because we got a comment that came in that said, "Can we clone him? I'm disappointed that he's all the way over on the other side of the country." I think that you clearly, what you talked about resonated with this particular participant, but I'm sure with many of the participants on the call tonight. I really appreciate how you talked about finding a balance in terms of working with the doctors and the treatment team. We've already got questions that came in, so I think that we're going to have an active question and answer period. So thank you very much.

I'd like to now introduce Melissa. Melissa is a Sharsheret peer supporter, and she is going to share her experience and some of her takeaways about communicating with her treatment team that she is going to share with us. Melissa, go ahead.

III. Personal Story

Melissa Stein:

Yeah, hi everyone. Before I start I want to thank the doctor. I'll also say I wish you lived around the corner from me. Be really happy to have a doctor who's as thorough as you, so thanks for your time.

I went for a routine mammogram in April of last year, 2016, and was diagnosed that day with breast cancer. The tech there said to me right there, "You need to have some type of surgery no matter what they say." I had a unilateral mastectomy last summer, and I was diagnosed with stage two post-surgery. I did chemo and radiation, and I just, at the beginning of July, did my exchange plastic surgery. Sharsheret's been a big support to me through my whole breast cancer journey, and I'm so happy to join the call tonight and have a chance to give back to Sharsheret, so thanks to everyone for giving me this opportunity.

I wanted to give a few examples of what happened to me which alerted me to be my own advocate. I should tell everyone, you got to listen to

your gut. I didn't like my oncologist, or the office staff at the beginning. My interactions with them were really strained, and I didn't feel like they were easily accommodating. This all happened last summer, so everyone was on vacation, it was very hard in communicating. I was told that I had to start treatment as soon as possible, and that I had a small window of time to make decisions. I wish I had met with another oncologist, but I didn't listen at the time to my gut, it was so overwhelming. I since learned to take a breath, trust my instincts, and make decisions from a thoughtful place, not an emotional one.

When I first went for chemo treatment there was a lot of confusion, and it seems like no one knew what was going on. I again felt a lot of pressure to proceed, even though there was little clarity about my case. I learned to keep track of my records and information. The hospital just seemed to be such a large place, and communication between the departments was not always reliable. When I went for my second chemo treatment, the staff in the oncology office was unclear as to whether I was having my first or second chemo treatment. It was discovered that there was two charts going on me, and no one really offered any type of explanation.

I walked into the infusion center that day and asked for reiki. The hospital kept raising that they provide this, all different types of services during the chemo. I must have asked about 20 times during my chemo session for the reiki, and the woman showed up just as we were finishing. She said, "Okay, I'll work with you for about five minutes." She said, "Wow, you're really stressed. I think you probably need this." I was like, "Yeah, thanks. I really needed that."

The very next day, I went back to that hospital for my Neulasta shot. They took me and my mother into this very small room. They then brought in another patient with three family members into the same small room. A nurse starts talking to me about my private care and information in front of the other patient and the family. Well, to say that we got upset was an understatement. I did end up getting the shot, but after such a mess that day, the mess the day before with having two charts going on me, I told the head of the infusion center that I was never getting any treatment by anyone but herself. There was just too many mess ups. This is when I started asserting myself and advocating for myself. It was then I decided to get a second opinion.

I then went to two other doctors, I got two more opinions, and both told me that I did not need chemo. I had already had two rounds of chemotherapy, I then switched oncologists and started radiation. Another takeaway is that it's okay to go for second opinions. After I decided to go for my second opinion I started to feel validated and heard in a way that I really had not felt before. Just back to the beginning point of trust your gut when you're meeting all these doctors.

Along the way I learned that sometimes it's more helpful to speak to nurse practitioners, physician assistants, or others on my treatment team to better understand my medical status and to walk me through my options and what's currently going on with me. Before my surgery, this last plastic surgery, I insisted on having additional appointments with my surgeon. I totally wasn't clear at all about what to expect. I went for one appointment and I couldn't remember anything that the doctor said. I went back again, and I went back a third time. My doctor was a little irritated, but I insisted that I wanted to know exactly what my breasts were going to look like, and what exactly was going to happen to me, because I was feeling so nervous. After having all this information I thought it would be helpful to me.

During my chemo care and after my mastectomy, I had another health scare. Was seeing my oncologist and it was suggested I have a particular screening. It turned out that I couldn't have that screening because of my implant, and I don't know why I wasn't told this at the beginning. I walked in and they asked if I had any metal in my body. I've learned that I need to ask many questions about my future health care and understand screenings and what I need to know as a breast cancer survivor.

Another tip I would recommend is to speak to your insurance company, find out what they cover for you. Some insurance companies will pay towards a wig. You should be getting a prescription from your oncologist for a cranial prosthesis. I found that not everyone knows about this. While it's different for everyone, my insurance company was able to cover the cost of my wig at 100%. I have an unlimited benefit. On the same line, though, I learned that even when insurances say they will not cover something; it could be worth exploring further. My insurance company told me that when I wanted to go to a particular breast rehab center that it wasn't in my network, so I went somewhere else just for regular physical therapy and I was not happy where I was going, so I called the breast rehab center and they were willing to negotiate me, and they would have negotiated me from the beginning, but I just took my insurance company's word for this where I should have advocated more for myself. This taught me to really explore all the options.

Having breast cancer is very emotional. Seek out people that understand. I learned a lot from peer support through Sharsheret and from working with nurses and therapists. One of the peers that Sharsheret introduced me to has become a really close friend, her name's Alexis. She happens to live about 20 minutes from me, so we're able to meet in person. During some critical decision times we went walking a few times, and that was really helpful. She passed to me this amazing sleep pillow for after surgery, and bras, and was such an amazing support.

My oncologist happens to bring the social working in to all my appointments because I've gotten quite upset during appointment time. I

found that that's been very helpful and good. I want to encourage everyone not to be afraid to ask for help and to get all different kinds of help you need during this journey.

At the end of the day this is just my personal experience. You're your own best advocate and you have to find what works best for you. As I said, Sharsheret understood what I was going through and was able to help me figure out what worked best for me, and they can do the same for you. Thanks so much for listening.

Shera Dubitsky: Melissa, wow. Thank you so much. We are grateful that you shared your hard earned wisdom with us, and I think that you highlighted some of the points that Dr. Drazin had made and really showed it to us in a real situation that so many people on tonight's call, I'm sure, can relate to. Thank you very much.

IV. Question & Answer

Okay, we are going to now have just some time for some questions. To ask a question you can go ahead and type it in the text box to the right of your screen, and we will address them in the order that they've been received. Okay, Dr. Drazin, one question that we have, which we actually get a lot here at Sharsheret is, asking for women, let's say, who are diagnosed with earlier stages, even as early as DCIS, is it okay to ask for a PET scan of the entire body and, I guess, just asking for those kind of screening in general?

Dr. Noam Drazin: Yeah, that's a great question, and I like the opportunity to answer that. It's interesting because it's becoming more of an issue as costs of care have been increasing lately. The general consensus in the national guideline, both by the American Society of Clinical Oncology, as well as the NCCN, which is the national recognized cancer network that helps community oncologists and academicians out in the country, is that PET scanning, or CAT scanning, or bone scanning is not at all necessary unless the disease is stage three or above. I think you should feel very comfortable in not necessarily asking for a PET scan, or a CAT scan, or a bone scan if you have early stage one or stage two disease, because the chances of having advanced disease with early stage cancer is very, very low.

You have to take into account ... Forget about cost, because that doesn't ever really come into play. From an insurance standpoint, it may not be covered, but from the standpoint of screening as a necessity, there is a risk for the amount of radiation you're getting, and I try to limit screenings, CT scans, and PET scans, and bone scans in patients who don't need it, because the risk of the scan itself adds up over time and may be more risky than the benefit that you get from detecting something early.

Shera Dubitsky: Okay, thank you. We got a question, how often do you go for checkups post cancer? I guess with all cancers, I don't know if that differs in terms of the cancer, but how often do you go for a post checkup after treatment?

Dr. Noam Drazin: Okay. Yeah, I guess it depends on the cancer, it depends on where you are in terms of the disease. Let's just split it up into localized disease. If someone has had early stage cancer, breast cancer or ovarian cancer, has undergone surgery, radiation, or chemotherapy, the general consensus is that they see their oncologist every three months for the first two years, every six months for the next two years, and maybe annually after that. Then it really depends, once you hit the five year mark, whether or not you continue to see your oncologist. I tend to hold on to my patients beyond five years, but there are a lot of health systems out there that are encouraging oncologists and specialists to get their patients back to their primary care doctors to do the rest of the screening. That's how often I see breast cancer patients with localized disease, or ovarian cancer, as well.

When it comes to advanced cancer, I typically see those patients if they're on chemotherapy or any other type of treatment as often as every cycle, which may be every two, every three weeks. If they're not on current therapy at the time, it's pretty much every three months forever. That's how often I see.

In terms of very early disease, like DCIS or stage zero breast cancer, in those situations I may only see patients yearly or every six months, and differ some of their care to their primary doctors.

Shera Dubitsky: Okay, great. Melissa, question actually came in for you, but I'm going to tag it with another question that came in on the same topic to Dr. Drazin, but I'll start with you, Melissa. How did you find your second opinion?

Melissa Stein: How did I find my second opinion? I happen to live in the New York area, and I have an oncologist in my social circle who actually was a, he's a radiation oncologist. He actually was the first person I called when I had my initial mammogram and he sent me to a particular doctor. I really reached out to a bunch of different people, I'm just trying to think back, because I went to one doctor here in New Jersey, and then I went to a doctor at Sloan Kettering. Sort of through my parents and networking, we were trying to figure out where to go to.

Shera Dubitsky: Okay, so it sounds like through networking.

Melissa Stein: Yeah.

Shera Dubitsky: On the heels of that, Dr. Drazin, is there ever a time that you can actually ask the doctor that you're working with for a second opinion? The part two

to that question is, how often will the doctor and the second opinion doctor perhaps communicate with one another? Particularly if there's not a disagreement, but a different perspective?

Dr. Noam Drazin: Yeah, those are excellent questions. I'd say the majority of cases, patients feel embarrassed to bring up the issue of second opinions with their doctors because they feel badly for going around them, or potentially looking for the other doctor to provide them with confidence. In those cases, the doctor themselves may not ever know the patient sought second opinion consultations because they usually don't tell the second opinion physician who they're currently seeing. It's all done kind of mysteriously.

I would encourage, if you have the opportunity to have a good communication with your oncologist, to ask, and you should ask whenever you want. I think that in a complicated case, I think there's always a role for having another set of eyes and another brain look at things. It tends to be more common in cases that are a little more complex, that the answers may not be so straightforward and the treatment choices may not be so straightforward. In those cases you should feel very comfortable saying, "Listen, do you have someone who you would recommend that I go to to see, just to get an idea having someone else look at it?" There's always been a bit of hesitation on the patient's side, because they're worried about what the doctor's going to say, but in a good relationship, a more mutualistic or shared decision making relationship, that physician should not feel threatened or worried that their patients are going to leave.

When it comes to communication, in those situations where you are potentially referring your patient to another colleague in another hospital center or another practice, then you're going to reach out to that person, as well, and then I usually get a consultation report and occasionally a direct phone call when patients have been seen. Then I also bring it up and I make sure to discuss it with the patient and make sure they feel comfortable staying with me. It's not just about the treatment. It's about the treatment and the personality and the relationship. If you're going to get the same treatment, but they're going to get along with that other doctor better, then that may be the better fit. That understanding has to be developed and it has to be understood before continuing therapy one way or the other.

Shera Dubitsky: Okay. Continuing-

Melissa Stein: Could I reply back for just one moment?

Shera Dubitsky: Sure. Sure.

Melissa Stein: Thanks. The doctor just reminded me, my case was quite complicated once I had gotten to this point, and I was very intimidated by the first doctor, because she was very adamant about what she was telling me. When I did go finally for the first of the second opinion, he had already had my chart, had reviewed everything before I got there, had called multiple doctors about me before I arrived, and had said to me, "I want you to go to Sloan Kettering and get another opinion, and I would have told you this from the beginning so that we can decide this." He consulted with the other doctors and et cetera. That was also a key to me. It increased my trust in him, because he was so open to making sure we were getting the right care for me. I think that that's something too.

Shera Dubitsky: I love that you added that.

Melissa Stein: I would be on alert for a doctor to be so clear on this, because nothing's clear in treatment for this disease.

Shera Dubitsky: I love that you added that, Melissa, because again, I think it highlights what Dr. Drazin was saying about having a relationship and just taking in information and seeing what clicks for you in terms of that relationship. Thank you for that.

Dr. Drazin, sticking with second opinions, somebody asked, "When is a tumor board involved, and how is that different than a second opinion?"

Dr. Noam Drazin: Yeah, that's interesting. Tumor boards are not common in small town community practices, but they may be very common in academic centers. In my particular institution there are multiple tumor boards. There's a breast tumor board, there's a lung tumor board. What it is, is a built in second opinion, or that's how I explain it to patients. The surgeon usually presents the case to a group of other surgeons, to pathologists, to radiologists, and to other oncologists as a challenging case. They discuss it and then they talk about what should and shouldn't happen, or what they would recommend.

It's not about telling someone that they've done the wrong thing, it's all about what they as a cohesive group would recommend as a team. Sometimes that's done and it doesn't require the patients to go meet somebody else, doesn't require a billing of an insurance company, which may be something of a sticky matter when it comes to getting second opinions out of your panel of doctors that your able to see. It allows kind of an internal owned second opinion which provides confidence to that patient that they're getting the right thing.

It also provides confidence to the doctor. I always enjoy when my cases are being presented to tumor boards, because it's my own kind of spell check that I'm doing the right thing and it's been validated by other physicians who treat the same type of cancer.

Shera Dubitsky: Great. We have a question from a woman who is talking about being in active treatment. She wants to speak with her doctor outside of scheduled appointment, but sometimes feels like she has to get through the gatekeeper of his office. Any suggestions on that?

Dr. Noam Drazin: Yeah, that goes to one of my original slides where you have to, at that first appointment, get the topic of correspondence and communication out there, is how am I going to reach you, doc? How do I do that? Do I have to go through the secretary? Can I send you a message by email? Could I send you a secure message through the electronic medical record? Getting that out there without being the, kind of worse case scenario, where you're undergoing treatment and you have a problem and now you can't reach your doctor. It's really important to do that up front.

Shera Dubitsky: Okay. We have several questions that are specific in terms of screening and Tamoxifen that we're just not going to have time to get to, but I would certainly encourage you, for the people who asked about the screenings, to certainly call Sharsheret or to actually call your doctor's office and ask the particular question about screening and Tamoxifen based on your particular situation.

Just, I think, on the heels of what Melissa had talked about in terms of having a social worker present, somebody did ask, Dr. Drazin, have you ever seen patients who have their own professional patient advocate come in for appointments?

Dr. Noam Drazin: Yeah, I'm smiling now only because my mom, my 76 year old mother, who is a retired microbiologist, has now started to do her own business of being a patient advocate. It's very common here on the west coast. It's for patients who can pay cash, it's an hourly type rate, and it's very common. It's incredibly useful for patients who don't have family members or good support.

Now, for those people who can't afford that, because there are very few people who can, there are help systems out there that have patient navigators, nurse navigators, that do that, or case managers for a particular practice who could help with that. That's becoming more popular as we understand that treating patients isn't about just the doctor and the patient, but it's also about the family and the social implications and things like that. It's something we see a lot here in LA.

Shera Dubitsky: I'm just going to end the question part with a tip, actually, from somebody who called in, and I like this. She said, "Make a list of questions from the moment you leave the doctor's office until the next visit, and prior to the next visit, pick the three most important and prioritize the question during the appointments, because I think that that's a very effective way to make the best use of your time with your doctor. Then at the end of the

appointment, ask the doctor for the other concerns that you have, what's the best way to be able to speak to them about it."

V. Conclusion

Shera Dubitsky: Thank you everybody for the great questions. I want to just highlight again the handouts that Dr. Drazin referred to. Again, if you go to the right of your screen you can access these helpful documents just by downloading, clicking them open, and saving for future use. One of them is Sharsheret Communication Tips that the doctor talked about, and the other one is Who's Who on Your Treatment Team. For those of you who are not on the computer but are participating just on the phone, you can access these downloads on our website after the webinar.

You will be receiving an evaluation in your email within the next couple of days, so please just take a few minutes to complete the survey. Your feedback is valuable to us as we are committed to staying relevant by enhancing our programs to reflect the growing and changing needs of the women and families of the Sharsheret community. Sharsheret's expertise, again, is in young women and Jewish families, but our 12 national programs are, as I said earlier, open to all women and men regardless of background.

I want to thank Dr. Drazin really for masterfully helping us navigate and maximize communication with your treatment team, and I also want to thank Melissa, again, for sharing her story and bringing these issues to life.

Tonight's presentation will be available on audio or on transcript on Sharsheret's website, and you can access it by going to our website, sharsheret.org. You look at resources and you'll see a tab for teleconferences and webinars.

I'd like to, again, thank Merck and our collaborating partners. I hope that tonight's webinar was a helpful guide to helping you have more effective and purposeful communication with your doctors and treatment team. Again, visit Sharsheret's website at www.sharsheret.org, or call us at 866.474.2774 to discuss tonight's topic or any other concerns that you are facing. Also, like us on Facebook, follow us on Twitter, and enjoy the rest of your summer, and have a good night.

VI. Speaker Biography

Noam Drazin, MD, specializes in the treatment of a wide range of solid tumors, cancers of the blood and lymphatic system, and blood disorders that are not related to cancer.

After earning his medical degree from Albert Einstein College of Medicine in New York City, he completed an internship and a residency at Cedars-Sinai Medical Center. He received his hematology/oncology fellowship training in the combined program of Cedars-Sinai and Olive View/University of California, Los Angeles (UCLA) Medical Center.

Dr. Drazin has special interests in education and communication, having completed intensive training in promoting effective communication with cancer patients and their families. He encourages patients to enroll in clinical trials as a way to receive the most advanced care, and he makes community presentations on the latest therapies and research in cancer care.

VII. About Sharsheret

Sharsheret, Hebrew for “chain”, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer. Our mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk, by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Since Sharsheret’s founding in 2001, we have responded to more than 67,000 breast cancer inquiries, involved more than 8,000 peer supporters, and presented over 250 educational programs nationwide annually. Sharsheret supports young Jewish women and families facing breast cancer at every stage--before, during, and after diagnosis. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life. All Sharsheret’s programs are open to all women and men.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare professionals

VIII. Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care professional. The document does not recommend the self-management of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

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