

# Take Control: Navigating the Emotional Roller Coaster of Cancer

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Presented by:



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Elise: Good evening everyone and welcome to today's program. At this time, all participants are in a listen only mode. Later, you will have the opportunity to ask questions during a Q&A session. You may register to ask a question at any time by pressing star then 1 on your touch tone phone and you may withdraw yourself from the question queue at any time by pressing the pound key. Please note today's call is being recorded and I will be standing by should you need any assistance. It is now my pleasure to turn the program over to Shera Dubitsky. Please go ahead.

## **I. Introduction**

Shera: Thank you, Elise, and good evening everyone. Welcome to Sharsheret's national teleconference, "Take Control: Navigating the Emotional Roller Coaster of Cancer". We have many women calling from states all across the country who share similar concerns and questions about the emotional roller coaster of cancer. Again, I am Shera Dubitsky. I am the Director of Navigation and Support Services for Sharsheret. I'd also like to thank Shira Kravitz who organized this evening's event and really want to thank her for really putting together such a wonderful teleconference.

Before we begin, I would like to extend a big thank you to the Julius and Emmy Hamburger Memorial Fund for generously supporting tonight's program. It's very rewarding to partner with those who see the value in the kinds of support that Sharsheret offers. For those of you who are not as familiar with Sharsheret, we are a national non-profit organization supporting young Jewish women and their families facing breast cancer or ovarian cancer. Our mission is to offer a community of support to women of all Jewish backgrounds diagnosed with breast cancer or ovarian cancer or at an increased genetic risk by fostering culturally relevant individualized connections with a network of peers and health professionals and related resources.

Our expertise happens to be in Jewish women and young women. However, we are eager to support all women and families reaching out to Sharsheret for support. As I just mentioned, our expertise is in the concerns and needs of Jewish women. We get phone calls from women all across the Jewish background. We have different backgrounds, but what we have seen is that there are a lot of commonalities all across the spectrum. I just wanted to briefly highlight some of the concerns and issues that we are hearing about that really relate to the emotional impact of a cancer diagnosis. First of all, as many of you know, those in the general population have 1 in 345 people carry the BRCA mutation. Those of Ashkenazi Jewish descent, that number is 1 in 40. We can certainly imagine the amount of questions that we are receiving about genetics that has to do with anxieties around testing, anxieties around decision making, how to share information with family members. There are certainly a lot of emotional issues that we are dealing with in terms of genetics.

Another thing that we are seeing is that there is a shared value system across the Jewish spectrum. One of those things has to do with the fact that the family is the center of the Jewish community. That's a wonderful thing because we see that the community is really rallying around the woman and her family to offer support when she is openly disclosing her diagnosis. Again, they are getting meals and rides to treatment and caregiver relief and childcare relief. Like most extended families, sometimes the community can be intrusive and women are calling to try to figure out how to manage that. Also, for women who, let's say, want to continue growing their family or to begin growing their family, to be in the community that value family so much. You can imagine how difficult it is for that woman who may not be able to grow her family naturally and may need to look at in vitro fertilization or adoption or surrogacy.

Also, the holidays, there is a range of emotional experience there as well. People say that they feel inspired by holidays, but sometimes it can also be very painful to be facing a holiday and certainly even logistically. For those women who are used to hosting holidays themselves, they have to maybe delegate that for the year because maybe they are recovering from surgery or continuing with treatment. It's another reminder of the impact of the cancer. Certainly, we get a lot of emotional phone calls from single women who want to know what it's like to go out there in the dating world with a history of cancer or history of a genetic mutation. We are dealing with that and sometimes that can be very isolating. Certainly, with marriage, many of the women have to tinker with the relationship because obviously the spouse or partner is also feeling the impact as well.

At this point, I'd like to introduce Dr. Karen Hurley. She is a licensed clinical psychologist specializing in hereditary cancer risk. She received her A.B. in Psychology from Bryn Mawr College in 1983 and her PhD in Clinical Psychology from Temple University in 1998. She spent 8 years on faculty at the Memorial Sloan Kettering Cancer Center conducting NCI funded research on patient decision making about prophylactic surgery and other psychosocial issues relevant to familial cancer. She is now in private practice in New York City with adjunct faculty appointments at Memorial Sloan Kettering, Teachers College, Columbia University, and City College of New York. She has provided psychotherapy and consultations to over 400 individuals and couples and families who have to deal with the BRCA mutation, Lynch syndrome and other forms of hereditary cancer.

In addition, Dr. Hurley has conducted numerous professional education seminars and patient workshops for hospitals, professional organizations and for people in the community affected by cancer and cancer risk. She is a member of several national advisory boards including Sharsheret's own Medical Advisory Board which we are very grateful for as well as FORCE, Bright Pink and the Cancer Support Community's Breast Cancer Registry. In 2014, she received a Spirit of Empowerment Individual Commitment Award at the 8th annual FORCE conference in recognition of her work on behalf of the Hereditary Cancer Community. Dr. Hurley?

## II. Navigating the Emotional Roller Coaster: Newly Diagnosed and In Treatment

Dr. Hurley: Thank you so much for having me and for the opportunity to support your very important work. If we could go to our first slide, I was asked to speak about cancer being a roller coaster. We hear that description often and starting with that moment when you hear your diagnosis. It is kind of looking straight down a hill. I thought this picture really captured it very nicely. There are so many things that make that a very apt metaphor. The way that going through treatment gets your hopes up one day, punching you into disappointment the next when it looks like maybe the treatment isn't working. Winding up on a track that you can't get off of, winding up on this track of appointment after appointment. Also, there's the strong emotions that go along with this that also feel like a roller coaster. These are emotions that feel outside of the range of our normal every day experience. There's so much of the cancer experience that feels out-sized and out of control.

If we could go to the next slide, perhaps one of the sharpest drops that really puts a twist in your stomach is when nothing turns out to be definitely something. Earlier, Shera, you were talking about the statistics for carrying a BRCA mutation. So much of cancer experience expressed in numbers, 1 in 9, 1 in 45, 1 in 100. It can be pretty isolating when it turns out that you're that one. It could be specially frustrating if you feel like you've been doing everything right and you get a diagnosis anyway or it could be upsetting equally so if you are somehow blaming yourself for winding up being that one. Both of these things can then throw you for a loop. We can go to the next slide.

We can extend the roller coaster metaphor even further. There are other twists and curves that make this ride of cancer particularly heroic. For example, cancer experience, diagnosis and treatment create a whole cascade of hassles, appointments that interrupts your schedule and your routines, having a surgery and then you can't lift things, going through chemo then things don't taste right. You don't know what food to buy. Your clothes don't fit right. You're tired all the time. You can't do what you're used to be able to doing. Psychological research actually shows that these kinds of hassles, especially when they're stuck up on top of each other are more closely tied to moods and distress than big events.

Furthermore, you're not the only person or you may not be only a person who is going through these hassles as other people who are in your life have to adjust along with you whether that's your spouse, your family, your kids, your co-workers. Even if they are being accommodating and going along with good cheer and helping you get through this, there can be this collective feeling of strain that again is taking you out of the ordinary. Lastly, and sometimes people don't recognize this, that some of the medications that go along with cancer treatment can affect your mood, again, putting you on even more for roller coaster. For example, going on or stopping steroids which are sometimes used along with chemotherapy. You may not even recognize why you're not feeling like yourself.

If we can go to the next slide please. All of these upheavals then really boils down to feeling like things are out of control. It's not just a temporary lack of control until treatment gets over, but it's realizing that our sense of control, the control that we typically have over ourselves, our emotions and most especially our future has always been somewhat fragile. There's sort of an illusory quality. Sometimes we think we have more control than we actually do and cancer has a way of stripping that illusion away and that can be an especially disconcerting. Again, creating that drop in the stomach feeling. Next slide, please.

A common reaction then when people are feeling that lack of control is they then shift to a different image which you may also recognize and that's the one of going to war against cancer. Shifting into that battle mind, I'm going to fight it, definitely has advantages. It's an energizing image, that feeling of rallying the troops. It feels heroic, but that rush of feelings that you're going to get control back may not be sustainable. It doesn't work as well as an image or it might even create frustration if you're, say, in a waiting period. You are waiting for test results to come back or you are facing something that can't be changed.

The other issue is that the battle mentality creates this kind of get it done mindset where you push your emotions to the side. That's what soldiers do. They put their feelings aside and it's the mission at all cost. This can be problematic especially if you're in the middle of making a big decision like you're trying to make a treatment decision or trying to decide whether you're going to have a prophylactic procedure, you're in battle mode, get it done, do it. Then, you realized that you weren't in touch fully with what it would feel like afterwards to live with the consequences of your decision in the long run. Those emotions that feel distressing may actually also contain important information for you that would inform your decision. Next slide.

Another way that people try to regain the sense of control when they feel like they've lost it is to try to control their emotions directly. For example, people may have told you to try to stay positive, that that's what's going to get you through and to avoid making thoughts. Hope and optimism are definitely beneficial, but if you're trying to stay positive because you are afraid of having negative thoughts that they're going to harm you in some way either mentally or physically, then what you are actually doing is living in fear. Other people try to protect themselves by worrying, imagining the worst so that then they don't get let down later, so trying to smooth the roller coaster out by just taking the more negative path and then you can't be let down.

There's a lot of research in this area as well. The technical word for it is metacognition which is basically your thoughts about your thoughts. Ironically, both worrying about your thoughts and forcing yourself to be positive can be detrimental to you and it's almost like one phrase I used. When you're worrying, it's like trying to control the future with your psychic superpowers. It's not really possible, but we cling to that tendency that somehow these worrying thoughts will change how things turn out. Next slide.

If we can't stop the roller coaster, we can't smooth out the tanks, we can't make our minds and our feelings stop doing these loop de loops. What can we do? One way to ease off of the intensity of that roller coaster feeling is to start seeing your thoughts as passing events. Clouds that have shapes and colors, but they have no weight. A phrase that I use when I'm working with patients is lifting up off of the thoughts, allowing just enough of a lift to allow for the possibility of having a different kind of a thought and to maybe rest in the space between the thoughts. This image of the passing cloud may be familiar to people who do contemplative practices such as meditation, prayer, yoga. Researchers are finding that this ability to lift up the thoughts is a key ingredient in certain kinds of therapy as well. If you've experienced cognitive behavioral therapy, it also creates that space where thoughts can be examined and changed and reframed. Next slide please.

To give an example of what I mean by lifting a thought aside, I was thinking about a grade school student that I was tutoring last summer and this is a 9-year-old. She was interested in arts. We were reading this children's book on arts. We were reading about Matisse and found out that late in his life he had to lift up his self-image as a painter because he could become too ill to paint. Instead, he found a new way to express himself using an assistant's help and he called this drawing with scissors, making collages and some of his collages have become some of his most endearing work. Then, I turn to my student, Jayla. That's not her real name. I said, "Okay, let's check this out." I want to give this example just that you don't have to be Matisse. You don't have to be a special person or have some kind of genius to be able to make this shift.

I asked her to imagine what would happen if you broke your arm? She made a list of the things that she wouldn't be able to do and the things that she would still be able to do. For example, she said, "You couldn't cook as well. It would be harder. You couldn't paint walls. You couldn't play. You couldn't move the arm. You couldn't hang stuff up or you couldn't do sports." Okay. What could you still do? "You could pour water in a cup." That was one of my favorites. "You could walk. You could still paint stuff, but it would be different. You could use your phone. You can take a picture. You could read a book." Okay. You got 2 nice lists. How do you feel when you think about what you can't do? "Sad." How do you feel when you think about what you can do? "Good." There it was. Next slide.

In psychology, we call that particular phenomenon the focusing illusion, when what we can't do takes up all of our attention and what we can still do, it's actually maybe much greater out of focus and therefore it seems out of reach. It's generally true that people can't imagine being able to adjust the situations and they can't really project how they are going to feel until they get there. One of the most consistent findings in the health psychology research actually is that people going through difficult experiences in general report better quality of life than you might expect. We are flexible. We do adapt. It doesn't happen overnight, but we do get there. Next slide.

How does this happen? Is there some kind of special resilience that people have to have? Basically, what it means is redefining what quality of life means to you based on your body and your situation as it is now in the present. It doesn't mean that you're always going to be this way so what's possible may shift and shift again as you are making your way through chemo, through surgery, through recovery. Questions that you can ask yourself to bring this process out into the open would be things like asking yourself "What's important to you now?" That's reassessing your priorities. You can ask yourself "What's your measure of a good day?" When you're healthy, a good day might be being able to jog for 5 miles. When you're not feeling so well, maybe it's being able to walk down the block and back. If you re-calibrate towards that new goal, you can still feel satisfied within that that you are doing what you can. What does quality of life mean to you today? That can also shift from moment to moment. Then, ask yourself what you can do, what's going well.

You may have feelings coming up about that. You may feel regret about your typical, your usual definition and having to let that go. If you can allow those answers to shift and shift again, it gives you the power to create a good enough day out of what you have at hand. Being able to define what's going to make this particular day a bad day is a place where you do have control. Next slide.

For those of you who can't see, the next picture is a picture of a mug that has a phrase that has become very familiar to people, "One day at a time." It is familiar to the point of almost losing the meaning of it, but I have never found it to be more true than when dealing with cancer. In real life, doing one day at a time is not that easy. It takes remembering. It's a mental discipline, if you will, but at the same time it has that lightness that we are talking about. Lifting up of thoughts about what the future might be or what you think it should be or that it will always be this way and allowing just enough space to make the day doable. Next slide.

There are different ways of allowing room to redefine what's going to make a good day. There's multiple things that you can do to get to this shifted perspective and different people will find different things more or less to their taste. For example, I've already mentioned meditation and yoga. That's one way. Cognitive behavioral therapy. Exercise is good, not only for your physical health and for lifting your mood, but it also naturally shifts you into a can do kind of mode because you are active. Another really good technique is expressive writing. There's a researcher, James Pennebaker, who has found that if you write for 15 minutes a day for 3 days in a row about deep personal feelings, so maybe connected to the day that you were diagnosed or some other major events in your life that if you do that, it has lasting benefits for both your emotions and also your physical health. Lastly, talking to other people, hearing yourself and being heard is also another way to lift up off the thoughts in depth perspective. Next slide.

I can't over emphasize that having good social support during the cancer experience is essential and it's not so much how many people are in your life

who are around you, but having this feeling that you've got at least one person that you can say anything to without being judged. Sometimes you'll have someone who has a lot of family and friends around, but they're holding back because they don't want to worry other people or burden them. That act of holding back and isolating yourself, that tendency has been shown to lead to more distress and depression in the long run. That can really spiral back out of control ironically when you are trying to control the level of worry and distress that you and other people are feeling. Next slide.

I want to leave you with some food for thought that you can take with you. Cancer can be like a roller coaster and we see in some ways in which the image really holds true. Cancer also can be like a battle and that image also has benefits, but you're not down by any of these images unless you find that they serve you. Roller coasters are scary. Battles are heroic. Both oddly have that quality of being physically alive in the moment. You could have these images and maybe examine to what extent does this image speak your truth and if it doesn't feel like it's capturing everything, you can allow other images to come to you. You want to ask yourself whatever image you're having about what your cancer experience is like. Does it speak your truth? Does it empower you? Does it comfort you? A battle image or a roller coaster image doesn't offer comfort and doesn't connect you to other people. Next slide.

I want to say that you can also ask yourself about your beliefs about worries. What are your beliefs about the thoughts and feelings that you are having? Are you censoring your negative thoughts? Are you fearful of your thoughts and feelings or do you feel like you can't stop dwelling on them? It's basically looking at your relationship to your thoughts, but even more so what is your relationship to your worried self, your distressed self. Next slide.

In short, trying to stop the roller coaster and to get away from all the ups and down of your feelings can essentially be like trying to get away from yourself. I can't promise that you won't have intense feelings or disappointments that things are not always going to go the way that you hope as you are moving through treatment, but you can stay open to what's possible. It's not easy, but it has to be just doable enough. You do have control about how you relate to your thoughts, to all of your thoughts and to offer every thought that comes to you an equal amount of compassion. This open compassionate feeling towards your own experience can help you move towards living fully and well right in the middle of treatment, right in the middle of your survivorship. That you're not grimly trying to hang on until the end of the ride when you can then climb off and get back to your real life, but right now when you need the best of yourself the most. I will close there and turn the program over to our next speaker. Thank you very much.

Shera: Great. Thank you, Dr. Hurley. I love that you end it on a slide talking about compassion because you gave such a clear and compassionate overview of some of the issues that many women on today's call are facing after a cancer diagnosis. I think that your takeaways certainly apply to survivorship and your

presentation is a great springboard to discuss the issues of breast cancer and ovarian cancer survivors including those living with advanced breast cancer or ovarian cancer. I'm not going to go through my bio, but I think it's enough to say that I've been in Sharsheret for over 10 years and much of what I'm going to present this evening comes from the hard earned wisdom of the women that I speak to on a daily basis.

### **III. Navigating the Emotional Roller Coaster: Survivorship**

Our survivorship program actually came out of feedback that we've received from many callers who will say things like this, "You know, when I was first diagnosed, it was tough. It was like a punch in the stomach, but okay, I got myself together and I got my treatment team together. I made my treatment and surgical decision and I was okay. I went through surgery and it was hard to rally again, but I was okay. Now, I have to undergo treatment and the thought is how do I think deep again to find that strength, but okay, I did it and I was okay." Now, it's 6 months later. For some, 2 years later. For some, 5 years later and they say, "You know I was basically okay, but it's hitting me now." I think the way that I look at it is that I think that we're not wired to take a hit physically and emotionally at the same time because we really wouldn't be able to function.

I think what ends up happening as the body is undergoing surgery and treatment and is recovering and healing, the psyche is sort of off to the side tapping its watch. When the treatment is over, the psyche says to the body, "Are you done?" The body says, "Yeah, I'm all done." The psyche says, "Well, good. It's my turn." I think it's at that point that many women that I have spoken to are feeling like they're only now digesting that they went through cancer or they had surgery because they were at high risk for hereditary cancer and they look back and they said, "What? Was this my life?" I think that that's why it fits often after the medical piece. The problem I find from many women is that the people in their life, their family and their friends, they want to wrap up cancer in a box with a pretty pink ribbon or with a tail ribbon and they say, "Okay. You're done. Fine. Let's move on and everything will go back to the same."

The problem is that cancer survivorship or dealing with a chronic diagnosis of advanced cancer doesn't get wrapped up so neatly. It's here that we see a difference in how our loved ones see survivorship versus those of you who are facing survivorship yourself. The other problem that we see is that looks are deceiving. For many of you, you may start looking like your old self and you may be looking healthier and you may have more energy, but that doesn't necessarily match your insides. Looks are deceiving where people just look at you and they assume, "Well, you must be fine again because you look good and your energy is good and you are active again." Again, they don't really understand that internally you are now starting to deal with some of the issues that are unique to those who are surviving cancer. We often hear and I'm sure many of you have heard the expression, the new normal. I think that really what happens after a

cancer diagnosis or again if you find out that you are a carrier of the BRCA mutation that it really does change your emotional DNA forever.

I think when we use the expression, new normal, that's what it's referring to. Although I did have one woman who said that she wasn't so unhappy with the old normal and she wasn't looking to change. She wasn't necessarily looking for a new normal. I think for many people what we are seeing is that the way that their emotional DNA changes is that they may become more magnified versions of themselves prior to diagnosis. If we are seeing somebody who tends to be a warrior, we may see that a little bit more exaggerated. If we see somebody who is a doer or needs to be in control, that may be a little bit more exaggerated and the same thing with, let's say, anxiety. Not always, sometimes people either give up being a warrior or feeling anxious. Some people now take it on, but I think overall we see that maybe people become somewhat more magnified version of themselves.

The dilemma that we often see is for the issues that Dr. Hurley was describing. We are also seeing in survivorship and that once somebody faces a diagnosis, there is a tendency to see everything through the cancer glasses. Probably the most obvious is when we talk about fear of recurrence. Every ache and pain I think that women are more aware of and more concerned about. It could just be that they maybe have a back spasm from lifting up something too heavy, but the immediate thought is, "Huh, I wonder if this is the cancer back again." For those of you on the call who are living with a metastatic breast cancer or advanced ovarian cancer, again, every ache and pain may be a worry that perhaps the disease is progressing.

It's hard not to see everything through these cancer glasses. I remember one woman sharing a story that she was so grateful to have transitioned into survivorship and she was going to her son's graduation from kindergarten. She forced her whole family to get there several hours early and they had to be in the front row. Her thought was, "Thank god I made it here and I want to be as present as possible." What ends up happening is that this thought, because of cancer glasses associating it with the graduation, was that she ended up feeling more stressed out and the family ended up feeling more stressed out. I think that clearly her cancer experience influenced this kind of event.

I think that we can't talk about the emotional impact without talking about loss. I think that there are many losses that those of you on the call may experience. Certainly, I think people lose a trust in their body that somehow their body lets them down and how can they ever really trust that that can't happen again. Certainly, many women are reporting that they have either had a change in relationships or that they've lost relationships and had been disappointed with how people were not able to be of support. I think those of you who are moms on the call, I think that there is a sense perhaps of losing your children's innocence now having to deal with such a serious diagnosis. For some of you, not being able to get pregnant or breastfeed. For those of you who attend the Mikvah,

which is the Jewish ritual bath ceremony, perhaps due to either temporary or permanent menopause as a result of surgery or treatment, not being able to do that.

I think that there is certainly a change and for some a loss of sexuality and a loss of a sense of self of who are you and your self-image. We get many phone calls from women who talk about the loss of financial stability. Certainly, we hear people talking about the loss of how they dreamt their life would unfold and, again, there's that innocence that is taken away. For those of you who are finished with treatment, there is a sense of a loss of a safety net of not being seen by a doctor as regularly as when you were seen when you are undergoing surgery and treatment. Those are the losses, but I also think that there could be a lot of things that were found.

Many, many, many women and in fact probably most of the women that we speak with here at Sharsheret, we see that there's an incredible resiliency and inner strength that many of you didn't know that you even had because why would you need that. I think that there's a quote out there that says "You never know how strong you are until having strength is your only choice." I think that for many women they have clarity in their relationships. They may be taking a second look at the people in their life. They may be taking a second look at the priorities in their life. I think that women have found a great sense of humor when dealing with this.

Certainly, many women have become incredibly resourceful and not just in the area of breast cancer or ovarian cancer, but I think that sense of needing to be resourceful can apply and be adapted to many different situations in your life. I think for the children, I believe that it really gives an opportunity for children to learn the tools of coping in life. I myself was a young teenager when my mom was diagnosed with metastatic breast cancer and the message was we are going to face this as a family and that this isn't going to break us. I think that as a result of that attitude, my brothers and I are really able to face adversity and challenges in our life with tremendous inner resources and tools.

What's next? Survivorship is uncharted waters for each of you and this in itself can raise anxiety. Whether you are finished with treatment or you are still undergoing treatment, the fight has been challenging and in many cases difficult. It's important to remember to live the life that you have fought so hard to live. One of the things that I think could be helpful for those of you who are transitioning into survivorship is to maybe come up with a mission statement for yourself based on what is important to you and then come up with objectives to meet that mission statement. I think you can break it down. What do you want to achieve on a daily basis? What would you like to achieve on a weekly basis, a monthly basis, a yearly basis? I think by setting up a mission statement with these objectives that really is a more manageable way of facing your future. Clearly, the mission statement can be adjusted as can the objective.

I often describe survivorship as a volume control knob on a stereo where sometimes the volume of anxiety goes up really high. When you have to maybe go for follow-up appointments whether it's screening or doctor's appointment or you are waiting for results of these tests, the volume goes up really loud, but I would say for the most part that I find that women are able to live comfortably with the volume as background noise where there's always a reminder that you had a cancer diagnosis or at high risk for a cancer diagnosis. There are other things that come to the forefront, taking care of your family, taking care of work responsibility. I find that most people are able to live with it as background noise and I often joke with women that I have spoken to that I have never spoken with a woman who has actually figured out how to turn the volume control knob off completely. If she is the one who figures it out, we are going on Oprah and making our millions.

I think similar to what Dr. Hurley was saying, it is important to embrace your emotions and to embrace the triggers. Triggers really come in a range of intensity. For some women, they describe it even as a mild post-traumatic stress disorder. Some people say that they feel a more severe post-traumatic stress disorder. Some women don't see it as that and maybe just simply see it as a trigger. What I would often recommend is imagine that somebody is standing by your side and you put your arm around them and you bring them closer. I think that's what you should do with the triggers, to sort of put your arm around it and say, "All right. I knew you were coming. I was expecting you. You can stay and hang out, but we have things to do." I think that the more that you embrace these triggers, the less energy that it takes to fight these triggers off, similar to what Dr. Hurley was mentioning earlier.

Also, not everything is about cancer and it is important to find cancer free zones. What could that look like as an example? Sometimes when you read the newspaper where you see on social media story about cancer. If you know that historically that this has been a trigger for you, don't read it. That should be a cancer free zone. If people start talking to you about your cancer experience and you don't want to talk about it, then you need to say, "Listen, I'm not interested in talking about that. I'm out. I'm shopping or I'm at some sort of wedding or a party and this is a cancer free zone for me. I would really rather not talk about that." I really want to empower you to be able to take care of yourself in that way and to have cancer free zones.

It's also important to explore your options. Earlier, I talked about fertility and adoption. If that's something that is on your radar screen for your future, you may need to add those experts in that field onto your treatment team. You may be adding a fertility specialist if you don't already have it. You may be adding a social worker or a psychiatrist. You may be deciding like, "You know what, now that I'm dealing with this, it's feeling too much. I may need to go into therapy. Maybe medication will be helpful." Again, it's not all or nothing and it's not necessarily permanent, but again, to explore the possibility. You can maybe get involved in advocacy. Maybe this is the time now that you're taking a second look

at your life to explore new hobbies or interest and certainly another thing that you can do is for the support that you've received you can pay it forward to people in your community. Certainly, we love having the women who were once callers become peer supporters for other women calling into Sharsheret.

It's important to find your voice. This is not a time to test relationships. Certainly, people cannot be mind readers, whether it's family members or friends. It's important to be clear about what your needs are. What I have found actually having spoken with many friends and family members, is that it's a relief to them to know clearly what the needs are and to understand what you are going through even in survivorship so that they can better adjust how they're going to interact with you because no two people respond the same way. We can't fault people for not knowing the right thing to say and that it's important to openly communicate so that ultimately you can get your needs met.

I also think that it's important to figure out what your takeaways were from this experience. What's your learning curve? Apply what you've learned through this experience and try, as I said earlier, to maybe adapt it to other circumstances and other situations. I think it would be a shame to go through this and not come out having learned something about yourself and maybe doing things differently in your life. I wanted to put this slide up here because we have a kit that is personalized for those of you who are survivors, again, including those living with advanced cancer. You can tailor this kit to meet your unique needs and to address the unique issues that you are facing. I want to encourage all of you to come to the Sharsheret website and you can order this for free. You can do that on the website.

Also, I mentioned earlier that you, yourself, can pay it forward and become a peer supporter, and we also have peer supporters who do address survivorship issues. If you find yourself struggling with a particular issue, give us a call and we will find you a peer supporter and it's not uncommon for peer supporters to have their own peer support. Certainly, be in touch with us in the office and we can make that match for you. I am now going to hand over the teleconference to Abbie. She is a Sharsheret cancer survivor and she is going to share her personal story about navigating the emotional impact of cancer. Abbie?

#### **IV. Personal Story**

Abbie: Hi. Thanks, Shera. In order to explain the process I went through in dealing with the emotional aspect of a cancer diagnosis and treatment, I think it's important to understand where I was coming from. For me, everything I knew about cancer came from the movies. I've seen Terms of Endearment and Steel Magnolias and Stepmom, but my cancer was unscripted. It was literally that roller coaster that you were talking about, totally blindsiding me every step of the way. Even my diagnosis was backwards. I've found out that I had cancer after mastectomy, not before. Even with the surprises that jumped out at every doctor visit and during

every phone call, I still felt on top of the situation. I had Google. I have Sharsheret. I have family. It was pretty much fine.

It was actually over a month after my surgery while I was going through reconstruction that I found myself really floundering. I had a good prognosis and eventually, with medication, I would recover. I was, like I said before, fine, but for some reason, after I no longer needed pain medication, after I was driving and making meals and returning back to real life, a cloud moves in, settling over my head permanently. I couldn't understand what was wrong with me. I was up all night, staring at the ceiling, writing on my blog, wondering where the insomnia was coming from. At one point, I drove at around 3 in the morning, stopping in the parking lot, simply to sit there and sob. Intellectually, I knew what was happening made no sense. There was no reason to be upset. After all, there were so many worse cases than mine, so many women with worse prognoses. I shouldn't really complain. The more I knew that, the worse I became, adding guilt to that mix.

Still, I thought it was just me, that I was crazy. I spoke to a friend who comforted me by telling me that I had a right to be crazy, not that that helps at all, if anything it made it worse because now my insanity has this magical seal of approval. I still didn't put a name to what was happening. I couldn't fault depression because, in my mind, that didn't make sense. How can I possibly be depressed? I was alive. I have no right to be depressed. My friend's advice notwithstanding. I kept up a really good front, but I knew I was falling apart. In fact, when Robin Williams committed suicide that summer, I told my husband that I could understand that, not that I was suicidal, but I understood the desperation. It was what I was feeling on a constant basis. I battled this all summer. When it came time for my second surgery, I went to a doctor for a pre-op visit and broke down in her office. I told her I was crying all the time, that I wasn't sleeping, that I couldn't shake whatever it was and she gave me some antidepressants.

I took the prescription, but then I stopped mainly because I felt I was not that person. I didn't want to be that person and again, logically, it made no sense. Later that week, I was at a wedding and a friend from my community came to my table. She was a breast cancer survivor. I must have looked terrible. I know I felt pretty awful. I was sitting at the table by myself, not talking to anyone. She spoke to me, told me about her treatment, about the meds she takes, and she said every day she takes what she calls a little happy pill and I was shocked. I spoke to my Link, the person Sharsheret connected me with when I mentioned that I was given a prescription for antidepressants, she laughed and said that she was on the British version of the same thing.

Slowly, I discovered that depression and breast cancer, probably any cancer for that matter, go hand in hand. Like so many other stages in my diagnosis and treatment, this was again one I did not anticipate. The one that completely blindsided me. Perhaps it was because no one ever talks about that part. No one wants to see the residual pain that tends to creep up long after everyone else

has packed cancer into that neat little box that Shera had described and stamped it with the done stamp. I modified my Google search and found story after story of depression after cancer, depression from Tamoxifen, depression from PTSD, from a mastectomy. It was the silent side effect no one talked about or wanted to deal with. For me, it was the final betrayal. I've been betrayed by my body and now here was this condition that I could not intellectualize. There was no logic. It was clinical in nature and required treatment that for me involved antidepressants and medication.

My mother wouldn't hear of it. She would just call me to cheer up. It really took speaking to other woman to understand that this was a common step. A step that was for the most part curable. It's interesting that breast cancer for me felt celebrated everywhere. October was a nightmare with pink banners and smiling cheerleaders on every corner and everyone and their brothers wore ribbons in solidarity. There was so much about surgery and scars and being strong and there is silence in regards to this. I found it alone, embarrassed to tell people to reach out, guilty that I was feeling this way. It was a part of cancer that I didn't see in the movies and didn't read in the books. That's tragic because there is hope. There are things that can be done.

I'm no longer on antidepressants. I took them religiously for almost a year and then tried my luck without them and so far, it's been good. I've spoken to other women and I tell them what Shera said just before. You spent so much time dealing with the physical pain or surgery and treatment that your emotions do kind of sit on the sideline. Once you start feeling stronger, it's like they show up and say, "Hi, I'm here. I'm taking over," and everything feels like a ton of bricks out of the blue. It's normal, but it can get that way and that's when knowing it's normal is not enough. I'm glad I found the support, but I wish I'd known how many women needed that extra help beyond yoga or exercise or diet. I wish I'd known that it wasn't a stigma, it wasn't a bad shame, you can handle this kind of thing. It simply is what it is. Knowing that and doing something about it makes all the difference. For me, I'm glad that I knew that.

Shera: Abbie, thank you very much. I want to mention here that Abbie had shared this with me and her story was really the impetus for us wanting to address this issue in a teleconference. Thank you for sharing your story.

## **V. Question & Answer**

We are now going to just take a few questions and you can do so by dialing star 1 and questions will be addressed in the order that they are received. I do want to mention that we will be offering an Ask the Expert session in the upcoming weeks following this webinar and that all of you are invited to submit any additional questions that we may not get to tonight via email. I and Dr. Hurley will respond to these questions in an Ask the Expert blog post which will be posted on our website. I ask that you keep your questions broad in nature so that everyone can benefit from the discussion. We do have one question, Dr. Hurley,

that came in which is, "My sister was recently diagnosed with breast cancer. How can I best support her in terms of the emotional impact?"

Dr. Hurley: It's a great question. My suggestion would be to follow her lead because as the emotions are shifting from day to day and the task, the challenges are shifting from day to day. I'm a survivor myself and I found that the friends who were able to track my mood so when I needed someone to listen and be serious when I had tears; that was helpful. Then, maybe a few minutes later I felt better and then crack a joke and then they are able to shift with me and start laughing. They didn't think that either of those days were normal. It's a little bit like being a good follower in a couple's dance is to just go to slow down, which needs to slow down, distract when she is asking for distraction and to give compassionate presence. It doesn't have that pitying look like, "Oh, are you okay?" Rather, "Hey, I'm here. How can I be with you now where you are?"

Shera: I just actually want to add to what Dr. Hurley said and that is that a lot of times people try to always find the right thing to say. One of the things that I've learned from women is don't work so hard. You don't have to work so hard to say the right thing. I think sometimes it's just enough to say, "Whatever it is, I'm with you." Another question that came in is, what are our recommendations for explaining the emotional side effects to family and friends? I'm wondering, Abbie, if you want to take that.

Abbie: I think when you had said that whole idea how everybody really wants everything to be done. Everybody kind of looks at you and says, "Okay, you're fine." Understanding what happens after, like with me when I had to explain it to my husband, when he couldn't really understand why I was so depressed or why I was struggling with this. I really use the example that you had given that I was dealing with all the physical aspects of it and tripping along and putting up the front for my family, for my kids, for everybody, but the emotional aspect was hitting me constantly on a daily basis. When I put it in that perspective for him, he kind of understood that. He kind of got that logical explanation for it. Even like I said, there was no real logic that way. I couldn't intellectualize in a way, but understanding that the emotional part was coming later, that it was coming now was easier for him to understand. I think that helps even with my close friends. When I explain that, they were able to understand that.

Shera: Great. Thank you. Dr. Hurley, we got a question from a 39-year-old who was diagnosed and she has a young daughter. She wants maybe a suggestion on how to approach the issue of health without sending her on an emotional roller coaster.

Dr. Hurley: First of all, I thought of your comments about being worried about the children losing their innocence as they are witnessing you going through treatment. I thought that was spot on. Sometimes women will feel like they're doing something to their children by having cancer, essentially blaming themselves. I think that one thing that may be helpful is to trust in children's resilience. They

are looking to you to learn life's lessons like, what is it like when you have something that's hard to do? What is it like when you have feelings? We don't have to protect the children from those, but rather support them and being able to understand it in a way that's more easily digested for them. There are lots of good resources out there for how to talk to children about cancer and you might be able to point these out to people, but I think trusting is where having learning what our strengths are to trust the children or having that parallel experience at their developmental level.

Shera: Again, what I would also add to that is that you are going to set the tone that often children are going to look to you to see how to deal with this. They may be taking some social cues in terms of how to manage this. I think that you can certainly decide for yourself what's the message that you want to give to your children. Certainly, we are talking about health that a message can be, "Look, I'm taking care of my health. I'm being responsible and that's not something we should be afraid of. It's actually a good thing. I've gotten people who are on my treatment team who know me and who are going to take care of me."

Again, I think that it can just be reframed for children. Dr. Hurley, we have one last question and I'm going to just broaden it a little bit because it talks a little bit about losing hair. I think just in terms of change in body image whether it's hair or scars from surgery that it may be raising anxiety because it's a constant reminder of the cancer experience. Perhaps we can end on this question if you wouldn't mind addressing that.

Dr. Hurley: Sure. I think that one thing that's important to remember is that there's what your body looks like now and then what you think that means. Like sometimes you'll hear people talking about the hair loss of chemo and saying, "Oh, you're losing a sign of femininity." Where in truth we inhabit women's bodies and so therefore we get to define what our femininity, what our womanhood is to the extent that you can give compassion and attention and embrace your body in the moment and what's happening to it. You can grieve the loss of your hair, but then rub your bald head.

What does it feel like to have this head, this skin and whatever else it is. After I had my mastectomy and had the implant, I called my implant the new girl. Thinking about the image of there's a new girl coming into a classroom, you want to make her feel welcome. I was trying to make the implant feel welcome as this is my body as it is now. That was a spontaneous image for me. Allowing a spontaneous image that lets you embrace and comfort your body as it is now I think is tremendously important.

## VI. Conclusion

Shera: I agree. Thank you, Dr. Hurley. I just want to remind all of you that there will be more opportunities for questions via the Ask the Expert and questions can be sent to Shira Kravitz at [skravitz@sharsheret.org](mailto:skravitz@sharsheret.org) and more information will follow. Your feedback is very important to us. Much of what we do here at Sharsheret and on teleconferences really comes from you, so please complete the online evaluation that will be sent to you. There will be a transcript and audio available and you'll be able to access the transcript and audio of the webinar at [www.sharsheret.org/resources/transcripts](http://www.sharsheret.org/resources/transcripts). If you are having problems finding it, certainly call the office and we can send you a link to this transcript and the audio.

I want to again thank the Julius and Emmy Hamburger Memorial Fund for generously supporting tonight's program and to thank both Dr. Hurley and Abbie for your insight and clarity on these issues. Stay connected with us.

Dr. Hurley: Thank you so much for having me.

Shera: Sure. My pleasure, our pleasure. Stay connected. You can call us at 866-474-2774. You can reach out to us on [info@sharsheret.org](mailto:info@sharsheret.org) or go to our website [www.sharsheret.org](http://www.sharsheret.org). I want to say that if you haven't already had an opportunity to see our videos either on our website or on YouTube, these videos are words of inspiration from other women who have faced either a cancer diagnosis or are at risk for hereditary cancer. I think that a lot of their words will resonate with you and also give you a hopeful message. Thank you for joining us and we want to wish all of you a good night.

## VII. Speakers' Biographies

**Shera Dubitsky, MEd, MA, Director of Navigation and Support Services**, is a graduate of Columbia University and a doctoral candidate of Adelphi University Institute of Advanced Psychological Studies. Shera supports and connects newly diagnosed young women and those at high risk of developing breast cancer or ovarian cancer with suitable peer supporters, advances and develops programs addressing the unique needs of the young women and families of Sharsheret, counsels individual members of the Embrace program, and facilitates its monthly support group teleconferences.

**Karen E. Hurley, Ph.D.** is a licensed clinical psychologist specializing in hereditary cancer risk. She received her A.B. in psychology from Bryn Mawr College in 1983, and her Ph.D. in clinical psychology from Temple University in 1998. She spent eight years on faculty at Memorial Sloan-Kettering Cancer Center conducting NCI-funded research on patient decision-making about prophylactic surgery and other psychosocial issues relevant to familial cancer. She is now in private practice in New York City, with adjunct faculty appointments at Memorial Sloan-Kettering, Teacher's College-Columbia University and City College of New York. She has provided psychotherapy and consultation to over 400 individuals, couples, and families with BRCA1/2 mutations, Lynch syndrome, and other forms of hereditary cancer. In addition, Dr. Hurley has conducted numerous professional education seminars and patient workshops for hospitals, professional organizations and for people in the community affected by cancer and cancer risk. She is a member of several national advisory boards, including Sharsheret's own Medical Advisory Board, as well as FORCE, Bright Pink, and the Cancer Support Community's Breast Cancer Registry. In 2014 she received a Spirit of Empowerment-Individual Commitment award at the 8<sup>th</sup> Annual FORCE conference, in recognition of her work on behalf of the hereditary cancer community.

## VIII. About Sharsheret

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

Since Sharsheret’s founding in 2001, we have responded to more than 50,000 breast cancer inquiries, involved more than 5,300 peer supporters, and presented over 250 educational programs nationwide annually. Sharsheret supports young Jewish women and families facing breast cancer at every stage--before, during, and after diagnosis. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life. All Sharsheret’s programs are open to all women and men.

Sharsheret offers the following national programs:

### The Link Program

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

### Education and Outreach Programs

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

## **IX. Disclaimer**

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

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