Navigating Difficult Conversations with Loved Ones and Family

National Webinar Transcript

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Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

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Melissa Rosen:

Thank you for joining us today. My name is Melissa Rosen, and I am the Director of Training and Outreach at Sharsheret. I want you to know that you are joining Navigating Difficult Conversations with Loved Ones and Family.

Melissa Rosen:

Today's webinar will be a little bit different in that it will be 75 minutes, with the last 15 minutes for Q&A. If you have to leave early, we certainly understand, but this is going to be a very helpful, practical presentation which will be recorded.

Melissa Rosen:

I want to take a moment to thank those who have enabled today's program and allowed this to happen. This webinar has been dedicated with love in memory of [Margo Allswang 00:00:51] of Blessed Memory by the Allswang and [Finefall 00:00:55] families. It's also been made possible with support from the Florence and Laurence Spungen Family Foundation.

Melissa Rosen:

I also want to make you aware that the Spungen Foundation supports our family-focused program, which helps to educate and support caregivers, all caregivers, friends, spouses, children, parents, those caring in-person and from afar. I mention this because it may be of particular interest to those of you who have logged on today.

Melissa Rosen:

As a reminder, as I said, today's webinar will be recorded and posted on Sharsheret's website along with the transcript. Participants' faces and names, of course, will not be included in the video.

Melissa Rosen:

You may have noticed that while participants were muted upon entry, please keep yourselves muted throughout the call. We also recommend you choose speaker view. This will enable you to see the slides and the speakers clearly. You can find this option on the upper right-hand corner of your screen.

Melissa Rosen:

I do want to note that we've received many, many questions prior to today's presentation. Note that I combined a lot of them that were similar. So listen for your question and not the exact words you asked. Of course, I know there'll be more during this presentation, so please feel free to use the chat box at the bottom of your screen, and we'll have some Q&A time at the end.

Melissa Rosen:

As you know, Sharsheret has been providing telehealth services for the breast and ovarian cancer communities for 20 years now. I recently heard someone describe this year as a time of creative connection, and I really do believe that's true as we've continued to provide necessary support, just as we always have, and found meaning in the creative ways we've been able to connect with you during this past year.

Melissa Rosen:

As we move into the content of the webinar itself, I need to remind you that Sharsheret is a national not-for-profit education and support organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret is not a substitute for medical advice or treatment for a specific condition. As always, you should seek the advice of your physician or qualified health professional with any questions you have.

Melissa Rosen:

Okay, let's get to it. We are so very fortunate to have today's speakers with us. This is actually an encore presentation for them. They've spoken for Sharsheret before and were so well-received, we locked them in again for another really truly important conversation.

Melissa Rosen:

Dr. Lisa Blum is a licensed clinical psychologist who specializes in promoting healthy couple and family relationships. Dr. Blum is an ICEEFT-certified therapist and supervisor in emotionally focused couples therapy, EFT, and one of the few research-validated therapies for helping couples and families strengthen relationships and build stronger connections.

Melissa Rosen:

Dr. Blum is in private practice in Pasadena, where she co-founded the EFT Resource Center, a center for therapy and workshops for individuals, couples, and families.

Melissa Rosen:

We also have with us Dr. William Saltzman, who is a clinical psychologist and professor of Marriage and Family Therapy at California State University, Long Beach, where he directs the MFT graduate program. For the past 25 years, Dr. Saltzman has worked nationally and internationally developing and implementing treatment programs for children, couples, and families contending with serious and chronic illness. He has trained and supervised thousands of mental health providers in the community and published over 50 articles.

Melissa Rosen:

Honestly, today's presenters have a wealth of knowledge and an easygoing manner of discussing these very important topics. So we're so incredibly lucky and fortunate to have us with them. We're going to welcome them to the screen right now and spotlight them and get them started.

Dr. William Saltzman:

Thank you so much, Melissa, and hello everybody. It is great to be back with Sharsheret. Lisa and I were thrilled with our initial time meeting you all, and we believe so much in the mission and the service that is provided by this national organization. Lisa?

Dr. Lisa Blum:

Yes, ditto to what you said, Bill. Really glad to be back here and just helping to support the community here. Thank you for having us.

Melissa Rosen:

Our pleasure.

Dr. William Saltzman:

Yeah. As we jump in, just as a note ... I don't know. Lisa, do you want to talk about our language about partners?

Dr. Lisa Blum:

Yes, just a quick word about the use of our word partner or couple when we're talking today. What we're going to discuss is really about how to have a conversation with any important two people together, and sometimes that might be your life partner, sometimes it may be a care partner who's helping you in this journey and process. It may be a sister, a mother, a daughter.

Dr. Lisa Blum:

we just want you to know that we're wanting to be as inclusive as possible. When we say couple or partner, we're talking about whoever is on this journey with you, the person with whom you need to have important conversations.

Dr. William Saltzman:

Absolutely. We named this webinar Navigating Difficult Conversations because this seems to be one of the ways that couples contending with cancer get stuck. Over the long difficult road from diagnosis through the various phases of treatment, recovery, possible recurrence, or end of life, there are so many opportunities for partners to lose track of each other that they end up feeling misunderstood, hurt, and alone.

Dr. William Saltzman:

My guess is just by the number of you who are on this call, it resonates with you the idea about difficulty of having certain conversations and certain tender and difficult areas and how that can be a real stuck point.

Dr. William Saltzman:

So a critical issue is whether the couple is able to share difficult emotions and talk about potentially scary and uncomfortable issues, or whether they avoid these conversations with one another or both and both of them can shut down and possibly turn away from each other.

Dr. William Saltzman:

This is important because when communication and expression of emotion is shut down, the quality of life for both partners can go way down, and the experience of painful isolation, helplessness, and hopelessness can go way up.

Dr. William Saltzman:

Based on the research, we know that when there is this kind of separation or stuck point in the communication, experience of loss of support and doing this alone, that this correlates with actual

enhanced risk for depression and anxiety for both partners, as well as undermines immune function and even medical status.

Dr. William Saltzman:

So to jump in here as a reference point, let me briefly share one of the couples and families I worked with. I had the great opportunity to work at Cedars Sinai Medical Center and a cancer support community for four years, developing programs and working with these couples, and many of them were breast and ovarian cancer cases.

Dr. William Saltzman:

A little bit about this case. This is a couple in their 30s. They've been together for six years, married for three of those years. Have one child, three months old. Very different styles in these people. The guy was a big guy, very slow, methodical, very careful and quiet, whereas his wife, very quick and responsive, very proactive, has really good emotional antenna. She gets things done. Let's see. So very different styles. Both loving toward each other.

Dr. William Saltzman:

Of course, the issue was that three months after their first child was born, she was diagnosed with breast cancer. She started with chemotherapy right away, then moved to surgery with a single mastectomy, and then radiation. So they were really compounding stressors from the very beginning.

Dr. William Saltzman:

So what I'm going to do is I'm going talk to you just very briefly about a complicated case, but I'm going to highlight some of their stuck points and the conversations that did not happen for them. As I'm talking about this, I want you to think about what are some of the fears and worries that they ran into that you think made it difficult for them to be able to bridge their communication at key times, so that we'll ask on the chat your input on that.

Dr. William Saltzman:

So to start off with, prior to the diagnosis, this couple already had a traumatic relational experience. Two years prior ... And I'll call these folks John and Maddie. Maddie had a miscarriage. John was away on a trip. He got a call and Maddie told him, "I lost the baby."

Dr. William Saltzman:

At that point, he didn't know what to do. He didn't quite understand how big of a deal this was. So he actually did not come home. He didn't do anything at that point.

Dr. William Saltzman:

Afterwards, he realized that this was a big fail, that his relationship took a big hit after that. He said, "She changed. She felt more distant. It felt like she didn't trust me. There's a shadow on us."

Dr. William Saltzman:

She agreed during that period that she felt angry, hurt. She felt unimportant and alone, that he's not there for her. It felt like she lost the trust and she pulled back. That's prior to the diagnosis.

Dr. William Saltzman:

Two years later, after the birth of their child, she was diagnosed. John went to the meetings with the doctors with her. Once again, he didn't know quite what to make of the diagnosis, didn't know what to think. His approach then was to stay positive and even saying things like, "Listen, I know this will work out."

Dr. William Saltzman:

Afterwards, he realized that he was putting his foot in his mouth. Maddie confirmed in our initial conversations that, listen, she said, "I was terrified. They had lost the staging. There were spots on my liver. Didn't know if it had spread." She was terrified. "Am I going to live? Can I be a mother? What am I going to do here?" Despite his efforts, she felt alone once again.

Dr. William Saltzman:

When he said that, "No, we've got this. There's no problem," she felt that that was like a break in their relationship. She had doubts about him and she didn't feel safe at that time. So they're missing each other tremendously.

Dr. William Saltzman:

In the next phase, while she is having treatment and they're at home, he took off time from work, tried to be very present. This time they also had a huge problem with Kaiser Medical and a problem with the nursing staff. She felt that he did not speak up much for her or advocate for her.

Dr. William Saltzman:

During that time, when she was getting chemo, she did much better than expected and she seemed to be doing well. He appreciated her positive view and can-do approach and willingness to carry on.

Dr. William Saltzman:

But as we found out in our initial conversations, actually during that time, she was hiding her exhaustion, her fear, and uncertainty. She tried to take on her regular tasks with being with a baby, but she really felt over her head.

Dr. William Saltzman:

John was describing her to friends and family as being really tough and a real trooper, and even felt that she was doing so much at times, he felt that, "She doesn't really need me around." Whereas she described quite clearly, she said, "Listen, this is how I acted to the outside world. I'm telling them, yeah, I'm doing great and everything." She's beat and she felt exhausted and alone.

Dr. William Saltzman:

The problem was she said that John seemed to buy into what she told the outside world. But she thought that, "If he was more attentive to me, he would know that that is not how it was." Once again, she felt unsupported and alone and also had the message that, "He doesn't care about me."

Dr. William Saltzman:

Another just bend down the road, even a few weeks after that, John thought that they were doing okay and that he was doing a lot around the house. He felt that things were going well. She felt that things were not getting done at home and that she was failing as a mother.

Dr. William Saltzman:

She was seemingly annoyed at his seeming selfishness and laziness, staying up late at night, sleeping late, and especially during this period when she actually moved into reconstructive surgery with her expanders, that she was frequently in pain and tired. He didn't realize how fragile her health was and she felt like he did not have her in mind.

Dr. William Saltzman:

He felt increasingly criticized. Whatever he did was not enough. He made this statement. He said, as he would become defensive when she became critical of him, "I am the worst part of her cancer." At that point she felt that she needed help. She had her mom move in with them.

Dr. William Saltzman:

When mother-in-law moved in, this became a crisis for him. He had been taking care ... He thought he'd been taking care of the child. He's had time with the child. But he felt, once moved in, that he didn't feel at home, didn't have space to parent, that mother-in-law and his wife would tag team, that at the slightest sound from the baby, they would snatch the baby from them and take care of him. He was missing all this time.

Dr. William Saltzman:

He actually had a huge fight with mother-in-law, in which she took him away during what he called, "Our tummy time together," when the baby was on his stomach and playing. He said, "Don't interfere," and mother-in-law got angry, wife got angry, and he exploded and left the house. For the wife, she was thankful and grateful that her mother was there. She felt that, "This is what I need."

Dr. William Saltzman:

After that explosion is when they came in to see me, and at that point they had a lot of misses. There were a lot of arguments, a lot of distance.

Dr. William Saltzman:

So in the chat room, I want you to imagine why was it hard for this couple to have these conversations at these different points. You might just even pick one of the crises and miss points they have and maybe describe perhaps what might be the fears and worries that kept them from having a critical conversation. While we do that, I'm going to just briefly outline the goals for our presentation today.

Dr. William Saltzman:

So we want you to take this time to reflect on what important but difficult conversations you in your life are needing to have with your partner or support person or loved one. Think what needs to be in place to have these conversations go well. We're also going to talk about practical methods to successfully engage in these conversations.

Dr. William Saltzman:

So feel free to enter your input about how this couple got stuck and got into these points where they were really quite estranged from each other and a lot of wear and tear. Also, I invite Lisa to join me to maybe process some of this stuff. So we've got, "Some of you were raised with different ... " Absolutely. Very different views of it and expectations for each other, as well as very different interrelating styles and abilities to check in with each other.

Dr. Lisa Blum:

I also see what Corinne said about expecting the other to intuitively know what they're thinking and feeling. That's a really big one amongst couples. It's thinking that it's evident and my partner should know what I'm needing and feeling. Very understandable, not true. So that's something that often gets in the way.

Dr. William Saltzman:

Yeah. He was terrified of losing her. I mean they weren't honest with each other. But I think, as you work with a couple, it's for good reason why some of these breakdowns happen. There was fear. Even as described in the next point, he was terrified of losing her, and his way of dealing with it was pulling away, exactly. She was terrified of losing him, motherhood, and her way of dealing with it was wanting more closeness. I think that's also very insightful.

Dr. William Saltzman:

They were afraid of these things and they felt like they got locked into these very rigid ways of responding to each other and didn't find a way out.

Dr. William Saltzman:

Right, they need to have those conversations, what we call bridging conversations that we'll talk about today, and what needs to be in place to have those conversations, the type of safety and trust, because, as you remember, even coming into the diagnosis, there was a vulnerability in the relationship. There was already a loss of safety and a closed rapport. So it became difficult for them to have those conversations.

Dr. William Saltzman:

Well, we'll come back to the chat. I just want to jump on to this next part in terms of, just generally, what are the characteristics of common, scary, or difficult conversations? Generally, conversations become difficult when they can elicit strong emotions for one or both partners, or the sharing of these intense emotions becomes fearful for them.

Dr. William Saltzman:

It can include conversations in which one or both partners may feel exposed, vulnerable, or fearful of the partner's response, or even when they feel like it's my responsibly to talk about this and they become fearful of making the other partner feel bad or provoking the type of reaction you talked about.

Dr. William Saltzman:

Very quickly, I'm going to just go through some examples of scary and difficult conversations, or these stuck points. We got a lot of great comments from you all in your applications for this program. It can include telling a partner or loved one about a new cancer diagnosis, a recurrence, or about a worsening prognosis.

Dr. William Saltzman:

It can involve talking about changing relationship dynamics, when one partner has to step into the caregiving role and the other, unfortunately, into the role of cancer survivor, and the disorientation and irritation, wear and tear that comes with this.

Dr. William Saltzman:

While it is hard for the survivor to start these conversations, it can often be even harder for the caregiver, the other partner, to do so, because of the view that they're already dealing with so much. I don't want to add to this. There's another extra opportunity to bottle that up.

Dr. William Saltzman:

It can involve a number of things. I'm going to skip ahead here because of the time. But I think you have a sense even of your own difficult conversations and things that might have been avoided. Talking about sex, or lack thereof, the embarrassment and worry about body changes and how to initiate and rebuild physical intimacy. With every couple I worked with, that was one of the main issues.

Dr. William Saltzman:

And, of course, how to explain even advanced cancer. Moving from treatment to palliative care and end-of-life issues is huge, especially with children. We'll touch on that in a bit as well.

Dr. William Saltzman:

Special situations that you mentioned in your comments that are especially challenging can involve when you have a cancer diagnosis and treatment early in a relationship, or even during dating. As one person wrote, "How do I explain my "acquired lack of breasts", as medical records call it, to potential new partners? Also, how to explain how uncomfortable I am with my changed body?"

Dr. William Saltzman:

And this issue about with young kids, how to talk with kids in ways that is going to say enough but not too much and to help them even understand about ongoing treatment and the possible risks. How do you talk with kids of different ages in a developmentally appropriate way?

Dr. William Saltzman:

Basic conclusion is that the avoidance or hesitation involved in these conversations makes sense. But that avoidance comes at a high cost. So something for you guys to think about is what are some topics on which you and your partner gets stuck that make you tend to avoid? You don't have to share those, but go to that place. Let me turn it over to Lisa at this point.

Dr. Lisa Blum:

Okay, Bill. Thank you so much. I'm going to share my screen again to share a few slides with you. Give me one second here. Okay, sharing is not ... Okay, there we go.

Dr. Lisa Blum:

So what I want to share with you is the relational approach that Bill and I both come from in our clinical work and in our research work. By relational approach, what we mean is that getting through crisis, getting through anything that's traumatizing is made much more manageable and doable by having a relationship that you can depend on.

Dr. Lisa Blum:

And so, the very importance of shoring up your connection with your partner, your care partner, is the very first place to start. We are going to talk very concretely about specific things you can do in these conversations, but this is one of the first most important specific thing. Pooh and Piglet really give us a sense here of what it means to shore up your connection.

Dr. Lisa Blum:

So Piglet sidles up to Pooh from behind. "Pooh," he whispered. "Yes, Piglet?" "Nothing," said Piglet, taking Pooh's paw. "I just wanted to be sure of you."

Dr. Lisa Blum:

This is what we mean by connecting first, just getting to a place where you can feel close and connected to your partner, before you head into any kind of difficult conversational territory. What we know is that this is so important because when we feel alone or isolated, as bill has already referred to, that alone before we even talk about a trauma like cancer, just feeling separate and alone is already traumatizing, because our brains read distance from a loved one as a danger signal of life or death importance.

Dr. Lisa Blum:

You could imagine how this is true even from our oldest evolutionary history, where if we were with a group of people out on the big open plain and there was a wild animal coming toward us, our chances of survival are much greater if we have a group of people to marshal a response with. If we feel safe within a pod, we have a greater chance of survival.

Dr. Lisa Blum:

And so, in our modern era, we don't so much live with our pods anymore despite current circumstances. It is very easy to feel alone and isolated. And so, figuring out where do I want to really connect in, who is the close person that I can be with to help me get through this is very, very important.

Dr. Lisa Blum:

We know that when you have this secure connection, it offers us both a safe haven and a secure base. A safe haven is that place where when it gets scary out there in the world, you know where to run back to. That's your safe haven. A secure base is that place where when you start there, you get your courage together to go out into the scary world. Having that kind of connection really makes us much braver and more courageous.

Dr. Lisa Blum:

In fact, mammals in particular have this ability to seek others for calming and comfort, and that is actually one of our greatest strengths, that the fact that when we are stressed, when we are dealing with deep, deep challenges, reaching for another really helps us become stronger. I'm going to geek out on you for just a moment to give you this really cool science study that helps to even demonstrate the truth of this.

Dr. Lisa Blum:

So they asked a woman to go into an MRI machine and they told her, "There will be a little X on the screen above you. When you see that X, it means that you will be getting a shock on your ankle." The women were to rate afterward how scared they felt or what they felt when they saw the little X pop up and also how great was the pain. They asked the women to do this in three different conditions: either going into the MRI machine alone, going into the MRI machine but having a stranger hold their hand, or going into the MRI machine with a partner holding their hand, someone with whom they felt connected and safe.

Dr. Lisa Blum:

What they found was that when the women were in the machine alone, they experienced that little X coming up on the screen as highly, highly activating of anxiety. Because they were in a functional MRI machine, they could see all the fear centers of the brain lit up. So the experience is this is going to be really scary, and they rated the pain they received from the shock on their ankle as strong, painful.

Dr. Lisa Blum:

When they were in the machine with a partner holding their hand, the women did not experience as much anxiety when the little X came up. They reported it as mild anxiety and they reported the pain as mild. With the middle situation, when a stranger is holding their hand, it's falling between those two ends.

Dr. Lisa Blum:

And so, what's the take-home point of the study, and I'm really giving you the quick version of it, is that the way we perceive stress and the way we perceive pain is actually mediated. It's moderated by whether we have a connection to someone that we love and feel safe with. This doesn't have to be a romantic partner. This is anyone with whom you feel a sense of trust and safety.

Dr. Lisa Blum:

And so, I'm sharing this study just to let you know this isn't just you know folk wisdom, this is actually science. There's a lot of developing science about how our brains respond to stress and trauma. We know that if you could go through it, either literally or metaphorically, holding the hand of someone else that you trust, the experience would be less severe and less challenging. It doesn't mean not challenging, but less challenging.

Dr. Lisa Blum:

And so, in relationships, what we're really looking for to have a secure connection, like what do we mean by a secure connection, it's somebody where you feel like you have these three things with them.

You have accessibility. Can I reach you? Where you have responsiveness. Will you respond to me if I call out to you? And engagement. Will you give me your attention? Will you make an effort to interact with me to understand what's happening for me?

Dr. Lisa Blum:

Because the meaning of that to each of us is I matter to you. So if you will be accessible, if you will respond, if you were engaged with me, then I must really matter to you. That is what helps to build the secure connection.

Dr. Lisa Blum:

In the vignette that Bill shared at the beginning, you could hear how all of those things, accessibility, responsiveness, engagement, got worn away, worn away. Because the couple wasn't having the opportunity to have these interim conversations that were much needed to try to do repair, they weren't having the opportunity to rebuild their secure connection.

Dr. Lisa Blum:

Now there's something else in addition to the relational part of this, the part where you're connected to another. There's also the individual part of it where it really helps for each person in the care partnership to be able to regulate themselves, because it's very hard to have a conversation with somebody if one or the other of you is not regulated. And so, let me explain what I mean by that.

Dr. Lisa Blum:

This is a graphic of something called the window of tolerance. Bearing that middle green part, this is describing where your nervous system is regulated. It's in a balanced state. You are able to be both rational in thinking. You are able to be both aware of your emotions. You are not overly stressed. You are not shut down. You are in the middle, in the green, as we say.

Dr. Lisa Blum:

But our nervous systems, of course, frequently go into the red zone, the hyper-aroused state of our nervous systems where we become overreactive. Sometimes this gets called as overly emotional. We can lose clarity of thought. We can get stuck on certain anxious rumination. We're very distressed, hard to calm down. That's called the red zone.

Dr. Lisa Blum:

There's also another opposite of that, which is I call it the blue zone because that's how I learned it, but we'll call it the gray zone here, where your nervous system is in a shutdown state. It's hypo, under-aroused. This can happen, of course, because extreme stress, one way of coping with extreme stress is a shut down.

Dr. Lisa Blum:

And so, here in the gray zone, we can feel depressed, lethargic, unmotivated. A lot of people will describe it as numb. It is a way of coping with stress. So it's not that there's anything bad or wrong here, it's just different states of our nervous system. It's helpful to be able to think about where am I? Which

window am I in as I'm about to engage in this important, difficult conversation with my care partner? And where is my partner?

Dr. Lisa Blum:

Because as you well know, as we have all experienced this, that if one of you is, say, in the red zone and is very over-reactive and anxious and you try to have a conversation in that state tends to not go very well.

Dr. Lisa Blum:

Same is true, though, if one or both of you is in the gray zone, where you're so disconnected from your emotional well-being as a way to fend off all of the stress that it's hard to marshal much of a response or much engagement with your partner, and engagement is one of the things you need to feel connected.

Dr. Lisa Blum:

And so, what happens when we're not in the green zone, if we're in the red zone, you'd got a lot of conflicts, heat, disconnection. Because neither partner feels like the other one is hearing them, you end up feeling quite alone. As well if you're in the gray zone, you can feel very disconnected, shut down, and feel quite alone because you can't really engage well with your partner.

Dr. Lisa Blum:

And so, all of this is a prelude to say that when you're going ... Oh, sorry. I'm not ready for that one yet. All this is a prelude to say that when you're going to have an important conversation, we want to ask you to start with figuring out how you can connect with your partner first, your care partner. So that might mean taking a walk together, that might mean going for a movie that makes you both laugh and feel a little more relaxed, some way of really engaging with each other that feels connecting, and doing a check, and each of you can do a check : where am I, which window am I in, and can I get myself into the green zone if I'm not there? Let's wait to start the conversation until both of us can be in the green zone.

Dr. Lisa Blum:

Bill's going to talk a little bit for a moment about identifying the conversations that you might need to have, because we want you to be thinking about those as we go into the next part that is the real nitty-gritty nuts and bolts of how to have these conversations. So let me stop share. Bill, you can talk about the conversations you need to have. You are muted, Bill.

Dr. William Saltzman:

Unmute. Okay, good. Now you can hear me. Great. So, yeah, I think it's good to have a warning system when you are getting jammed up in the relationship to identify thoughtful stuck points or conversations that are not taking place. The place to look is inside of yourself and also between you and your partner.

Dr. William Saltzman:

Inside, you might be thinking a lot about a certain issue or a problem. You're worrying about it. You're not sure how your partner feels. You're left in this dark, gray zone and your anxiety can be building up.

Dr. William Saltzman:

Also, the sense of you and your partner on different wavelengths, that your partner doesn't really get what you are feeling, when you feel that real distance between you, or also, I think even quite commonly, if you were fearful about how your partner might react if you did bring something up. So you're jamming it down.

Dr. William Saltzman:

What that looks like between partners, close people is a lot of silence or discomfort around an issue. Maybe there's a lot of different triggers, things that you're reminded of, whether it'd be sexual estrangement or, therefore, not closer, certain times of the day or things that you do in which you do feel that distance in which this really triggers this silence and being shut down.

Dr. William Saltzman:

Also, if issues seems to come up a lot and there is no resolution. So these are some of the barometers for, yeah, we might be having a stuck point here.

Dr. Lisa Blum:

Great. So we're going to dive in now to some very concrete, nitty-gritty suggestions for how to have these conversations. As I know you could imagine, there are so many different particular topics that are important to talk about.

Dr. Lisa Blum:

So we can't delve into the specific content, but what we hope to do is to give you some real guide wires that are relevant regardless of what specific conversation you need to have. So we're trying to offer to you some tips on how to, not so specifically the what. But during the Q&A, you can definitely ask us all kinds of what questions, like how can I say this to my child? You can ask us all those what questions in the Q&A, but right now-

Dr. Lisa Blum:

Oh, sorry, Bill.

Dr. William Saltzman:

Just to mention that there's handouts available. So you don't have to write down all of the steps. It's really detailed out.

Dr. Lisa Blum:

Exactly. So there's a link that I think Rachel's going to put in the chat right now to a Google Doc that will let you get handouts for all of this. If you don't have easy access to Google Docs, don't worry. When they send out the email after this tomorrow or the next day, you will get a link or a PDF to this document. You will have it. So do not worry about having to scroll a bunch of stuff down. Just feel free to let it wash over you right now.

Dr. Lisa Blum:

Okay, so I'm going to share my screen again and we're going to start with tips for talking to young children, because many of you did have questions about that, about talking to young children.

Dr. Lisa Blum:

And so, what I'm going to say here is going to be varied. Whether you're talking to a very young child or a middle-aged child, you would change the language and you would change the specificity of some of your vocabulary and things like that. But these guide rails stand regardless of what age child you're talking to.

Dr. Lisa Blum:

So the first thing is tell children the truth simply and in a few words. Maybe not the whole truth with all of the details, but tell them something that's core and essential to them knowing. While that can feel really scary to do, children know when adults are hiding or lying or minimizing. Then that actually raises their anxiety more because they think it must be so bad that adults can't even tell me.

Dr. Lisa Blum:

So if you tell them something simple. So for a very young child, you want to use simple words, short words. You might say something like, "There is a lump or a bump in mommy's breast that is growing and it doesn't belong there. The doctor has to take it out and I'll need some medicine to help make sure it's gone." Something very simple, true. Not the whole kit and caboodle of everything that's going to happen and everything you're going to go through, but just a simple truth.

Dr. Lisa Blum:

For an older child, you might be able to use more medical language. You might be able to say, "There is a tumor growing in my breast. This means that the cells are growing too fast. It's not supposed to be there. We need to get it out before it spreads anywhere else or any further." So your language might change, but the essence is the same.

Dr. Lisa Blum:

It also is really helpful to say less and then let your children ask more. So they will ask more if you've set up a conversation with them where you're inviting their questions. That's actually one of the last bullet points on here is be sure to let them know that questions are welcome.

Dr. Lisa Blum:

They will ask if they don't understand. They will ask if they need to do more. It's better to err on the side of less and be guided by their level of need to know rather than you saying too much and burdening them and worrying them.

Dr. Lisa Blum:

Tell them what's going to happen next, the very next step. So what can be overwhelming to all of us is the 16 things that have to happen to deal with this crisis. You're not going to give that your kids. But you do want to give them the next thing.

Dr. Lisa Blum:

So if the next thing is that you have to go in for a surgery, tell them about that. If the next thing is that you're going to be taking chemo and you might need a lot of rest and be in your bed a lot, tell them that. Tell them just the next thing so that they know what to expect, because as is true for all of us, the more we know what's happening next, the less our anxiety is.

Dr. Lisa Blum:

Tell them also who will care for them or how they will be cared for, because even though, of course, this is a crisis happening to you, and we want kids to be empathic and understanding that you are going through something difficult, they, of course, as a little person, even as a big 15-year-old person, are very dependent on you their parents, their caregivers for their survival. So if they're very worried that something's going to happen to you and then how will I be okay?

Dr. Lisa Blum:

So what you want to tell them is whatever's happening next, here's how you will be cared for. Here's who will wake you up in the morning when I'm in the hospital. Here's who will help you with your homework when I can't be here to do it with you. Here's where you will stay overnight when Daddy has to be with me in the hospital.

Dr. Lisa Blum:

So it's very helpful to kids to know exactly ... Even if there's going to be changes and maybe grandma's coming to stay or whatever it's going to be, is they know exactly how they're going to be okay. That helps them a great deal.

Dr. Lisa Blum:

You also want to let them know how they can help or be a part of the caring response to you. This is not to say that you're going to make them a caregiver or put a burden on them. But just as you think about if your best friend tells you that they have some crisis going on in their life, you naturally want to know how can I help? What can I do? That's part of being there for that person. That's part of showing your love. If we block children out from that, we're cutting off a natural instinct that they have to want to be part of the family that is caring for you.

Dr. Lisa Blum:

So make it something very age-appropriate. Tell a young child, "What I would love from you is when I come home from the hospital, I would love to have one of your home-made get well cards," or telling an older child, "Something that will be really helpful to me, honey, when I'm resting during my chemo treatments is I'll probably need to drink a lot of water. So if you could check in every now and again and just make sure that my pitcher is full, that would be so helpful to me." So give them a role, let them know what they can do to help age-appropriate, not burdensome.

Dr. Lisa Blum:

Lastly, as I said, invite the questions. Let them know who are the adults in this care response team that can answer questions for them, that their questions are welcome. If ever there's a time where your child asks a question that you don't feel ready to answer or can't in that moment, it's okay to say, "Honey,

that's a great question. I'm so glad you asked. I need a day or two to just think about how I'd like to explain that to you, but I promise I'll get back to you," and then make sure you do.

Dr. William Saltzman:

I was just going to put in one small thing is that there's good reasons why parents often tend not to have these conversations with the children, because it feels like you're inflicting pain and worry on them.

Dr. William Saltzman:

So all of these avoidance things make sense, and you as a protective and caring parent, it's hard to even open this stuff up. But I love the things that Lisa has shared, and with the understanding that it's a greater kindness to open this up.

Dr. William Saltzman:

I work with a lot of kids in which they didn't know what was going on with mom. This one child who didn't know ... When mom is going multiple times during the week for her chemo, he thought that every time she went in, she might die, that this was life-threatening each time.

Dr. William Saltzman:

And so, make the time to have this context because otherwise they can be left with their worst imaginings, and that is much worse.

Dr. Lisa Blum:

Yeah. Thank you, Bill. Okay, I know we'll talk more about kids in the Q&A, but I'm going to move on to conversations with adults now. Again, just giving you some guide wires here for how to have these conversations.

Dr. Lisa Blum:

First, what I want to say is there is no perfect here. There's no way to have an exactly perfect conversation. We're not aiming for that. We're aiming for the best we can do in the moment. One of the things that's really important here is to have a lot of self-compassion and a lot of compassion for your care partner, because these are difficult things. They're difficult conversations. We all get overwhelmed with our emotions.

Dr. Lisa Blum:

It's okay if the conversation doesn't go well at first. You can break it up into different chapters. You can have it over time. The important thing is that you're trying to have them.

Dr. Lisa Blum:

And so, we're going to offer some guidelines for before the conversation, some things to do and prepare during the conversation, and then after the conversation. I'm going to go through these relatively quickly, but do know that this is all in the handout. So it'll be there. You can look at it, reflect on it.

Dr. Lisa Blum:

It is important to plan a time and a place to have an important conversation. You need the space, you need the privacy, you need not to be interrupted. You need to be sure the kids can't hear. So that can take a little planning.

Dr. Lisa Blum:

It's helpful to make a date to talk about it and give your care partner a headline of what you want to talk about so that he or she can also start to mentally and emotionally prepare for that. So in other words, you might say, "I need to talk to you about my worries about how we're going to financially get through this next six months," or whatever it is. Give a headline so that your partner can begin to collect his or her thoughts.

Dr. Lisa Blum:

It's okay for the conversation to happen in installments. There is no benefit to doing it all at once. Take a manageable chunk.

Dr. Lisa Blum:

Plan out what you want to say. By that, what I mean is not every word of it, but plan the most important message that you really need your care partner to get out of this conversation. So there might be a whole bunch of information and details you need to talk about, but there's usually also a core worry, a core hope, a core need, something that you want your partner to walk away from that conversation with.

Dr. Lisa Blum:

So try to get clear about it yourself in your own head as best as you can so that you can be sure that you are communicating that and sticking to that in the conversation.

Dr. Lisa Blum:

Also, acknowledge to yourself and with your care partner what might derail us from having a successful conversation here. So what I mean as if you, in the past, have had a lot of difficulty talking about the role of your mother coming in to help with the care and the conflicts that sets up with the other members of the family, and you know that that conversation often tends to go off the rails, I mean acknowledge that, say that, "This is one of the hard conversations for us. Let's both work on getting in the green zone first. Let's both agree that we're going to stop this conversation if it starts to get too heated. Not to ignore it, but to take a break so we can come back to it."

Dr. Lisa Blum:

So in other words, acknowledge where you want to get to and also acknowledge where the likely hard curves are that may throw you off-balance. Then I said get yourself in the green zone before you start and check where your partner is. So those are all things to do in advance of this conversation.

Dr. Lisa Blum:

During the conversation, this is really important. Start the conversation with something that connects you. Grab their hand, share a happy moment from the day before that you didn't get to tell your partner

about. Start with a hug. Do something that says, "Hey, we're here. We're together. We're in this. I need you, you need me. Let's be a team as we start this difficult conversation."

Dr. Lisa Blum:

That, believe it or not, is one of the most effective ways to keep the conversation in the green zone because you feel connected to the other person. Maybe it means you watch a funny movie before you have any difficult conversation. Maybe it means you read your fourth graders funny joke books, silly funny joke books, something that brings you together.

Dr. Lisa Blum:

Also try to end the conversation on that. However it's gone, say, "Thank you for connecting with me. Thank you for talking to me. I know that was difficult. We're both worked up. But can we have a hug anyway." So if you can sandwich the conversation with connection, that's really helpful.

Dr. Lisa Blum:

Like with kids, say what you need to say directly. Don't beat around the bush. That only raises anxiety. If you can, use physical closeness and touch to soothe. You might want to hold hands. You might want to sit next to each other on the couch. You might want to use eye contact as a way to co-regulate with each other, meaning your nervous systems actually help each other to stay connected and soothe by using eye contact.

Dr. Lisa Blum:

Sometimes that feels too intense if the emotions are too strong, if the intensity of eye contact doesn't work. In that case try walking together. Walking together, literally matching steps and walking together, is also another way that our nervous systems co-regulate with each other, and that can make it easier if face-to-face, eye-to-eye is too strong.

Dr. Lisa Blum:

If either of you goes into the red zone, stop and take some time to calm down. Discuss what you're each going to do to regulate, and then come back together. Regulate is just a fancy way of saying calm down.

Dr. Lisa Blum:

Likewise, I didn't put it in here, but if either of you goes into the gray zone, if either of you really just feels like, "Oh, I'm shut down. I can't feel anything. I can't think straight. I have nothing to say right now," that is also a sign that it's not the right moment to continue. Acknowledge what's going on, talk about was there a trigger? Did something happen? Even if you don't know, say, "Okay. We both need some time to come back into the green zone. Let's wait until we can get there."

Dr. Lisa Blum:

The yellow zone really refers to on your way into the red zone. So sometimes you can catch yourself getting too escalated, and you can pause. You could take a moment. You can get a drink of water. You can strategize with each other how to calm down before continuing.

Dr. Lisa Blum:

Have the conversation in installments. There's no prizes for doing it all at once. Before you end, check with your partner for understanding. If there was some really important either content, like information you needed to share or if there were some really important feelings that you needed to share, ask your partner to say it back to you. "Can you tell me, please, what you understood was most important to me in this conversation? Then I want to tell you what I heard you say."

Dr. Lisa Blum:

That confirmation of understanding is critical, because in emotional states, we don't hear well. We really don't. Actually, part of our hearing goes offline when we're very activated. So we need to confirm understanding.

Dr. Lisa Blum:

Okay, that's during. And very briefly, lastly, after a conversation, do check in with your partner. "How are you doing after our conversation? How are we doing together?" After a hard conversation, give yourselves time and space to process and to rest. You've just done a lot of emotional work. Don't ask a lot from yourselves right after a conversation.

Dr. Lisa Blum:

Confirm if or when you need to circle back from more conversation. There might be some very specific things you need to follow up on with each other. It's really helpful to make dates. It's really helpful to put it in your phone, because we all want to avoid these difficult moments. And so, if you have it down there, we're going to follow up on X, that helps you get back to it.

Dr. Lisa Blum:

If you find that either you keep trying to have these conversations and it's not going well with your care partner, or you find yourselves avoiding very important conversations that you need to be having and it's getting in the way that you're not having these conversations, do you ask for help. Ask for help from a family friend, from your Sharsheret social worker, from a clergy person, from a professional mental health person. Ask for help. This is the time to not try to go any of this alone, but to really use the resources that you have.

Dr. Lisa Blum:

Okay, so we are coming to the time where we want to do Q&A. Bill is going to mention something very quickly that you have in the handout, that are two specific techniques that might help you when you get stuck.

Dr. William Saltzman:

Great. Just before I do that, I just want to reaffirm that this is a great approach to have these difficult conversations. It's good to have both partners buy into this approach beforehand so that you guys are reading from the same page and that you establish what we've been doing isn't working. And so, if both people can be doing this, it works a lot better.

Dr. William Saltzman:

I also want to just say that with that couple, the vignette that I shared earlier, we used a lot of these techniques in our work over 10 months in which we worked together. I just wanted just to tell you that they did some repair work using this.

Dr. William Saltzman:

For instance, they were able to revisit the miscarriage. John started off from ... Instead of with his anger or defensiveness, he shared his soft part in which he could share his sadness and shame in the way that he did not respond, even shared his tears. That softened Maddie so that she could take in that there was a lot going on with him.

Dr. William Saltzman:

He also got a window on how alone and helpless she felt during both the miscarriage and the diagnosis, that he missed that, and was able to see behind her tough person approach, that she really had need of him, that he was very much needed.

Dr. William Saltzman:

So these kinds of things are all within reach, especially if you start to do some of these basic things about self-monitoring and co-regulation and these great skills that Lisa shared with you.

Dr. William Saltzman:

Now very briefly, so in addition to these guidelines that Lisa provided, we also have some handouts on what's called the speaker-listener technique. Some of you might be familiar with this. This is just a scaffolding to help you and your partner have a conversation, especially about these seemingly high-risk conversations or very tender or raw spots. There's some just basic rules about how you take turns being both the speaker and the listener.

Dr. William Saltzman:

As the speaker, the point is ... It's ideally to have what we call softened startup, that you don't start off, even when you're the speaker, digging into the hardest part. You monitor yourself. You try to get more into that green zone and you have a connective or a softer presentation. Or even as John did in this case, when he's shared not his anger or his defensiveness, but his vulnerability and that he was so sad that he wasn't there for her in certain ways. That de-escalated the situation.

Dr. William Saltzman:

So as the speaker, softened startup. Speak for yourself. Don't mind read. This is all in your handout. Keep things brief. Then you allow time for your listener to paraphrase. That is critical to make sure that they get it and you feel that you've been heard.

Dr. William Saltzman:

There's also just rules for the listener. They don't have to be advanced. They're supposed to do this kind of just active listening and to focus on the speaker's message. Then as you paraphrase as you go, it helps to keep you in line.

Dr. William Saltzman:

And so, this kind of sharing of the time and with the structure of the conversation can be very helpful. You don't need to be in therapy to do this kind of work.

Dr. William Saltzman:

There's a secondary technique called the egg timer, which also gives you a structure. Using an egg timer, each person gets five minutes to be in the speaker or listener type of position. So that's there for you.

Dr. William Saltzman:

So that said, let's end the content part of this and we invite your questions or comments. We're also going to go through some of the great comments that were put in the chat.

Melissa Rosen:

Thank you both so much. Wow! There's so much to take in. Thank you for having the forethought to having printouts we can look at later as we continue to process.

Melissa Rosen:

There were a lot of questions. We're going to try and get through as many as possible. But one of the first things I want to address somebody put into the chat box was how do these conversations change, particularly at a time like we're in now where we're so far away from some of our loved ones, if these have to be done Zoom or on the phone versus in person?

Dr. Lisa Blum:

Yeah. So hard. I want to just say there are no great answers to this because we all know how hard this distance is. Without the distance, you can't hold the hand, you can't give a hug. These things are really core to the way that human beings relate and feel connected.

Dr. Lisa Blum:

So what I would say is just do the most that you can with the technology we have. Right now I'm looking into the camera. It probably looks like I'm looking more directly at you. Do that sometimes, because we just need to feel the eye contact with another person.

Dr. Lisa Blum:

I do think that getting on camera and seeing a face and facial expression helps. So if that's possible, rather than just only the phone all the time, that's useful.

Dr. Lisa Blum:

Send each other little love notes. It's so old school, I know, but receiving something in the mail that's tactile, that your loved one took time to write. Send each other little mementos or little sayings or quotes to put up around, on the bathroom mirror or whatever, so that you feel the presence of the other person there. It takes extra effort, but these things help.

Melissa Rosen:

Good advice.

Dr. William Saltzman:

I think, just to add to that, in this time of pandemic and separation and kids at home and feeling uncertain, Lisa's advice about carving out a protected period of time is critical. We're being just inundated with stuff. And so, you've got to find some calm place to increase the odds that you can have a good conversation. It can work over the Zoom. I mean we do therapy on Zoom and we're surprised how well it can work.

Melissa Rosen:

Thank you, thank you. All that you were saying about people checking in, sending love notes, things like that, so when people check in, and this doesn't even have to be during COVID, but when somebody faces an illness, there are a lot of people who check in. But a lot of those check-ins are a little intrusive. They'll ask questions that really go beyond what that person needs to know, questions like, "Are you getting reconstruction?" "What's your prognosis?" things like that. So how do you respond without just being rude, even when that's warranted, to inquiries that are inappropriate?

Dr. Lisa Blum:

Bill, do you want to go?

Dr. William Saltzman:

No, take your shot at it. Then I'll jump in.

Dr. Lisa Blum:

Okay. I think that it is okay to be kind but direct. So I think it's important to say, "I hear the concern in your question." You could just say that whether you're feeling that or not. "I hear the concern in your question, but I want to let you know it's hard for me to talk about all those things with so many different people. I'd rather talk to you about this really funny movie I saw last night."

Dr. Lisa Blum:

So acknowledge the good intention that we assume is there in people asking a lot of intrusive questions. But simply state, "It's hard for me to talk about all those things with so many people. I'd rather discuss X instead." Some people will appreciate that because they don't know what to talk to you about.

Melissa Rosen:

Right. It also reminds people you're more than just a diagnosis. That's wonderful. What do you with a care partner who doesn't want to talk about these issues because they're afraid of adding to your burden?

Dr. William Saltzman:

Right. Yeah, that's such a common presentation. One of the things you can do is to also invite the person to talk with you and to kind of ... If you're aware that this is going on, you talk with them and you

acknowledge the good intent behind that, that, "I know this comes out of your caring for me. You were trying to protect me. You see me going [inaudible 01:06:38]. But I want you to know it's so important for me to know what's going on and what's in your heart or what's troubling. I'll let you know." Then you can set up maybe shared rules about, "I'll you know when I'm up to here and I can't take it."

Dr. William Saltzman:

So you can help to set the terms for that. The key is that soft startup again and to acknowledge the intent behind it.

Melissa Rosen:

Soft startup, that's a great phrase. That's good. Okay, so what about when you're having these important conversations maybe with your primary care partner or maybe with somebody who is a loved one, but not your person for this experience? How do you deal with the emotions that bubble up in the person you're speaking to, like maybe when you share a diagnosis? Is there a way to redirect conversations that are getting a little off the rails?

Dr. Lisa Blum:

It's really helpful to just call that out when it's happening. To be able to say, "Whoa! Time out. Can we take a pause here for a minute?" Then just describe very just neutrally whatever you think is happening. So in other words, I wouldn't say, "You've gone crazy and you can't have this conversation." I wouldn't say that. But just say, "I think our emotions have gotten too high here and this might not be the most productive way to have this conversation right now."

Dr. Lisa Blum:

Now, of course, this is hard to do. I don't want to make it sound textbook perfect, because if you are also very activated in that moment, it's hard to do that. But at least have in mind, like, "Okay, wait. You're freaking out, I'm freaking out. Okay, we need just stop. Let's just stop because I think we're both freaking out right now. Can we take a 15-minute break? We'll both try to calm down and then we'll come back together." So a lot of this is around being able to just name what's happening.

Melissa Rosen:

Great, thank you. Okay, we've got a lot of questions about BRCA mutations. Do you have advice for how to tell relatives that they should be screened for BRCA mutations or other genetic mutations? How would we approach that and also how can we cope if they're either ignoring the information when someone knows they would have done anything to have the information before a diagnosis, or acting on misinformation?

Dr. Lisa Blum:

Bill, we had talked about this. So is it okay-

Dr. William Saltzman:

Yeah, you can. Yes.

Dr. Lisa Blum:

Okay. Yes, and thank you for bringing that up, Melissa, because we meant to address it. Of course, your concern for your related loved ones who may need to get tested is out of love and concern for them. Of course, it is. However, we have so few ways to make somebody else do something that we want them to do.

Dr. Lisa Blum:

And so, instead what we can do is offer ourselves as someone to talk to about it. We can offer concrete information, "Here's a flyer, here's a website, here's a podcast about it." Offer concrete information. We can say, "I am here to talk it through with you, answer questions, or I know somebody great who can," and say, "I know this takes time to adjust to. I know this takes time to think about."

Dr. Lisa Blum:

"How about if we check back again in a few weeks? I can ask you where you are with it." If you check back in a few weeks and they're like, "No, no. I don't need it. I don't think I have." Okay, let it go and check back with them in six months. That is really all you can do, as frustrating and hard as that is. But you can only share your experience, share information, and offer to be a resource person to them.

Melissa Rosen:

Last question, how do partners address changing relationship dynamics? In other words, one partner stepping into a caregiving role, one partner becoming a provider for the family. So how do you get ahead of that change and address it before it may become problematic?

Dr. William Saltzman:

Yeah, I think the key thing is not to underestimate the stress and the change involved in that suddenly having to adopt these very different roles and all the cascade of feelings and self-judgments that come with this. So first put it on the radar that this is no small deal. This is a major stressor and life-changing thing.

Dr. William Saltzman:

And so, that said, and then you've got to open up the pipeline for ongoing conversations to navigate this, because it's not a one-shot deal. It's a day-to-day thing. When I was working, I worked with my cancer clients for a year, two years at a time, and the stuff was new things would come up the further down the road you'd get. Each part of the journey, the different phases of treatment and recovery, et cetera, have different challenges and different stuck points.

Dr. William Saltzman:

So you've got to build this kind of this safe haven in a structured way to ongoing bring stuff up, because it is ongoing. Yeah, it's a basic thing.

Melissa Rosen:

No, that's very smart advice. Okay. So I want to acknowledge that we didn't get to all the questions. Behind the scenes, we're going to talk to the Drs. Blum and Saltzman and see if we can get some additional answers out to you either in a blog or something like that. But I do want to take a moment to

thank both Dr. Blum and Dr. Saltzman for sharing their expertise and making these very difficult conversations just a little bit easier.

Melissa Rosen:

Right now in the chat box, we're going to put a link to a very brief evaluation survey that you can click now and still listen as we finish up, as we finish up the last few pieces of information here. The evaluations really do inform future programming. In fact, Drs. Saltzman and Blum are back because of evaluations. So please take a second.

Melissa Rosen:

Again, I want to thank the Spungen Family Foundation and the Allswang and Finefall families for helping make today's program possible. I want to remind you Sharsheret is here for you and your loved ones during this time. We provide one-on-one emotional support and other programs to help you and your family navigate through the cancer experience. All are 100% private, 100% customized, and 100% free.

Melissa Rosen:

So thank you very much. You can always email clinicalstaff@sharsheret.org, or hop on our website with many different ways to contact us. The last thing is I want to remind you that we have several programs on a wide range of topics planned for the next couple of weeks, including our Shalom Shabbat program, a holibake with Instagram star Mandylicious, and a COVID and cancer update. So please check out our website regularly to see what topics are coming up. That link was just posted in the chat box.

Melissa Rosen:

Again, thank you to everybody for joining us today and we look forward to seeing you at another webinar soon.

Dr. William Saltzman:

Bye, everybody. Be safe.

Melissa Rosen:

Thank you, everyone.