Supportive Oncology:
Ensuring Whole-Person Cancer Care

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Melissa Rosen:

Thank you so much for being here with Sharsheret tonight for an important conversation about supportive oncology. My name is Melissa Rosen. I am the director of training and education at Sharsheret. Supportive oncology is a great number of things but let me start by telling you what it's not. It's not hospice care. Although a person can receive supportive oncology toward the end of one's life, supportive oncology is sometimes called whole-person cancer care. It's sometimes called palliative care, but when we call it that, we run the risk of confusing it with Hospice care. Palliative care, just like supportive oncology, is meant to be an integral part of cancer care from start to finish. It addresses physical needs such as treatment side effects, as well as emotional concerns and practical matters such as financial issues, religious matters related to treatment and much more. It is meant to be a companion to one's cancer treatment plan, and tonight we'll explore supportive oncology and how to advocate for yourself or a loved one or even for one of your patients. Before we begin, I have a few housekeeping items to share.

I would like to thank our sponsors for tonight's webinar who enable us to continue to offer meaningful programs. Thank you to Gilead, to Merck, to Pfizer and the cooperative agreement DP 2400061 from the Centers for Disease Control and Prevention. Tonight's webinar is also being presented in partnership with Astera Cancer Care and we thank them for that. The webinar is being recorded and will be posted on Sharsheret's website along with a transcript for you to use as a resource. Participants' faces and names will not be on that recording. I'm pleased to say that we now have closed captioning available to display live captions on the bottom bar, click captions and then show captions. You also have the option to be anonymous during today's live webinar. You can turn off your camera and even change your name in the zoom square. There are instructions in the chat box now on how to make those changes if you wish.

A reminder for our Embrace community, we invite members of our Embrace community, those facing metastatic breast or advanced ovarian cancer to stay with us at the end of the webinar this evening for an intimate breakout session with tonight's expert speaker and Bonnie Beckoff, our director of support services. I'm excited to say that we've received many questions throughout the registration process and I know questions will also arise during tonight's presentation. So, please use the chat box to put your questions and we will address them during the Q&A at the end of the session.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for almost 25 years because cancer is so much more than a physical experience. If you are interested in finding out more about Sharsheret's free, confidential, and personalized services, please email us or visit us at our website at sharsheret.org. And that is now also in the chat box. Before we welcome our supportive oncology expert we are so very fortunate to have with us tonight Maggie, a Sharsheret program participant with a personal experience with supportive oncology and she's going to share a bit of her story with us tonight. Maggie, thank you so much for being here.

Maggie:

Thank you, Melissa. And hi everybody. My name is Maggie and my cancer journey started eight years ago. I was 41 feeling like I had just gotten my self-care under control and knew what I was doing. I'd gotten good at relaxing and was running three to four times a week, ate veggies, but cancer came for me and I was diagnosed with DCIS stage zero breast cancer. I needed a mastectomy and I opted for a bilateral and had a lot of reconstruction, so that meant no more running. And without that release, my thoughts were, I mean, frankly they were just running all over me. So, my nurse navigator referred me to integrative oncology and to the supportive oncology department. So, I met with a therapist, he taught me how to meditate and that was such a game changer. I became more peaceful, I became more present and it kind of kicked off this relationship with supportive oncology where I sought these services to care for all of me and not just for the cancer part of me.

And two years later, after a lot of meditation, I was in not such great physical shape anymore. So, I found their cardio-oncology exercise program and did 12 weeks of intensive workouts with oncology knowledgeable trainers and got into much better shape. And I was feeling really better than ever. And I felt like I was taking really good care of me, but I couldn't control the people around me. And people came at me with all kinds of things. I'm sure a lot of you can relate on the products I should be using to try to control cancer. And that sent me spinning. So, I went to integrative oncology and the doctor there really set me straight on what supplements to use and what I really should be putting in my body. And then four years later I was devastated to be diagnosed with stage four metastatic breast cancer.

I went back to psycho-oncology and got a lot of support and counseling and I realized that one of the things I was really anxious about was what I was putting into my body. There's the soy, there's the sugar, there are all these messages that I was getting and I didn't know what to do with. And so she referred me to nutrition oncology and a registered dietician there set me really straight on what made sense and what was good for my body. And my treatment is letrozole and IBRANCE. I'm still on the same treatment almost four years later, but those come with some side effects. And my body was starting to feel like I was probably a hundred years old. So, I sought out in our supportive oncology department, we have acupuncture and massage therapy and they're amazing. There are so many good reasons to get those services done at your oncology, in your supportive oncology setting if you can.

One is that they're about half the cost of what it would have cost me to get those in the community. And the other is that they, all of these doctors are working in collaboration together and practitioners are all working collaborations together. They all share the same chart. So, they all know what I'm experiencing and I'm sure I'm not alone in this, in that this medicine causes all kinds of stomach issues and I really didn't want to walk into an acupuncturist and talk about my diarrhea. So, going through supportive oncology is amazing because they have the chart. They know this is a side effect.

They just come in and say, rate your diarrhea from zero to 10. And it took a lot of the pressure off of me from having to talk about something that's just awkward, but a real thing when you have cancer. So, that's it in a nutshell of the many, many things I have done in supportive oncology. I feel like if there was an award for trying things in supportive oncology, I would be a contender. But I feel like it has put me in a place of being way better in my mind, way better in the entirety of my body and just has really helped me to feel empowered to live my best life.

Melissa Rosen:

Maggie, thank you so much for sharing your story. I loved that throughout your cancer experience you took advantage of this and I love that there were so many different parts of supportive oncology that you took advantage of and it's just so helpful to hear personal stories when we are learning about things we might not be familiar with. So, really, thank you so much for being with us this evening. All right, as we move into the primary presentation, I also want to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and by tonight's speaker is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem.

As always, be in contact with a qualified healthcare provider to address those issues. We are so very fortunate to have with us today, Tina Basenese. I know personally how dedicated she is to the idea and the practice of supportive oncology. Tina has a lot of letters after her name, including MA, APN, ACHPN, and she's worked in the field of Hospice and palliative medicine in numerous capacities since 1999. As a 2003 graduate of one of the nation's first palliative care nurse practitioner programs at NYU, she developed, directed and practiced in two inpatient palliative care programs, served as the director of two Hospice agencies, developed an outpatient palliative care program and most recently developed, directed and has a robust clinical palliative medicine and supportive care practice for Astera Cancer Care, a large multi-site oncology and hematology private practice in New Jersey.

She's also currently the vice chair of the Palliative Care Committee for One Oncology. In addition to being a board-certified clinician and an administrator with over 25 years of experience in the field, Tina is an author, an educator, a mentor, a presenter and board member of the New Jersey Palliative Care APN, Advanced Practice Nurse Consortium since its inception in 2009. She is passionate about sharing information and coordinating good care. Her mission is to ensure patients, loved ones, physicians, nurses, and healthcare administrators become familiar with the impactful benefits of incorporating supportive care early on in the care of anyone living with a serious or life-limiting illness. And tonight she adds you to the list of people she will educate. Welcome, and thank you so much for being here today, Tina, this is such an important topic.

Tina Basenese:

Thank you. I'm so excited and thrilled that Melissa asked me to speak to you. I feel embarrassed that I hadn't heard of your organization before, but I feel like I'm going to talk about it constantly now and recommend it for everyone. Just what a fantastic organization you are. So, thank you so much for allowing me the opportunity to talk to you tonight. So, I get very, I have a bunch of slides and they may have a lot of words but ignore the words and just maybe listen because I do kind of go off on tangents and talk a bit about really my patients and the clinical experiences I've had over the years. And I have to just say even what Melissa talked about, I wish that my oncology practice had cardio-oncology and nutrition oncology and massage therapy and acupuncture right there in their practice. I mean now it's like I'm spinning like all the things I need to start, but I think that that's fantastic that she took such advantage of all of those things. I have a slightly different slant where I'm going to go tonight.

And a lot of it is, it's not as holistic. Some of it is real medical management, some of it is about advanced care planning and decision-making, but a lot of it is about advocacy and autonomy and just teaching doctors and nurse practitioners and physician assistants and nurses, social workers and front desk staff and the billing department and the triage nurse and anybody about what it is you really need. This isn't one size fits all and Melissa's opening was just so perfect. Because so many of you can relate to exactly what she's talking about. That to me, what palliative care means more than anything else is access and information. And I'll explain more about why I describe it that way, but everybody that does palliative medicine sees it that way. And you'll hear me probably use my language a little more than supportive oncology. And I have like some definitions and things like that. But let's just dig in and see where the conversation goes. So, let me just try and share my screen, see if I do it correctly.

How'd I do? All right, thank you. Okay, so I have supportive oncology and somebody keep me on time if you can maybe give me like the half an hour or 20 minute whatever, mark. Okay, so for me, I put supportive oncology in air quotes, and that's because I think that it's, that's kind of like a loosey goosey kind of term to me. So, what I want to kind of get through, the point I want to get through tonight is some of the stuff that is probably what you're already living with. Getting that diagnosis, how does that affect you on a multidimensional way? And who is that team that takes care of you and are they meeting your needs? Self-empowerment, what's in your toolbox. How do you best receive support? And are you getting that? Making decisions about your cancer treatment and making decisions about later in your life when maybe you're closer to the end of your life and you want to make sure that other people are supported in the information they need to make decisions for you.

And on the other side of that is just always continuing to maintain some semblance of hope. And hope changes all the time. And there's different things you might hope for a good scan result, hope that your platelets go up, hope that your children are going to be okay with this information. Hope that you don't poop when you are going to the doctor's office or to your diner. There's all different things that we're wishing for. And then we're going to really take it down to where's the brass tacks? What are we going to do? Taking action, planning, healing, thriving, and integrating all of these different types of care, whether it be palliative and like I said, and or supportive care because they can be slightly different and they also can be kind of exactly the same sometimes. Utilizing the survivorship. But again, you guys are better experts in that than me.

And then like the stuff that we don't love to talk about, which is how do we decide when it's time for Hospice? So, many of you, you've been there the day that you get told it's cancer and this is the club that nobody wants to join. I hear from everybody that you get that information and then it's like Charlie Brown's teacher starts talking and it's like you're not exactly able to pick up on what everyone is saying, what the details are. And I don't need to explain this. Panic, confusion, disbelief, hopelessness, anger, all these feelings. And then you have all these people that love you that want to process it with you. They don't know how to support you, they don't know what to say. They may say the wrong thing. Melissa touched on, or Maggie, I think I said, did I say Melissa 10 times before? And I met Maggie 10 times. Okay, sorry. Maggie, I owe you an apology. You deserve all that credit. And I gave it all to Melissa. She didn't deserve that credit.

No, but what Maggie was saying before too, people are giving her advice and you don't know what to do with that information. Sometimes it's just overwhelming. So, I guess the message for me is there a way that you can pause. And just allow yourself to not have to share that with the whole world, but really just keeping it in your inner circle, your closest people. And I think that that's what people that have gone through and have told me too. You see some people throw it up on Facebook and then there's like all the comments coming in that seems overwhelming. I have some suggestions on how to manage all that overwhelming love you get. And obviously the impact affects you in every sense of who you are, financially, spiritually, socially, physically. So, I'm sure that at that moment, you have to now pick a team and how do you do that? So, oftentimes it's the person that diagnosed you, that sent you for that imaging that gives you ... oh, my lights are going out in my office.

That will give you the recommendation. That's sometimes a good avenue. Sometimes it's not always right? It may not be the right person for you. So, looking maybe a local medical society or cancer organizations carefully ask friends and family. Sometimes their experience is not going to be ... it may not be the right match. Online searches don't often yield something very good. But there's organizations like ACS and Cancer Care that often can lead you in the right direction. But what you're looking for in your team is a lot more than treatment. More than more than just that they have good clinical trials or they have in our areas like you know, they have an affiliation with MSK, Memorial Sloan Kettering or MD Anderson or Dana Farber. Really it's kind of like, I would want to look for Maggie's oncology group, somebody that really has supportive care.

That they have all these avenues and tentacles out to whole person care. So, you want to ask those questions, you want to talk to somebody immediately about like what are your services? Can I see brochures and flyers and things about what your other services are other than just your cancer regimens, your NCCN guidelines? Still, I have people in treatment for years and then they go for a second opinion when they have a recurrence or they have progression. And I think what I find is that those guidelines are pretty, they're standardized. And so you pretty much, when you have a good connection with a team, you don't have to go to those big centers. You need it to be close and convenient oftentimes.

And not hiking into New York City and the cost of that and all of that sometimes. So, finding out are there regimens? Are these regimens the same regimens they use everywhere? And when Melissa and I talked about this last night I said that I felt like this was going to be maybe not as important to you. She asked me to just keep these couple of slides in there. So, if this is ... I'm going to get more into the meat about what palliative and supportive care is at the moment. But I do think it is really important to get the right team. So, coming in with your notebook, with all of your questions, expecting that they're going to make the time for you. You deserve that. And there's going to be a lot of rush, a lot of standardized conversations. And sometimes, and again, how I kind of talked in the beginning, like we need you to teach us what you need.

And unless we are a cancer patient ourselves, we don't always know exactly what you need. We think you need to have cancer cells killed. And that's the most important thing. Well that is very important. But there's so much more about you that's important. So, you have to kind of teach us that that's what you need. Tell them how do you like to hear information. Who do you like to be in your circle that's going to receive that information? Or are you very private. Some people don't want to bring anybody with them. But I always think if you're comfortable with that and sharing this information, it's always good to have a second set of ears. Make sure that you have full disclosure.

You don't speak the primary language of your provider that you expect and ask for an interpreter. So, I have a patient right now that every time I meet with her, she speaks some English, but her daughter is always with her and her daughter speaks English. And so most of the time we would think that the daughter would just do the translating the daughter every time if I start the appointment and I don't have the interpreter, she says, it's okay, we'll wait until the interpreter gets here. And I appreciate that actually. And I don't want her to loosely interpret what I said. I'm talking about some very serious information that's uncomfortable. So, I will want somebody to say how I say it. I don't want it to be like, maybe I don't want to say it that way because it might hurt her. I want to say I want her to hear how I'm presenting the information.

So, interpreters, if you can't hear, if you can't see if you're in pain, if you're nauseous. I just had somebody the other day, it was a new consult and the poor guy was throwing up for like the first 10 minutes of the appointment. I said to him, "Why don't you take a minute? Why don't you go get an ondansetron and I'm going to turn my camera off, I'm going to turn my sound off and I'm going to come back in 10 minutes and just take a minute." So, I came back and he was feeling a little bit better, but he still didn't feel great. And I said, "Okay, let's hit the high hard ones. What are the most important things we need to get through? And then I'm going to let you go. And then instead of seeing you in two weeks, I'm going to see you in the next five to seven days and then I'm going to send my triage nurse to call you." And this is what we did.

"She's going to call you tomorrow, she's going to call you two days after that." And that's important that most people aren't going to offer you to get off of that appointment or leave the appointment. Because that's your spot. But you have to say, "I can't hear you right now. I don't feel well enough to have this conversation." So, standing up for yourself, asking for clarification. We talked about advocacy. I'm not hearing you exactly. I need you to be more direct with me. Or your tone is making me a little uncomfortable. Telling them things about you. Talk about your family to offer (information) … one of the doctors I work with always writes in his notes what nationality somebody is.

If they're an immigrant, if they're a survivor, the Holocaust, World War II, he'll always write that in there. He'll say they worked in factory on a ... They developed pottery and they worked in the firing section of the pottery plant. He'll write all of that in there. So, share, find a way to tell them about yourself so that they can connect with you better. And then start to understand what you would need more. I'm going to talk about somebody tonight and she told me something today that I didn't know and she gave up children for adoption. So, when I first met her and I said, "How many children do you have?" She told me she had four kids.

So, today I was talking to her and she has advanced ovarian cancer. And I said, "Would it be okay if I talked about you tonight?" She's like, "I would love you to do that." Because she was raving about how important this is. She's like, "How am I learning about you now? I've had this cancer for four years, five years. How are they just telling me that you exist and this service exists?" And so I was trying to reflect a little bit on tell me more about you. And she told me she had four children. She didn't tell me she gave two up for adoption. And that is part of her story. So, I'm thinking she's got four players that are out there that are part of her care team. And that's not necessarily the case.

Tina Basenese:

Okay, so I think that the most important thing is that you get the right people on your team. There's one thing that I want to recommend is that caringbridge.org is, if you haven't used that before, CaringBridge is a website where you can email. Are some of you guys ... if there's anybody that's familiar with this? If yes, nod. Yes. Okay, good. So, you're all familiar. I use that. My best friend died of metastatic triple negative breast cancer and I was her scribe and used CaringBridge all the time. So, we talked about what is supportive care versus palliative care. So, I say toma-to, tomah-to. I felt that supportive care and Maggie kind of taught me otherwise, supportive care to me was to specify in medical terms, supportive care is considered non-curative treatment. You even hear like palliative intent, that means that it's incurable illness. That the intent is to just kind of mitigate symptoms, decrease cancer burden, but not to cure it.

It's about preventing and managing what I thought was more like the side effects of treatment and of the cancer itself to minimize toxicities of the treatment itself. And to focus on the patient's experience of living with cancer. Where I found palliative care, the focus of palliative care is to relieve suffering. So, that's not just focusing on pain and symptoms and toxicities, but it's on the experience that the patient and the family have. That it's the suffering that's involved. . . . And how they're experiencing what their family's going through. So, to ensure that treatment wishes are outlined for patients in advance and that we empower them to speak up. So, here, this is just kind of showing that how many things are similar in palliative and supportive care.

That it means continuing treatment. It means managing side effects, it means anticipating side effects. It means quality of life. So, there's no end of life in here. It's all about living with a serious illness. So, I want to talk to you for a minute about medical decision-making. And so to me, I think that's also very important that you have a team in place in your organization, in your cancer team that is comfortable helping you make these important decisions. Not everybody wants to talk about this, but everybody should have an advanced directive. So, I can't see everybody, but I would ask you to challenge yourself. If you don't have these already done, you should do it just because it's just to be good to your family, just to be good to yourself to make sure that this is documented so people have information. So, there's a few different types of these documents. One is called a healthcare proxy. That's just naming someone to be a surrogate decision-maker. A living will is the part of it that's more like instructions.

I call that the playbook. And an advanced directive is really a combination of a healthcare proxy and those instructions together in one document. So, picking somebody and some alternates to be the people that will make decisions for you. And then giving them those guidelines about what they should do when a catastrophe happens and you're not able to make decisions for yourself. So, in advanced directive, excuse me, like the living will portion is about really bad times. You can't make a decision for yourself and likely you need life-sustaining treatment. So, these aren't like good times. These aren't like usually things that are often reversible. These are like the hardest of times. And so when people want to often avoid filling out these documents, when you explain it to them and say this is really about the worst case scenario, you probably can't get back to your baseline.

Then they go, well, if I can't get back to my house or I can't live alone or ... then it's easier to say like, I would consider not receiving these treatments. Some people will say that they would want them under all circumstances. So, it's important to talk about that. A POLST form is also called a MOLST form in some states, if you're on the West Coast, it's a state by state form and it's kind of like what they would call a DNR form. Most of the time you complete this form usually within two years of the end of your life if you felt like if one of those catastrophes happened and you would want to limit certain things like CPR, like artificial nutrition and hydration or like a ventilator. So, we can do another talk another time where we could go through these forms together. But all of those things, if you were to Google those words, you'll be able to find some detail.

Or if you put in the state you live in or the country you live in and you put Healthcare Proxy Canada, you probably would find something that would be specific. The forms that I use here in my practice are all the New Jersey state forms. So, I'm going to skip over this part. I'm sure a lot of you are doing this every day if you're living with a serious illness. You know how to, there's some days that you can do this with your eyes closed, and there's other days that no matter how fantastic everybody tells you it is, you're still in a dark place about living with this serious illness. So, all I can say is that in palliative care and in supportive care, that's what we're all about, is finding what we can be helpful for, changing that, flexing with that and being present when you're not feeling hopeful.

So, here's our plan. So, what palliative care is, it's a board certified specialty. It's a board certified specialty for doctors, nurse practitioners, nurses, social workers, clergy. It's awesome. In the last 20 years, the entire field has just blown up. I like to continue to use this language and not use it interchangeably with the word supportive. Now the name of my program is Palliative Medicine and Supportive Care. I'm happy to try and smooth out the edges of palliative care but us tonight, I would hope that I'm going to leave the impression that palliative care is not end of life care. It's life care. And the more we can tell people that, you tell two friends and they tell two friends and so on, we can change how people access this program. I have so many people that like they won't even see me because of the name of this. I have oncologists that say, we absolutely have to change the name of this. And I've been doing this for so long and I'm board certified not in the Lollipop Club or the Teddy Bear kids, or I'm board certified in palliative medicine.

So, for me to call it supportive care alone, that's not my specialty. It's like nobody wants an oncologist. Okay, so nobody wants a palliative care provider either. I'm sure you don't really want a cardiothoracic surgeon, but if you need one, you're going to go to a cardiothoracic surgeon. And that's what I feel like if you're living with a serious illness, you want somebody that does serious illness care, whole person centered serious illness care, and that's what palliative care is. So, it's offered alongside and after disease directed treatment. So, what I do all day long is I do alongside and once the patient goes into Hospice, I'm less involved. Not always completely gone. Your oncologist is not always completely gone, but it's not the primary person taking care of you and doing the palliative care. Now, when you're at the end of your life, Hospice is doing the palliative care. I'm going to speak quickly so I can get to those slides.

But the focus, like I said before, is to relieve some suffering, to improve quality of life, to treat pain and distressing symptoms, to assist you in decision-making and care planning. To enhance your overall experience and the experience of your loved ones living with this cancer, encouraging you to have better communication with us so that we can better support you advocating so that your care is aligned, that your providers are talking, expecting that, demanding that telling us that we need to know what you need. And not everybody's going to be open to sharing this, but we're trying to change the way we see serious illness and making it more than just treatment algorithms. It's covered by almost all the insurances. Now you pay a copay just like you would to see your oncologist. And this is an important part. What's different about Hospice is it's usually rendered by a single provider and usually by physicians or NPs. It's not a team. In theory, in some places you do have a palliative care team. I would say in private practice, not as much. I have social workers, but they do a lot of things.

They do transportation, they do financial counseling, they do psychotherapy, but there's not necessarily always a full team in palliative care like there is in Hospice. So, I think a picture is a thousand words. So, palliative care is this giant purple bubble. And Hospice care is just one piece of what palliative care is. Okay? So, that palliative care is for all those people in the purple bubble, all the people with serious illness, all the people where they say, you know what, we wouldn't be surprised if this illness isn't cured? But then there's this small cadre of people that are really nearing the end of their lives and those people get palliative care and Hospice.

The next slide, the next picture down below shows you that in good practice the patient is diagnosed and your palliative care starts right at the same time as you're receiving curative treatment. So, we're working side by side alongside hand in hand from the day you get a stage four diagnosis, you should be meeting someone from palliative care. In some organizations they're going to call it supportive care because they're not going to be as comfortable calling it palliative care. But you want to find palliative or supportive care when you get a diagnosis at stage three, stage four, you're going to want to be a part of this. I'm going to admit there's a couple of people think because am I the host now? So, I just-

Melissa Rosen:

No, no, I'm admitting them. Just because you've asked, 10 minutes. And I also just wanted to clarify something you said. You said once you get a diagnosis of stage four, you have palliative care, but palliative care starts at the start of any diagnosis. Correct? Not just stage four.

Tina Basenese:

Correct. But it is for people that have serious illness. So, I have a stage one breast cancer patient that I still see, and she's cured of her breast cancer, but she has depression and anxiety. Now the reality is there's only so many of us that do this specialty. At some point I have to give her to a psychiatrist or to a counselor or something like that because she doesn't really have that deep, multi-focused type of issues. I do opioid management, tons of antiemetics, bowel medications, itching and coughing and shortness of breath and all of those things. So, yeah, so to be clear, it could be anybody with a serious illness, but oftentimes those people are the ones that don't necessarily need it long-term. She had a really hard time coping with her diagnosis. And so I see her now like every six months, we just kind of check in, how are you doing, blah, blah, blah. And I think that's enough for her. There's other people I see once or twice a week. You know what I mean? So, it varies.

Melissa Rosen:

Thank you. Sorry, I didn't mean to get you off-topic.

Tina Basenese:

That's okay. No, I'm glad you clarified. Yeah. And so when I said like stage three, stage four, like those are the people that usually it's a little more complicated for them. So, I always say like I help take care of the sickest people in the practice. That's really the group that requires this the most. So, if there's limited resources, those are the ones that really should bubble to the top. The people that have uncontrolled vomiting, uncontrolled pain, important decisions to be made, family breakdown, in and out of the hospital, those kinds of things. Those are the people that we see. So, you see here, palliative care is like all along and we call it comfort care. Because we're all focused on the relief of their suffering. And then at the end of their lives, six months or so before, then we're going to try and transition them over into Hospice care. And you see the fade out of the curative treatment.

And then I think one of the things is most important that I want to make sure everyone understands that with Hospice, they follow that patient's family for 13 months after the death of their loved one. So, you get through all the first anniversaries you get through the holidays and all of that. And that's one of the beauties of Hospice is that even though the patient is no longer here on earth with us, that Hospice team continues to take care of that family. So, not everybody needs that. Some people say, "Thank you for the call, I'm good." Some people do need those touch points. But it is part of why even if it's very close to the end, it's still important to not say, "Oh, they're dying, they don't need it." It's like, well, even if it's a day on Hospice that gives this family these 13 months of services. I'm going to skip survivorship just because of time.

But I think you guys probably have a lot of folks talking about survivorship. But I would tell you palliative care for me still is a part of survivorship. Because there's a lot of left behind kind of symptoms. Sometimes there's the PTSD part, the psychological trauma, the scanxiety, every time you're due for a new scan, neuropathy, fatigue, all of those. I just think it's important for palliative care to continue to be involved. And I think in a comprehensive cancer program, they would make sure that survivors that need that have access to palliative care. So, this is language that we use in medicine. We call it the surprise question, would you be surprised if this person died within the next six months? That's kind of like the aha moment to try and get providers to say, it's time for me to give them the specialist care. And that would be Hospice care.

Because all along we're taking care of them. Back to that slide I showed you before. Like you're getting palliative care, you're getting curative care. But at some point we have to know when to say when, because this program is not for a day. This program is for six months or more. So, you don't want to withhold that. But what ends up happening is it's so hard to have that conversation. Or some people just really want the next regimen, the next regimen, or they're ready for Hospice, but their loved ones aren't. That we don't give them that option. That they can choose that earlier. So, this is the question I'll say to my doctor sometimes when I see my patients are really getting closer to the end of their life, I'll say this to them, "Would you be surprised if they died in the next six months?" And they go, "No." I'm like, "Well then what are we doing? Are we doing what's really in their best interest at this point? Do they need this team approach?"

And part of what Hospice is it offers medications and supplies and equipment and 24 hour access to caregivers. And what palliative care does oftentimes is the team approach, a nurse, a social worker, a chaplain, the team that knows how to take care of whole person care. Five minutes. I think I've talked about this enough, but just to say that Hospice basically is not a place, it's anywhere the patient says that they live, it's an interdisciplinary team, it's a medical benefit and a medical specialty. And so as I mentioned before in supportive oncology, I can tell you like in our practice, we have nurses on this diagram, nurses, physicians, social workers, dieticians, that's kind of it. So, we don't have therapists, we don't have ... I guess maybe you would say bereavement, but not really. Our social workers run some bereavement groups.

We don't have chaplains. So, people are complicated. They're not just a cancer cell. So, that's why I always encourage people that when the time is right to transition over, and besides the fact it offers you all these things, all the medications and supplies and equipment and to be able to go into a nursing facility for respite care for free, all these things that people often need. So, some people will say, well, I'll just stay on home health because I don't want to talk about Hospice. That's just too hard. But there's a real difference to stay on home health versus going into a Hospice program. That on home health you're going to get skilled nursing, you might get PT and OT, you're going to get a little bit of maybe home health eight hours. You may occasionally see a social worker if like you really got major problems. Usually it's related to some a substance abuse issue or maybe financial issues. But you're not going to get counseling support in home care where in Hospice you're going to get much more of that.

You're going to have much more home health eight hours. You're going to get the spiritual care and a physician that oversees the whole team. So, back to the concept of what I've been trying to hit home on about supportive oncology is that you have rights, you deserve compassion and empathy and honesty. You deserve personalized care innovation. And a lot of that is you want to find a group that's going to offer you all of those things, these wraparound support services we've been talking about, and that you have a relationship with your team that feels really good because I can tell you there are some people that I know that don't feel like they get the right information or they don't feel connected. And I don't know how you could do this without feeling like you have a team that really cares about you. So, I have just some resources here for you. If you were looking for information about palliative care, I thought I wrote some other ones down.

Melissa Rosen:

You know what, Tina? We can actually share those resources in a follow-up email that we usually send.

Tina Basenese:

Okay, good.

Melissa Rosen:

Yeah, that would be great. I think I want to make sure we have time for questions. So, what I'm going to do is bring us to your follow. Can you unshare so we can bring the two of us back up? Perfect, thank you. We have a few minutes for questions and there were some that came in through the chat that are going to be asked in the Embrace breakout afterward, but we also had questions that were a little more general. So, can you share some advice for a breast cancer survivor who is also a clinical social worker working with breast cancer survivors in terms of her own supportive care in terms of how she can care for herself while she's caring for others? I'm going to ask for short answers because I want to get as many questions in as possible.

Tina Basenese:

Yeah, well I think that's so difficult. I would think almost maybe like FMLA, like you need to kind of get away from it and allow yourself to have your experience. Because you have to have something in your own tank to give to these people. Because they need you too. And they deserve that. Just like you deserve that. So, I would say take the time you need for yourself. It's okay for you to say, I'm going to step away from this work right now.

Melissa Rosen:

That's a moving answer. Thank you. So, somebody asked, how does or does medical marijuana fit into this care model? And if it does, how does one go about that?

Tina Basenese:

Okay, so I prescribe medical cannabis. I love it. I think it's great. I think there's a lot of times that it's, there's some risks with it. Because of the psychogenic properties of that. I get referrals just for medical cannabis. I always do a full palliative care consultation because if you're asking for something like that, usually there's some kind of pain and symptoms that aren't managed. And it may be more than just cannabis. But the doctor's comfortable with, if they have this relationship with the patient to be like, oh, I'll have you see Tina for medical marijuana. And then they know that I'll get into everything and make it comprehensive. But that's their end because someone thinks that's cool and interesting to talk about. I think that if you've used cannabis before, there's a good, and it was comfortable for you, obviously. Then there are things like nausea that it's good for, it's good for pain, it's good for anxiety, it's good for sleep. But one of the things I like even more oftentimes is CBD. And CBD is just hemp.

So, in cannabis is THC and CBD together and some other chemicals make marijuana. But marijuana has the THC part is the part that makes you high. CBD is kind of the calming side. So, I'll say one other thing about it. I know we're short on time, but you really have to think about if you're going to give somebody THC and if you want to take THC because it's not benign. Okay, so there's going to be those things. So, some people will want it for appetite. I should have said that. That's another one is good for appetite.

But if you're taking CBD, if you're taking marijuana three times a day, so they eat, you smoke it or you eat it, or you take the liquid 30 minutes before you want to eat a meal, you're going to be high all day. So, it's not always perfect. I personally like CBD and I like it in the tincture form, the best. I never encourage people to smoke. Some people love the smoke. It definitely is the fastest, but the tincture is also fast and it's safer. And I would say think about CBD first. Doesn't help with appetite, but with all the other things it does, you can also use the topic.

Melissa Rosen:

Thank you. Somebody asks, as they're going through their cancer experience from the moment of diagnosis through treatment and hopefully into survivorship, she wants to drill down on the mental health support for dealing with a life altering illness. So, the question is, is it better to go to someone like a therapist or a psychologist or to go to somebody that's part of a palliative care team? I think you could double dip, right?

Tina Basenese:

For their-

Melissa Rosen:

Mental health.

Tina Basenese:

For their mental health related to their cancer diagnosis.

Melissa Rosen:

Correct.

Tina Basenese:

So, I would say that I would think you should start with somebody like me. You'd start with somebody from palliative care because mental health is also interchanged with how are you feeling. You could be very depressed because you are totally fatigued from your radiation treatment and your nausea and you're not sleeping and all of those things. So, sometimes mental health can be improved by managing those other symptoms. So, I think it's a good first start, stop and then we could refer you out to somebody. And that's what I do a lot is my patients then will see our social workers for counseling.

Melissa Rosen:

Perfect. Thank you. All right, I'm going to finish with one question and then a quick conclusion then we move on to the Embrace section. So, somebody asked a question that I'm going to reframe. The question was how do we get supportive care when we can't afford it and insurance doesn't cover it? So, I'd rather we talk as we finish about different places to get palliative care, whole person care, supportive care during the full extent of a cancer experience, from the diagnostic process to end of treatment and beyond, into survivorship, into end of life depending on what that is. And so I just want to kind of go through this.

So, clearly some private practices have a team led by somebody like you, but also is it possible, because all of the oncologists at Astera have admitting privileges at hospitals. So, if somebody is being treated by a doctor at Astera, can they in addition access things that Maggie was talking about or other things, whether it's PT related to cancer, like post-surgical complications or therapy or acupuncture or whatever it is. So, the hospital, the private practice, a place like Sharsheret, a hospital or outpatient chaplain, what am I missing? Any other places that they can access this type of whole person care?

Tina Basenese:

Palliative care is, although it's come a long way baby, it still has a long way to go. And so I think that most hospitals now have palliative care. So, if you're in the hospital and you feel like your pain's not being well-managed and things like that, you can always ask if there's a palliative care team and ask to be referred to them. In the community there's more and more community-based programs where like for people that are in the home in their private practice, because almost no private practice is doing this. That's the one thing that's super cool about Astera is that they are building this within their practice.

And OneOncology, which is like kind of the mother company of all these private practices all throughout the country, they all have palliative care programs and are nurturing them to integrate within oncology. So, I think you need to ask, do you have a palliative care program? If you don't, one of the resources I gave you, it's called get palliativecare.org. You can go on there, put your state, you can say like there's office-based resources for the ones that are in the office, there's ones that are going to be in the community. So, ask, go to that website, ask them to start something like that or to consider that. Sometimes it's the patient that's the change agent that says. And sometimes it's just-

Melissa Rosen:

Love that.

Tina Basenese:

... that will start a program. So, I think just tell them what you're looking for and again, I think we need you to teach us what you need. That's like can't tell you enough that that's the only way the message gets through. They don't teach this in med school, they don't focus on whole-person care. But I think Melissa, I didn't hit on the kind of the complimentary services and stuff like that too. I think again, you just have to ask if you have those services. Just direct.

Melissa Rosen:

We're going to send out your list of resources in the follow-up email. Sharsheret also has some additional resources that they can provide or that they know of other organizations. We're going to include those as well. I wish we had more time to continue this conversation. I love that this idea is continuing to take seed and growing and it's so important. I want to thank all of our speakers, both of our speakers for tonight, Tina Basenese for sharing clearly her passions and expertise with us. And thank you to Maggie for sharing her own story. I learned so much this evening. It was inspired by all the ways those impacted by cancer can be supported throughout their experience. I want to once more thank our generous sponsors Gilead, as well as Merck, Pfizer, the cooperative agreement DP 240061 from the Centers for Disease Control and Prevention. I want to thank

Astera Cancer Care for their partnership on tonight's webinar. Thank you very much. And for those of you who are leaving, have a wonderful evening.