COVID-19, Caregiving, and Cancer:

Strategies for Caregiving from a Distance and Managing

Self-Care

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Presented by:



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Elana Silber:

My name is Elana Silber, and I am the executive director of Sharsheret, the national Jewish breast and ovarian cancer organization. Let me first start by saying it is so good to see you all on the call today. We understand these are very trying times. First and foremost, the health of our community and the women and families we serve is our priority. So we wish you all on the call today good health for you and your family and appreciate you taking the time from this frenzied world that we're living in to take some time to learn for yourselves how to be better caregivers. These are very unprecedented times, and we understand the challenge. Before we get started, I just want to repeat one more time. We're very mindful of everyone's privacy. We are recording this call. So if you do not want your face on screen, feel free to turn off the video. Questions can be sent through the chat. Many were sent in advance, and we'll get to them at the end of the call.

Elana Silber:

So Sharsheret's model of support, and many of you are familiar, has always been to provide support to women and their caregivers by phone and by email. Given the current situation, we are well-equipped to be there for you and to support you as you support your loved ones. We have a program called the Florence and Laurence Spungen Family Foundation Family Focus Program. That is you. You are the people that are part of this program, and we are still conducting this program as we always do. The issues are different now and have changed, but we are ready and prepared to help you. So for us, while this is a transition, you should feel comfortable reaching out with anything and everything you need along the way.

Elana Silber:

We are very grateful to our sponsors who are enabling Sharsheret to stay up and running and provide these services to you. The Florence and Laurence Spungen Family Foundation and Susan G. Komen of Los Angeles. Their generous support is sustaining the organization so we can continue to be here for you. We're asking that everyone stay muted. A lot of your questions were compiled in advance. But if something comes up, feel free to put it in the chat. If we can get to it on today's call, we will answer it. If not, we will send you a response within 24 to 48 hours. We will hear you.

Elana Silber:

Today I'm really privileged to be here with our speaker, Shera Dubitsky. Shera holds three master's degrees in clinical, counseling and educational psychology and has completed her clinical training towards a doctoral degree in clinical psychology. Shera was on our staff for many years as director of support services, and now she serves as a senior advisor on our medical advisory board. Shera frequently lectures across the country on varying topics, including life skills, navigating day-to-day experiences and living side-by-side with a cancer diagnosis.

Elana Silber:

She has a love of humor, which I think we all need right now, and integrates her expertise with her comedic style. Shera has joined us today to speak to you about COVID-19 caregiving and cancer, strategies for caregiving from a distance and managing self-care. So while we're here for you virtually, we're really here in one room right now. Everything here is for you. I'm now going to turn the floor over to Shera.

Shera Dubitsky:

Thanks Elana. As you said, this is certainly uncharted territory for all of us, and there's a lot to be shared. So I'm going to do my best to cover what I think are the general concerns that we're all experiencing. You should know that this topic really resonated for me personally. My dad just had heart surgery last week in Florida. My younger brother and I are in the Northeast. My older brother is on the west coast. It was very emotionally difficult knowing that we couldn't be there for him when he had his surgery or even afterwards when he went home because traveling and the risk of the coronavirus was too severe.

Shera Dubitsky:

So I remember just feeling very guilty that I wasn't there. Also, because I wasn't there, I got the feeling I wasn't getting the full picture of what was going on, only what he was reporting or what my stepmom was reporting. I wasn't familiar with any of the local resources there. I just felt, in general, inadequate because I was so limited in what I could offer, and I was also very concerned for my stepmom who was doing all the hands-on support and I was worried that she was going to feel overwhelmed.

Shera Dubitsky:

So I reached out to a friend of mine who unfortunately has been a long-distance caregiver for quite some time. These are some of the things that she suggested to me. One was to designate a time for each of us to call him throughout the day so that he wouldn't be bombarded. He was very tired and we wanted him to know that he had a time scheduled with each of us, and he wouldn't have to worry about missing a call because he was napping. She also suggested that we appoint one family member to speak with the doctor and then designate some to Zoom time when we would all speak together to kind of get the full update.

Shera Dubitsky:

She recommended that we get the phone numbers of the local pharmacy and supermarket and restaurants that were doing deliveries to my dad's condominium complex and find out what kind of online support that we can offer and then really importantly stay in touch with stepmom and try to offer her support and find the areas where we could unburden some of her responsibilities remotely.

Shera Dubitsky:

So as we all know, the CDC has very strict guidelines around social distancing and isolating during this pandemic. So in my situation, we were in different states. But it's very possible that many of you on this call live down the road and still have to implement a similar plan. Certainly, if you're a caregiver living in the home, the outbreak of the coronavirus also impacts how you're currently able to care for your loved one. So I'd like to make some suggestions regardless of whether you are engaged in remote caregiving or if you're in the same home.

Shera Dubitsky:

So as always, the most important thing is follow her lead. What is very important to do is to be a good listener. Let her share the information and experience in a way that's most comfortable for her. While doing this, validate her feelings, right? Because living with a cancer diagnosis is already very emotional, and it's certainly much more complicated and magnified by the restrictions and the change in the health

care during this pandemic. Her feelings may vacillate between worrying about really big things like survivorship and more mundane concerns like food shopping and meal planning.

Shera Dubitsky:

I recently spoke with a woman who's living with stage IV breast cancer, and she is really worried about the impact of the virus on her health. Another thing that we spoke about is that, usually, her kids are in school during the day, and she gets a little bit of a break. But now, she's on mommy duty full time without those downtimes. This is somebody who was worried about colds and flu before the COVID-19, and now her worry has really become more panic since the virus outbreak.

Shera Dubitsky:

So it was important for me to validate her experiences and to say, "You're not overreacting." Once I was able to validate, we were able to strategize and discuss ways to cope. In general, across the board, regardless of what you're dealing with, it's important not to move into problem-solving immediately. Figure out where a person is at emotionally and logistically, and then you can start to strategize. We're hearing from women that surgeries are being postponed. Follow up with doctors is being put off. Meetings with the treatment team are being put on hold. We're hearing that even getting in touch with doctors has become much more challenging.

Shera Dubitsky:

With a cancer diagnosis and the risk of coronavirus, she may be feeling that everything is out of her control. So let her make the decisions. In the areas that she does have control, let her have them. You can certainly offer suggestions, but in the end, support her decisions that she's making. If this wasn't a global crisis, most of us would... not most of us, but most of the women that we're supporting would be getting communal support. They'd be getting meals and rights to treatment and in some cases, childcare relief and hopefully caregiver relief and some help in the home. But all these options are no longer available because the restrictions of the social distancing.

Shera Dubitsky:

So given that, it is important to be clear about what you can offer and try to assess what her needs are. So I think the starting point is really to create a checklist and then start to delegate. So figure out what are her current medical needs, what are her emotional needs? In general, is she worried that her medical and emotional safety net are compromised or absent now? You also need to figure out what are her just basic care needs. Then, once you kind of have a sense of that, then it's time to delegate. But keep in mind that support is not one size fits all.

Shera Dubitsky:

So I often think about my cell phone. It's great, right? It's a phone. It's a camera. It's an encyclopedia. But you know what it's not? It's not a hammer, right? So I would never use my phone to hammer a nail into a wall because A, it probably wouldn't be effective, and B, it would probably break my phone. Now, a hammer is great for when I need to hang something up or remove a nail. But I'm certainly not making calls off of my hammer.

Shera Dubitsky:

So when I think about that, I think about all the caregivers in the support network and to keep in mind that each one has their own strength and function. So it's important just to delegate wisely. A caller diagnosed with breast cancer noticed that she was often comparing her situation to others, and this raised her stress level. So to reduce her anxiety, she would imagine that every woman had a cardboard box filled with their own valuables. Now, it's very tempting to peek into somebody else's box. But it's important to remember that the contents and the valuables in each person's box is unique to them and may even be irrelevant to her.

Shera Dubitsky:

So keep in mind that people's circumstances are different. Our personalities differ. How we cope with things are unique to us. Even within own families, we deal with things differently. So rather than getting upset or frustrated with how a family member may be managing this, I believe we have to just show some compassion and embrace the fact that each of us will have our own take on this and collectively deal with it as a family.

Shera Dubitsky:

So for example, in my marriage, my husband happens to be the worrier. I'm the calm one. I noticed that when he starts to be calmer, I start to get much more anxious. So I thank him every day for taking that on in our relationship because I really feel like his worrying is a gift to us, and it's a very fluid dynamic. So I realized that we need to have worriers and people who are calm because if both of us were anxious, we would be too tired or worn out and just not on top of our game. If we were both calm or if we were both the same, we might miss out on getting what we need. So I think that both are critical in this. So let's respect that. Each of us manages differently and that's how we will function collectively.

Shera Dubitsky:

So now it's time to delegate. Organize a conference call with your loved one and with all caregivers. Who's good at researching services? Who can speak with the doctors and the treatment team? Who can coordinate ordering shopping and meals to be delivered? How can we help with the kids? Maybe we should have reading hour and take turns with that or doing projects online or helping with homework. I think that due to compromised energy, fatigue, stress and anxiety, it may be difficult for your loved one or her immediate caregiver to repeat what's going, on over and over and over again, to friends and extended family.

Shera Dubitsky:

So I would suggest designating someone to write updates either on an online resource like CaringBridge or on WhatsApp. You can get the links to these online services on Sharsheret website, or even better, you can call and speak with a Sharsheret social worker who is wonderful and can give you this information. Remember that this is a long-term process in terms of healing. So you have to pace yourselves. I also would recommend coming up with creative options on how to spend time remotely.

Shera Dubitsky:

So over the years, many women have said to me that they feel cringy when people try to say the right thing or do the right thing, and they're working so hard. Women have reported back that they just want people to feel more natural, and just being there without always having to work so hard may actually be the greatest gift of comfort that you can offer. My 22-year-old daughter moved to Israel four years ago,

and we speak at least once a day. Honestly, sometimes there just aren't things to talk about, but we kind of just want to connect. It was starting to feel pressured and forced.

Shera Dubitsky:

So what we decided to do was to try to spend time more naturally. So if she were here with me and we were both cooking in the kitchen, we wouldn't be speaking nonstop. So what we've decided to do is we turn on our FaceTime, and she's cooking in her apartment, I'm cooking here. Every once in a while, she may ask a question or I may share a thought, or we're showing each other what we're cooking. It just feels like a more natural way of spending time together. If she were here and we were in the family room together, we wouldn't be talking all the time. So now we FaceTime, and I may be working on my laptop, and she may be reading a magazine and every once in a while, we're speaking again. We just want to connect, but it doesn't have to feel so forced.

Shera Dubitsky:

I really am finding and hearing a lot about caregivers who are neglecting to take care of themselves. That's why Sharsheret decided to do this Zoom chat. So recognize that you are having feelings of guilt and sadness and anger over this situation. Once you recognize that, you kind of let go of that. Maybe create your own support system, reach out to Sharsheret. We can help, and we can give you some support and some tips. Remember that under normal circumstances, progress takes time. So just take things one step at a time. You don't have to find the answers to everything at once, and you may not be able to fix all the problems. Recognize that the options and solutions won't be perfect. So you have to kind of choose the best imperfect solution and just make some peace with that.

Shera Dubitsky:

Also, recharge your own batteries. I often picture a power strip that has so many things plugged into it, and that's definitely the quickest way to get burnout. Also, there are times when you have a power strip where every thing is plugged into it, and then I look over, and the power strip itself is not even plugged into the outlet. That's how I'm feeling sometimes, either I'm burnt out because too many people are relying on me, or I'm not accessible because I'm not plugged in for recharge. So I have to make sure that I'm recharging properly and routinely.

Shera Dubitsky:

It's important for all of us to have a healthy diet and to exercise, sit outside when we can and just take in nature's goodness. We may find ourselves juggling multiple roles due to the fallout from social distancing. So prior to the COVID-19 outbreak, many of us were pretty good at compartmentalizing our lives, right? We designated the time when we were going to be the parents and the spouse and a friend and a caregiver and an employee. We had recognizable boundaries. Social distancing is just making a mess out of that, and it's causing those lines to blur.

Shera Dubitsky:

So with kids home, we may be doing schoolwork when we were typically working on our own work tasks. Before this, we were able to have time to shop and to help someone and to cook and to socialize

and times to pray. But now it just feels like a Whack-A-Mole, that arcade game in which players use the mallet to hit those toy moles, which pop up at random, and we're trying to get them back into the holes.

Shera Dubitsky:

So we are attending to everything as they're popping up, and most likely, we're not giving our full attention to anything, and this results, again, in our feeling guilty and inadequate, and we're just simply feeling frustrated. So to the best that we can, create a schedule and make sure in that schedule that you're also scheduling time for self-care. This may seem obvious, and I'm sure at this point most of you are probably doing this, but create a space for working and a non-work space for yourselves.

Shera Dubitsky:

I just got off a Zoom call with friends of mine, and I was like, "People, it's time to triage, determine what needs and whose needs require immediate attention, whether it's you as the woman living with cancer or whether you are the caregiver." Some of you on this Zoom chat have now been thrust from patient to caregiver. So under typical circumstances, a woman undergoing surgery or treatment could expect again that many of her needs will be tended to by friends and family. This may be diminished at best and probably more likely non-existent again to these social distancing. So this is really an extra hardship.

Shera Dubitsky:

For some of our Sharsheret callers, not only are you not getting this assistance, but in some instances, you have to now self-care and find the energy and strength to care for your families. You now may be thrust into a position of having to care long distance for a parent who already had their care in place and all their needs tended to prior to the pandemic.

Shera Dubitsky:

So how do you adjust? You have to determine what you can take on. Don't take actions that will compromise your own health. Someone recently shared with me, and I love this, that we should probably be calling this more physical distancing and not social distancing because we can still be there socially remotely and that we can try to take care of some of the needs through technology. Being there doesn't always have to be full on hands-on. Again, as I said earlier, sometimes just being present may be good enough.

Shera Dubitsky:

In some instances, you may have friends who are offering to help even during this crazy time, and they're probably doing so sincerely. So perhaps you can reach out to some of those people who have offered to help and see if they can assist in maybe researching resources for your parents and then helping you to connect your parents with those resources.

Shera Dubitsky:

We are facing holidays. We have Passover and Easter ahead of us, which are traditionally spent with family and friends. We're finding ourselves facing very hard decisions. So for example, there may be family members alone. It's just unfathomable to consider that grandma is going to have to be by herself for the holiday. Another thing is many of you may be used to going away for the holidays or being with friends and family in their places, and you're not making it yourself. So you're now in a position where

you're making the holiday on your own, and you just may not be even feeling well enough to do that. I think we all have to acknowledge how disappointing this is.

Shera Dubitsky:

So again, we can just do the best that we can. We can't hold onto the traditions at this point, but that doesn't mean that the holidays can't be memorable. I had a woman share with me that she's worried about disappointing her family because she believes that she won't be able to shop for what she needs to make the full course Passover Seder, and she's worried about other people shopping or preparing for her because of the risk of contact. So we all have to shift our expectations. I said to her, "Okay. So you know what, maybe this year, the best that you can do at your Passover Seder is everyone's going to have matzoh and cream cheese. Maybe that's the best that it can be."

Shera Dubitsky:

She goes, "You know what, I haven't even considered that, and I've had all this pressure on me." She kind of laughed and said, "I don't know. That may be what it has to be." I said, "Look, the likelihood is you're probably going to get the brisket and soup, but that's the worst case scenario." It's not so terrible. I think as Elana opened up, she said these times are unprecedented, and we're not doing things as we traditionally do. But that doesn't mean that our solutions can't be memorable. I assure you that this holiday, probably more than anything else, is going to be the one that everyone remembers in the future. So you can set the tone for how this is going to be remembered.

Shera Dubitsky:

I'm pretty sure for that woman, her family will be talking about the year that they had matzoh and cream cheese for many years to come. Prior to the holiday, I think that many of you can maybe come up with questions that are interesting that you'll send out to everybody and then have everybody answer them, send them back to the point person, and then they can be read at each person's holiday table. In my family years ago, we created a sweatshirt with our favorite memories on it for everybody, and we continued to wear the sweatshirt every single year.

Shera Dubitsky:

So I think that perhaps you can ask everybody to write down maybe their favorite memories and again, send it to the point person who can share it with everybody, and it could be read at a table, and that in itself can become a keepsake. Find time, obviously, during the holidays to family Zoom, to stay connected during the holiday. So instead of reaching out one-on-one, get the whole family together on one Zoom chat. At the end of the day, you're going to set the tone for this experience. Decide what you want that tone to be and go with it.

Shera Dubitsky:

Then finally let's talk about option B. Sheryl Sandberg, who is the COO of Facebook. She lost her husband to a sudden death. So option A was that she was going to live a long life with her husband by her side, and they were going to raise their children together. So option A was no longer viable. So she decided that she was going to put option B into play and to create the best out of this imperfect option. I want to end with this quote that I absolutely love, and that is... I saw it on Facebook. So it is, "Optimism does not mean that everything is going to be great. It means that we can respond to everything with greatness or at least the best that we can."

Shera Dubitsky:

So I think that we'll open this up to some questions. I think Elana, we have questions that came in earlier so we can go ahead and start that.

Elana Silber:

Okay. Thank you, Shera. Thank you for giving us examples that I think we can all bring to our own lives. There were many questions that came in in advance that were medically related. While this call is not focused on the medical side of the issues you're facing, I want you to know that we will be addressing medical questions, general medical questions on Wednesday with Dr. Ruth Oratz, a top oncologist from NYU Medical Center.

Elana Silber:

So there is information on our website on when to join. I think it's Wednesday at 2:00 PM Eastern time. But if you're on this call, you'll likely get an email reminder about that. So feel free to email us anytime with questions for that, and we'll get you the dial-in for that call. So thank you Shera again for bringing the attention to the caregivers. We know that you are also, for lack of a better word right now, on the front lines of the support for your loved one and for yourself. So we're here to help you along the way.

Elana Silber:

So one of the questions that came in that I would love for you to answer that someone emailed is, "How do I care for someone with whom I have a complicated relationship? We're spending a lot of time with each other, Shera." People that probably previously we didn't need to, we could get out. But now, we're dealing with people that we don't necessarily have a great relationship with.

Shera Dubitsky:

Right. That's true. So I do want to get to that. But I want to cover something that you just brought up, Elana, which is that we did get a lot of medical calls and questions. But I do think that there are some emotional concerns to the medical questions. So if it's okay, I just want to touch on that for a second, and then we'll get back to that really important question.

Shera Dubitsky:

So I think it's important to recognize that many of these fears are valid but not unmanageable. Many times I think we overestimate the crisis, and we underestimate our ability to cope with that. So I know for myself that sometimes I go into my car, and I type my destination into Waze, and I'm quickly browsing through the route list because it comforts me to know where I'm going. So I'm happily driving along the way and then it says recalculate. That's the worst sound. Suddenly, I don't know where I'm going.

Shera Dubitsky:

As a Sharsheret caller once said, recalculating is simply a part of life, and not everything goes as planned. So like everything else on this roller coaster ride, it's how we cope with the changes and the new information, the period of recalculating that I think ultimately matters. I also am feeling that panic and fear are as contagious as the virus itself. Look, we're all wired to experience healthy anxiety because it helps protect us physically and emotionally, and these are legitimately stressful times, and we need to be protective. Our emotions are really heightened right now.

Shera Dubitsky:

So it is helpful to assess the difference between healthy anxiety and panic. It's also, I think, helpful to distinguish between our fear and what the facts are. Because oftentimes I think fear is a liar and we respond to it as if it's truth. Now, sometimes fear is based in fact. But most times, we're just engaging in creative writing because we don't know what the facts are. So we're filling in the storylines with these fears, and we happen to be overachievers when it comes to imagining worst case scenarios.

Shera Dubitsky:

So it's important to keep in mind that our emotions are filters for how we see and interpret the facts. So bringing that around to the questions about the medical, it is as important to check in with your medical team and figure out what are your fears and what are the facts?

Shera Dubitsky:

So now to get to the question, I think the question was, how do I care for someone with whom I'm having a complicated relationship with? I was thinking about that. That's hard and it's challenging. But I kept coming back to this answer, and that is I think we have to rely on morality versus sentimentality, right? This may be a time to detach emotionally. You have to maybe believe that morally taking care of people is the right thing to do. I think if you can do that, that helps keep your integrity and dignity intact.

Shera Dubitsky:

So if you can try to, just for this moment, take a pause, separate the past from the present, at least for now and don't expect that whatever you're doing will heal any past relationship, and you shouldn't do it for that reason. In the end, maybe you'll even find that it would be healing for you and not for the relationship.

Elana Silber:

Okay, Shera. One question came in just now on the chat, and I wanted to read it to you. There is a lot of counseling going on, telehealth going on, and Sharsheret has... I think, we have over 18 years experience with telephone counseling and peer support. So this person wants to know if you have any general advice on telecounseling. In particular, are there any questions that are helpful in accessing emotions over the phone? This is new for a lot of organizations than a lot of professionals. So your experience I think could be very helpful as people try to give support to each other and they want to admit these emotions.

Shera Dubitsky:

Yeah. So I'm also seeing that there is a lot of telehealth and counseling available. So I think the first place to start is with organizations that are reliable. So you may have organizations that you're already connected to. I would start there because at least you know that they're reliable, that they're responsible, and it may be a good springboard and thinking out loud with those organizations in terms of getting help. I also know that Sharsheret has a resource for mental health on its website, and you can certainly call Sharsheret to get that resource, and they can also help you with a referral and connecting you with a mental health provider.

Shera Dubitsky:

There are also resources locally that are doing a lot online counseling. So for example, there may be a Jewish family services in your community that now are offering things over the phone or some other social service locally that may be doing that. I would start with all of those, and I also believe that the government also has websites to offer some reliable suggestions for mental health resources. So that's just where I would start. I can't really comment on all the ones that are out there and whether they're good or not good. It's just too many for me to be able to keep track. So I'll go back to what we know is reliable.

Elana Silber:

Right. So thank you. That is something that people are taking advantage of, and Sharsheret is a leader in this type of counseling. What we can tell you also at Sharsheret is, in particular, there are ways that you could ask the right questions to get the emotional support you want. So we have, for example, in our peer support network, the women that are providing peer support to each other are trained by Sharsheret on what to ask and what not to ask. There are dos and don'ts. So if that's something that you would like more help on understanding, we have been training thousands of women on how to share support and ask the right questions to get... and like Shera said in the beginning of her call, to follow their lead and get that emotional support.

Elana Silber:

But we also have trained social workers on-staff who are providing this emotional support and getting the questions the right way. So I definitely encourage you to reach out. We have a team of eight social workers and a genetic counselor who can speak to you on how to support somebody and get that. That's part of this Spungen Family Focus Program and Counseling that we offer for caregivers. So if that's something that you need, we can work one on one. This call is not the end of the story. This is a general call. We will work with you individually to help you in your situation. So thank you for that question.

Elana Silber:

There's another question that came in. What do you do when your loved one is refusing recommended measures to protect their immunity? This is the example from the person who asked the question, like going to the market frequently. Another question, and this was part of it is that, my friend with cancer is still accepting meals, but I am feeling scared that I might be inadvertently passing on the virus to her. What do I do? So Shera, I'm going to turn it over to you. We're putting those questions together because there seems to be a lack of control on the caregiver's part or when you're trying to support a loved one. So any guidance on that would be helpful.

Shera Dubitsky:

Right. So I think we're all feeling this lack of control, and we can only do what we have the power to do. As I said earlier, it is important to validate someone's choices. So I think that you can gently offer alternative options by saying things like, "Look, I'm feeling really protective. This is on me. I just am feeling protective, and I'm wondering if there are other ways for you to get your needs met. Can we just brainstorm for a minute?" Also, if you're being asked to offer help in a way that's making you feel uncomfortable, I don't think you should do it. But I think that you can subtly offer other things that you can offer and that you are comfortable giving.

Shera Dubitsky:

We also kind of got another question. I want to tie it into this, which is somebody asks a question about people living in their home or apartment who are not taking the necessary precautions as per the CDC recommendations and guidelines. The reason why I want to bring that in here is because again, it's another area where you don't have control, and it is impacting you. So I think in these instances, you can say, "Listen, I care for all of us. What can we do to take care of each other?" Again, offer some suggestions. If it's not heeded, then you can only do what's in your own control.

Shera Dubitsky:

My dad called me in fact yesterday, and he said, "Your brothers are really angry with me." I said, "Why?" He said, "Because I went to the dentist to take care of something, and they're yelling at me, and I needed to take care of it." So at that point, first of all, it was already done, and I can't force him. I can't strap him down in his home. So I tried to gently say, "Okay. Look, dad. I guess you felt like it was something you needed to do. But can we maybe get on a call when you're feeling like you have those needs, and maybe we can figure out other suggestions." But at the end of the day, we just can't manage other people's behaviors.

Elana Silber:

Okay. This call just came in from Debra on the chat. How do you deal with individuals that tell you that sometimes quality is more important than quantity?

Shera Dubitsky:

So I'm not really clear, Debra, what you're asking. But I'm going to try to put my own take on that, and that is, you know what, we're in a time period where we realistically actually have emotional, logistical, medical, and physical needs. It's not a time where we can maybe categorize things as quality versus quantity. I would say that each scenario and each situation needs to be assessed and to determine what exactly is needed for that particular circumstance. I think that's as general as I can get with what I'm understanding unless Elana, you have another take on that?

Elana Silber:

No. I mean, for now, that works. But Debra, feel free to keep the chat going. But I also want to just get to... I'm trying to consolidate, mindful of everyone's time to some of the questions that came in separately. So there's one right now that says it's hard for people to ask for help. How can I trust that my loved one is being open and honest about her needs? I think this is huge because-

Shera Dubitsky:

It's huge.

Elana Silber:

... I just spoke to someone also, they just can't keep asking for help.

Shera Dubitsky:

So you're right. It's hard to ask people for help. So I think it's on the caregiver to try to find a more nuanced way of getting to that. So for example, you could say, "How have you been sleeping? How's the

eating? What have you been eating lately? Who are you in touch with? How are you spending your days?" And to kind of gather information and to maybe read through the lines to determine what the person should need. Then once you're able to do that, maybe to offer things without her asking. So for example, you could say, "Look, I have some time this afternoon. Can I do some research for you? Can I make some calls for you?" Or if you know somebody who has kids, your kids' ages, you could say, "Look, I'm going to be doing homework with my kid around one o'clock. Does your son want to hop onto a Zoom call, and we could do homework together."

Shera Dubitsky:

Just in terms of asking for help in general, this year I had a knee replacement surgery. So I created a team of about 50 women, and every week I would put out a Google doc asking for what I need, and people could fill in. So somebody had heard about this, and she's like, "I could never ask for help." Right? How do you feel comfortable doing that? So I said to her, "Let me ask you something. Are you married?" "Yes." "When did you get married?" "Two years ago." So I said, "Did you invite guests?" "Yeah." "How many?" "300." So I said, "So you didn't have trouble asking 300 people to give up five hours on a Sunday afternoon and then pay you for it?" Right?

Shera Dubitsky:

So we're comfortable asking people to do those kinds of things, but for me to ask somebody to drive me 10 minutes to PT was a big deal? No. In general, just know that you've asked people to do things before, and it's easier to do it under happier circumstances. But people who are your friends and family are equally happy to be there for you when things are more challenging.

Shera Dubitsky:

I also just wanted to add that I think that maybe your synagogue or your churches may also be a place... You can say, "I'd like to help this person. Do you have any ideas how you can do that or to call a family member and ask?" So again, there are kind of roundabout ways to get to that.

Elana Silber:

Okay. We have time for I think maybe about one or two more questions. So how do we provide support for a loved one who is experiencing paralyzing anxiety around COVID-19?

Shera Dubitsky:

Okay. So I think that we become a more exaggerated version of ourselves when we're faced with crisis and trauma. So if you're somebody who was probably a worrier before, that's probably going to be much more magnified at this point. So when I hear the words paralyzing, it makes me wonder what the baseline of anxiety is to begin with. But at the end of the day, we're all flooded with information out there, and we're all experiencing heightened anxiety. So I would say to this person, but also for all of us, we have to stop watching the news so much, and we have to cut down on social media. For myself, I've taken myself out of some WhatsApp groups because I was flooded with memes and videos. It's really nonstop. If she's worried about missing something, I think that you can reassure her that you will give her some general updates as things are changing.

Shera Dubitsky:

Also, I would suggest teasing out fear from fact and to just remind everybody on this call that there are a lot of people being diagnosed out there. But in general, most people are recovering from the virus. For some, the recovery is much more difficult, and we shouldn't minimize that. But for the most part, people are recovering, whether it's at home or even in the hospitals. I think that it's important to validate that it's okay to have anxiety because again, there are so many unknowns and so many extreme changes to our lives. But I would try to maybe reassure her that that's exactly why there are so many extreme measures being put into place and that it's important for her to find the areas that she has control over, like washing hands and social distancing and kind of let go of the areas where she lacks the control.

Shera Dubitsky:

If this is a person who either comes into this with higher anxiety or if legitimately the anxiety is more elevated to the point of paralysis, then it goes back to an earlier question about reaching out for mental health support. So again, you can call Sharsheret for resources. You can call, again, some local social service agencies. She may already have a mental health contact already. So I encourage her to call and ask, "Would it be helpful if I spoke to that person?" I think that that's really the best way that we can offer help in that situation.

Elana Silber:

Some of the points that you just made, I think do answer Kenneth's question, but I just thought would be interesting to bring it up for everybody. He lives in a family of nurses but because they know too much, sometimes it's hard to pull them back. Besides my wife being a former cancer hospital administrator, she's a three time survivor. I was the control when she was in treatment. How should I help convert her worries to concerns? I think some of what you said does apply, but if there was anything you wanted to add to the concept of worry, concern, fact ... to what we can do and to some of the strategies you suggested, if there was anything to add to that or you-

Shera Dubitsky:

Yeah. I'm comfortable with that.

Elana Silber:

I think there are some people who are answering you on the chat, providing a little bit of support to each other. There was one more question that came in beforehand, and if anyone wants to send it in, we just have a couple of more minutes. It's hard to set boundaries. How do I say no when I'm feeling overwhelmed as the caregiver?

Shera Dubitsky:

So I think overall that wanting to be helpful to people is really noble and sometimes maybe choosing others over ourselves. But in doing so, I think that we are shortchanging everyone. We can't give ourselves completely if we ourselves aren't feeling comfortable or complete because for everyone, our goal is just to have wellbeing. This comes, I think from within, right? So it's important to determine what works for you and in the context of those boundaries, how you can help others. So set up appropriate and workable boundaries and only offer what you can and appreciate that other people are just doing the same.

Shera Dubitsky:

We all know that example where, on an airline they always say, in case of an emergency, put your oxygen mask on before even putting it on your child, and that feels so counter intuitive, but that's the best way that we can help. So if the foundation is weak, then everything else is going to fall, and we're not going to be our best selves, and we can't give that to people. So I think that establishing a solid base and giving what you can give is really the healthiest option out there, and that's really what this is all about. It's about keeping ... this whole webinar, was about keeping ourselves healthy so that we can be the best support and help to those people that we love.

Elana Silber:

Thanks, Shera. I can't think of a better ending to the call because at the end of the day, regardless of what situation you're in, we are all in this together for ourselves and for our families and for our friends. We have to stay healthy. So we encourage you to follow the guidelines that are coming out of CDC. We are updating you all the time. But even those basic measures, we have to internalize them. We have to keep them to keep our family healthy, and they are very complicated and very distressing, which is where we come in. These are not easy times. In every family, there are struggles from one end to the other.

Elana Silber:

So we encourage you to reach out to our team. We are here, we are available by phone, by email, text, Facebook, however you want to reach us through the Florence and Laurence Spungen Family Foundation Family Focus Program. We are here for you and your family. We have social workers. We have a genetic counselor. There were medical questions that came in. We are going to have an oncologist on Wednesday to answer general questions. At the end of the day, medical questions, talk to your healthcare professional, but feel free to join us on these general webinars. These are a series. We'll be keeping them archived on our website for you to watch on YouTube and written transcripts, whatever makes it easier. We want you to have the information the best way you can have it.

Elana Silber:

So the next one, like I said, is Wednesday, we have a webinar, and on Sunday we'll be having an "Unseder" which will get us in the mood for the holiday with very helpful resources and an opportunity to come together with some spiritual support for one another as we enter the holiday. For everyone who's celebrating this season, we want to wish you good health, and we are all in this together, and we wish everyone continued good health, and we thank you for taking advantage of what Sharsheret has to offer. We can make a difference. So thank you and stay well.

About Sharsheret

Sharsheret, Hebrew for "chain", is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret's Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

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

Education and Outreach Programs

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

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