

“It’s Complicated: Understanding and Managing Your Relationships Through Breast Cancer Survivorship”

National Teleconference Transcript
May 7, 2013

Presented by:



Supported by:
The Federal Centers for Disease Control and Prevention

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I. Introduction

Jennifer: Thank you all for joining us this evening as we present the teleconference, “It’s Complicated: Understanding and Managing Relationships As a Breast Cancer Survivor.” I am Jennifer Thompson, the survivorship program supervisor for Sharsheret. Sharsheret is a Hebrew word for “chain,” and we are a national organization that supports young Jewish women facing breast cancer.

I will soon have the pleasure of introducing our distinguished speakers, who will share their insights into what is a critical subject for breast cancer survivors: understanding and managing critical relationships as a young woman and cancer survivor. First, I want to take the opportunity to welcome all of you from different time zones. Tonight, we have participants from more than 25 states, and many more are certain to join us as the transcript of the teleconference remains online after tonight’s presentation.

I’d like to thank the Federal Centers for Disease Control and Prevention for the grant that enabled Sharsheret to develop *Thriving Again*, a program to support Jewish breast cancer survivors. In developing this program, we spoke with more than 1,700 of you in person and through surveys about your needs as breast cancer survivors. Resoundingly, everyone shared that relationships with your partners, friends, family, and children were at the forefront of your minds.

In developing Sharsheret’s new survivorship program, we learned that you have concerns about how your physical changes impact your intimate relationships. You wanted to hear about how you could better communicate your changing needs and fears with your partners. You also expressed concerns about your relationships with children and family members, and wanted information on how to discuss genetics with your family.

Tonight, our speakers will address those questions and more. And with that, I’d like to introduce our first speaker, Dr. Marisa Weiss. Dr. Weiss is the president and guiding force behind Breastcancer.org, an online resource for medical and personal information on breast health and breast cancer. A breast cancer oncologist with more than 20 years of active practice in the Philadelphia region, Dr. Weiss is regarded as a visionary advocate. Dr. Weiss currently practices at the Lankenau Medical Center in the Philadelphia area, where she serves as the Director of Breast Radiation Oncology, and Director of Breast Health Outreach. She also served on the National Cancer Institute Director’s Consumer Liaison Group from 2000 to 2007.

Tonight, Dr. Weiss will address your concerns about how physical and emotional changes can impact your intimate relationships, and how you can communicate your changing needs, fears, and concerns with intimate partners. Welcome, Dr. Weiss.

II. Effect of Breast Cancer on Intimacy

Dr. Weiss: Thank you so much for having me. There's no question, a diagnosis of breast cancer is an assault on your physical and your emotional life, and your sense of self. It affects your identity and your self-image. You feel uncertain about the future. It shakes up relationships, it can disrupt how you feel each day, and how you look each day with hair loss, sometimes weight gain, scars, loss of erogenous zones, pain, nausea, fatigue, anxiety, depression, and a whole host of other changes. This happens right at the time of life when you expect to be enjoying the most exciting time of life, when you're dreaming about your future. The last thing you think about is to be confronted by this diagnosis and have your whole life disrupted.

When you think about the whole focus of oncology and your care, it's on the physical fight against the cancer; surgery, radiation, chemotherapy, hormonal therapy, anesthesia, a million doctors' visits, time of uncertainty. But, if you stop for a moment and think about who's really focusing on lingering side effects, as well as your emotional well-being, it does sound like it's a big missed opportunity.

I myself went through breast cancer three years ago. I don't know if I was a young woman, but I was 52 at the time, and I had a young life, to put it that way. I had 3 kids and a husband and multiple jobs. I know firsthand what it feels like. All of the changes that come along with the diagnosis certainly have a profound effect on your intimate life. There's the abrupt onset of menopause, as well as menopausal symptoms that come on with medications. There's menstrual irregularity, and you don't know if you're pre-menopausal or post-menopausal. If you're a religious woman, and you're trying to avoid being sexually active at different times of the month, it's hard to predict those times. If you have hot flashes, loss of energy, and anxiety, you're not going to have a libido. There are a lot of libido changes; loss of libido, vaginal dryness. Weight gain-that's an issue as well.

In addition to that, you can see how these changes can affect your life. We'll talk about solutions for a lot of these concerns, particularly hot flashes that can disrupt your sleep and your ability to even want to be touched, or have anyone be close to you. If you're having hot flashes, the last thing you want is anyone near you.

If you have vaginal dryness because of all the hormonal changes and the abrupt onset of menopause, then you'll need solutions for vaginal wetness, and also how to get the vagina back into shape where it can tolerate, and hopefully enjoy, intimate relations again. That's something we'll focus on in the Q&A: solutions for vaginal dryness including lubricants as well as techniques to get the vagina to do the job it's supposed to do. With arousal and stimulation, the vagina is supposed to get wet, get thick, get long and widen, so it can tolerate and accommodate sexual activity. Sexual activity involves a lot of thrusting and a lot of pressure, and the vagina has to be sort of rough and tough in order to accommodate that. Vaginal dryness solutions are a real thing.

In intimate relationships-if you have a relationship or if you want a relationship, you need to understand that your experience is not your partner's experience. If you think you're "damaged goods," you can't assume that that's how your partner sees you. I know that our next speaker will be talking about some of the emotional issues that happen in terms of sexuality.

There are a lot of women who are in relationships where their relationship got stronger. There are a number of relationships that can stumble when you have to find a new way to communicate. This may be the first hurdle or big obstacle that you've faced together. So much is shaken up at the same time. It is also true that some relationships don't make it. They probably wouldn't have made it if there was some other challenge, and the opportunity comes for finding somebody who you do want to spend time with, share your life with, and intimacy with.

According to many studies, there are just as many women who leave their partners as partners who leave them. This is because women feel like, "My life is short. I've had mixed feelings about you, and you haven't risen up to the occasion. You may have fallen down. I gave you some chances, and you were a jerk, you're still a jerk, you're out of my life." It's good to think about who you are, what you want, and what's next, and what new directions you want to take to recharge your sex life.

A lot of women start with romance as one of the first steps in foreplay, and often it's necessary to be resourceful; to find new solutions, a new lineup of sexual activities. It may not just be intercourse up front. It may be foreplay; it could be foreplay, oral sex and intercourse, or you could change up your routine and make things more exciting, but also be gentle and careful so that you take it one step at a time.

A patient of mine was recently widowed and had breast cancer 10 years ago. She wanted to get out and meet somebody else. We talked about it, and she went to her gynecologist for an inspection. She went back and

said, "What does it look like out in the marketplace?" The doctor said, "You have to be careful of STDs, and your vagina is looking good. You may want a lubricant." If you're an older woman, or even in your 50s, some of the men have erectile issues, which can impact on how possible sex is in the usual way; work-arounds have to be addressed. Of course, there's a whole host of vaginal toys that can be used on the outside, as well as the inside of the vagina. A lot of times, it's the outside, the vulva, or it's the tender tissues, like the front door of the house, that are tender, and dry, and fragile. You may experience pain even before penetration. There are toys that can help stimulate the outside, provide some lubrication, and basically facilitate entry later on.

For a lot of women who have lost erogenous zones, they may need to discover new territories; new areas that feel good. Stay away from areas that feel bad or weird. For example, if you've had mastectomies, then you may have numbness in that area. It may feel strange to you, and unpleasant. You have to really communicate that, and redirect the exploration some place else. It's also true that it's a lot of pressure to do all this with someone maybe you're not as comfortable with, or confident in. Sometimes you have to play around and find your own erogenous zones, and do your own homework. When you do have intimacy with somebody else, you're ready. It is really about rediscovering how you want to relate to people in an intimate way. Like someone said, the word "intimacy" is like "in to me, you will see," which I thought was very meaningful. Because when you bare all, when you can't hide things- although dark lights do help, and a nice nightgown, and some cool underwear, and fancy bras and underpants and nice candles. There's a lot you can do to get in the mood and set the stage.

There's no question that getting intimate with somebody again, having them see you, having them feel you, having them touch you, and you're touching somebody else and being intimate, is a big step. It is a big step towards your recovery, and that's exciting. To think that a large part of the treatment is behind you, and that you are ready, you want to, you're committed, you want to know what you can do to bring that important part of life back into your present life, and figure out solutions, and maybe even new, exciting ways to express yourself, to find your voice, to ask what you want, and to know who you are.

I think I'm going to stop there, and I'm happy to answer any questions you may have later on. You can ask me anything. For those patients who are on the phone, they know there's no filter you have to worry about. Thank you for your attention, and I look forward to listening to our next speaker.

Jennifer: Thank you, Dr. Weiss. We will all have an opportunity to ask Dr. Weiss questions during the question and answer period at the end of the teleconference. First allow me to introduce the next speaker, Dr. Katherine Puckett. Dr. Puckett is a Licensed Clinical Social Worker, and is the National Director of Mind-Body Medicine at Cancer Treatment Centers of America, Midwestern Regional Medical Center. She earned a Ph.D., from the University of Chicago, and a master's degree in social work from Loyola University. Her Mind-Body Medicine Program is designed to help empower patients and caregivers, to enable them to maintain or regain a sense of control, a sense of help, and a sense of effectiveness in the midst of living with cancer. Tonight, Dr. Puckett will provide an overview of how breast cancer can impact relationships with children, family, and community members, and offer strategies of how to communicate information on genetics with their family. Welcome, Dr. Puckett, and thank you for being with us.

III. **Impact of Breast Cancer on Relationships**

Dr. Puckett: Thank you so much. It's a pleasure and a privilege to be part of this teleconference. I think it's so important that this teleconference is about understanding and managing relationships. My bias is that it's all about relationships. We're all in relationships, and I think they are really the core of our strength and support, and potentially, can cause a lot of pain and hardship.

My experience is that a lot of people who are diagnosed with cancer are told, "You have to be positive to go through the journey." I've seen people coming here who come in, and they're smiling, and they say, "Everything's fine," and they're happy. They're trying to be because they've been told not to cry and not to think bad thoughts. I understand; there is some research showing that optimism and hope can confer some positive health benefits. But I really believe so strongly that we need to be real. I don't think it's real to always feel positive and upbeat. Anybody, even not fighting cancer, is going to have days where they just don't feel as good, or feel as happy, or feel as upbeat.

I really encourage people, whether it's a parent/child relationship, with friends, or the community at large, to try to be as real with each other as possible. So often, people try to protect each other by not being real, by not sharing what's really on their minds, because they're afraid they're going to worry, upset, or scare the other person. Maybe they themselves are afraid of looking vulnerable if they show their fears or worries.

I think it really helps to find a way to negotiate with each other. You might need some help; you might need a facilitator to learn how to do that if you haven't already been able to do that in a relationship. I think it really helps

people to put the issues on the table and be as real about them as possible.

With parents and kids, it depends on the age of the child and their stage of development how much a parent is going to communicate with them. I've seen so many parents who, out of love and caring, wish not to upset and scare their children, and therefore don't tell them what's going on. Whether it's the initial diagnosis, the kind of treatment, or things that come up down the road, a lot of parents think that they're protecting their kids by not talking to them about what's going on. Again, of course, you have to pay attention to your child's age. You don't want to be giving a lot of scientific information to a four-year-old. But if you have kids, I think you know that kids usually really understand when something is up. Even if they haven't been told, they know every time their parents blink or breathe, just about. They watch us, and they know so much more about us than we think they do. Even if we haven't told them what's going on, they're likely to have a pretty good idea. And if they don't know-- you know how it is when you don't understand something, but your mind fills in the gaps? They may be thinking of something that's much worse than it actually is.

I'm a believer in sitting down and talking with people. There's a really nice series of several articles from the American Cancer Society, specifically for helping parents help their children deal with the parent's cancer. There's an article about diagnosis, another about treatment, another one about recurrence, even one about dealing with terminal illness. Each one of those has a section on how to help kids at different ages and stages. It's a really good set of articles in public domain on the Web, on the American Cancer Society site. If there are parents having trouble communicating with kids about the cancer, that may be a really good resource.

Let me say one more thing about parents and kids. Going through treatment, and depending on what condition you're in, you may really have some restrictions on activity, and you may feel like such a loss for the parents and the kids not to be able to do the same things we always did. Maybe they wanted to go fishing or running together, or biking. It is fine to mourn those losses together, but I think it's really also helpful to find new ways of being together. The most important thing is to spend time together. Find a way to be together, to still have some fun and some pleasure together, even if it's different from how you used to do that before.

A parent who's not feeling well may be resting in bed a lot of the time. Maybe the kids can come in and snuggle together, or do an art project together in the bed, or read a book together, sing some songs, just sit and

visit. If they're in school, hear about their day at school. You don't have to be up and about to still enjoy time together. I really encourage people to think about ways to connect.

The same goes for friends. Of course, it's going to depend on the nature of your relationship, the closeness you've had already. I've known some cancer patients who are so private that they just didn't want anybody outside the family to know their business. That's their choice. You don't have to tell anybody who you don't want to know. I think it's helpful for the person with cancer to really think clearly about the strategy for communicating with people. Who am I going to talk to? What do I want to tell them? How do I want to communicate that? Sometimes people get really overwhelmed with a lot of people wanting information, calling all the time. It just might be too much.

Sometimes people figure out, whether it is CarePages.com or something similar, or a computer-based program, where a person or a family member of that patient can post information about how they're doing, and then other people can read about it if you've given them a password. They can go on and get an update or hear your news without having to have you field a whole bunch of calls or knocks on the door.

In terms of community, I think that the patient, of course, has the choice about what to communicate with people. Maybe the patient and their family want to really decide a strategy, similar to friends. What are we going to tell whom? What do we want to be known? If you have kids in school, they are probably going to talk about this, and it's going to help the kids to talk about it. But they may feel like they don't have permission to talk about it. Maybe they're embarrassed or ashamed or afraid. Talking those things through, and deciding together, "Here's what would make sense." Here are people you've probably planned to talk with; here are some people maybe you're not as close to, maybe you don't want to talk to." Thinking those things through can really help.

Some people are really open. They want to teach, they want to share, they want to advocate. Sometimes they say more than the patient would want them to say. Talking about these things can really help. One thing that I think is helpful to understand, whether it's with your own kids, or friends, or other people you know in the community, is that the stress and tension of going through any major illness, cancer specifically, and the treatment process, and recovery afterwards, can really be stressful and can add some extra tensions to relationships. Even if the patient and whoever we're talking about had a really good relationship, it may be strained by all of the extra emotional and physical challenges.

Sometimes, when people appear to be having a conflict about what TV show to watch, or something that seems so minor, they may be arguing over something that really is about something deeper. A lot of times, people are really feeling a lot of underlying fears that they are afraid to talk about. Sometimes they don't even recognize they're feeling them. If they do, maybe they are afraid to talk about them. Trying to tune in and pay attention to how you're feeling, and what's really going on, can really help.

In terms of tears, we have an article we like to pass out called "The Healing Chemistry of Tears". A lot of times, people are told, "Don't cry, keep a stiff upper lip." Actually, they've shown that the tears we release from emotions have a different chemical makeup than the tears we release if we're peeling onions. There is a healthy release to crying, and it's not a bad thing.

In terms of communicating information about genetics: think about the person who has the information to share, and the people who are potentially going to be told about that information or not. There's potentially some burden to both sides. A lot of times, the person who has the news about their genetic status can be thought of as a gatekeeper, or I've seen it called a "portal key holder." They may feel a great deal of responsibility to disseminate the results of the genetic tests. It may feel like something they are eager to do. It may feel like a burden that they have to do, but don't want to do. They may just really not want to do this.

Usually the reason that people don't want to share is related to fear of scaring or upsetting somebody else, particularly if they are children. We don't want somebody to live with the fear of getting this illness themselves. I think a lot of how this goes depends on the nature of the relationship that you had with that person or those people before you got this news, and maybe even before the diagnosis. Generally what we see is that if there's a pretty close relationship, it's going to be easier to talk about. If there's a relationship that's already strained, the chances are not so good that it's going to be discussed. There is an option of getting some help. It might be your physician, a genetics counselor, or a psychotherapist. Sometimes people are engaging in what they call a "family covenant," where maybe even if the person who got this genetic news doesn't feel comfortable sharing it with others, their physician will team up with them and tell family members the news. Perhaps the medical professionals may be able to explain the medical end more clearly, or because they're more of a neutral party, it may be easier for them to share what feels really difficult for the person who's recently gotten that genetics news.

Even for a lot of people who have this news and want to share it, they're afraid it's going to be devastating to the people who receive it. Literature shows that generally if you have a lot of anxiety at the beginning upon

hearing this news from somebody, there's usually a significant decrease in that level of anxiety over time. We're seeing that, usually, receiving this news does not lead to serious psychological distress. In the long-term, for most people, that's not going to happen. Even though it may be terrifying at the beginning, keeping the lines of communication open is so important. People are going to have a lot of questions. They're going to need to know where they can get answers to those questions, and there are decisions to be made.

If people have adult children who receive the news that maybe they've got the BRCA gene as well, they may be making decisions as to whether to have prophylactic surgical procedures to protect themselves. That's a huge decision to make. It's going to take some talking, some thought, maybe some crying together, thinking together. It's a big deal.

I don't believe that there's a right and a wrong about this. There's an ethical debate; are the people who have this news obligated to tell? Is it an ethical and moral obligation they have to tell people? There are some people who believe it is. Others believe that people potentially on the receiving end deserve a right not to know this news. I read about one family, actually it was a family who was here at CCA (Cancer Centers of America), where the patient found out that she had the BRCA gene, had two young adult daughters, and one decided she wanted to know this information, and one said if that news were available, she would not want to know. Two sisters: one made a choice one direction, one made a choice the other direction.

I think it's important to ask people, "If there were some news to share about this, would you want to know, or would you not want know?" Let them have say in whether or not they receive that information.

Jennifer: Thank you, Dr. Puckett. We will all have an opportunity to ask questions of Dr. Puckett during the question and answer period later, but now I would like to introduce our next speaker, Rochelle Shoretz. Ms. Shoretz is a two-time breast cancer survivor who founded Sharsheret after her own diagnosis at the age of 28. A graduate of Columbia Law School, Ms. Shoretz served as a law clerk in 1999 to the United States Supreme Court Justice Ruth Bader Ginsburg. She's a member of the Federal Advisory Committee on Breast Cancer in Young Women, and has served as a resource for major media on issues related to breast cancer in young women. Tonight, Ms. Shoretz will discuss some of the specific challenges women may face as single Jewish breast cancer survivors. Welcome, Ms. Shoretz.

IV. Dating after Breast Cancer Diagnosis

Ms. Shoretz: Thank you so much. I wanted to also say thank you to Dr. Puckett and Dr. Weiss for joining us tonight. It's really an honor to be presenting with both of you. I'm actually going to begin with a quick caveat. If I honestly knew everything there was to know about dating successfully as a Jewish breast cancer survivor, I likely would not still be on J-Date, so I'm just putting that out there.

That being said, there's the old saying that those who can't do, teach. Tonight, I'll offer some guidance on navigating the terrain of forming meaningful relationships as a young Jewish breast cancer survivor. In terms of readiness, for those who have completed acts of treatment, dating can be a challenge of physical and emotional readiness. Physically, your hair may still be growing back after chemotherapy, you may have put on a few pounds, and you may still be adjusting to your new body after implants or radiation.

Although well-intentioned friends and family may be telling you how beautiful you look, you actually may be struggling to recognize the person in the mirror. Emotionally, you may not be ready to put yourself out there, having finished a grueling year or so of appointments, procedures, and surgeries. You may be just plain tired. The first step in preparing to date as a survivor is taking stock of your physical and emotional readiness. Though the inclination from those around you may be to hit the ground running and do it, you actually may be better served taking some time to nurture yourself before you run head-on into a new relationship.

Get to know your body and its changes. Rest up. Begin to get excited again about meeting new people. For those who do feel ready to date, the ability to do so after you've assessed your physical and emotional readiness will make you that much stronger.

For many young women, the urge to begin dating quickly is compounded by concerns about fertility. It's that biological clock ticking, and the clock has perhaps also been altered by treatment, ticking even faster now. The significance of marriage and families in certain Jewish communities and families can make dating even more urgent. Many of the women of Sharsheret have had children after cancer. Some have adopted, some have used surrogates. Understanding the many ways we can form families can help take some of the pressure off to begin dating before you're ready.

You've taken some time to heal, to take stock of your physical and emotional readiness, and you've decided you're ready. You begin to wonder, "Why isn't anyone introducing me to their friends? Is it because I've had cancer?" More likely, your friends and family don't know that you've made the decision to begin dating again. You may find it helpful to send a quick e-mail or note letting those close to you know that you're ready to meet new people and welcome their suggestions.

And so now you're introduced by a friend or family member, or you've met someone online, and then you're faced with the big question we all face as survivors: when do I tell a potential partner that I've had cancer? As Jewish women, disclosure may include not only a conversation about the diagnosis, but about genetics. One in 40 Ashkenazi Jews is a carrier of a BRCA I or BRCA II mutation, which can be passed down from both men and women, and which increases the likelihood of developing hereditary breast, ovarian, or related cancers. Jewish BRCA mutation carriers will also need to consider the timing of the disclosure surrounding genetics.

In short, there really is no best time to disclose that you've had breast cancer; there is only the right time for each of us. In six years of dating, I've gone through the spectrum of disclosure. I've tried putting it out there on the first date, only to find that it scared some dates away. I've tried holding off for as long as possible, only to find that a quick Google search revealed more of my story than I had a chance to tell myself, or that a mutual friend spilled the beans before I had a chance to spill them.

Ideally, we should find a way for the people we date to get to know us for the people we are and not the patients we were. I think that last sentence bears repeating. The objective in dating as a survivor is to make sure that we reflect first and foremost to potential partners who we are as people, and not who we were as patients. There's a learning curve in that. Fresh out of treatment, we may be much more inclined to talk about the cancer experience. A few years down the road, perhaps less so, and that's okay. There's no rule that we must share everything on the first, or even second or third date. I don't ask the people I'm dating for their most recent medical records, and I'm not expected to offer up my own.

Though you may think that breast cancer is your dirty little secret, likely anyone you're dating has what they consider a skeleton in their closet, too. Take some time to determine how best to tell your story. Experimenting with timing-how much to share and when-is part of the learning curve of survivorship.

For those young women who are currently in treatment, perhaps for advanced or metastatic breast cancer, finding time to date can be challenging. When I look around the waiting room at the cancer center at

which I am a patient, I often ask myself, “How am I going to meet someone sitting here?” For single women living with chronic illness, the internet can actually be a great way to meet those who are not typically hanging out in the waiting room. Internet dating has truly opened up possibilities for meeting those out of our immediate networks, which can seem to grow smaller the longer we are in active treatment.

The internet is also a rich resource of information and support for young women facing advanced breast cancer. Disclosure can be a unique challenge for young women dating with advanced breast cancer. Many feel generally fine, living active lives for years after the diagnosis. Finding the right time to explain that advanced cancer can be likened to living with a chronic illness requires patience and sensitivity, to your own sense of readiness, and that of the person you’ve met. It’s not easy, and I certainly acknowledge that. While most women on the first date are debating when to talk about their last bad breakup, I’m continually thinking about when to talk about my last bad PET scan. I get it. It’s complicated.

Finally, a note about the unique challenge of dating in the ultra-orthodox or Hasidic communities, in which many dates are arranged by third parties. We at Sharsheret have served thousands of young women, and I want to assure you that young women from these communities do get married, and do grow families. Breast cancer is just one of many challenges faced by families in the community and Sharsheret’s education programs have gone a long way in enhancing education and understanding.

In closing, I want to validate how complicated it can be to toss breast cancer into the already complicated mix of dating. The silver lining for me has always been, “Hey, if I can make it through six months of chemotherapy and five weeks of daily radiation, I can certainly make it through two hours of a miserable date.” The light at the end of the tunnel just may be someone with whom I can someday share what has been an incredible journey. I wish that for all of you. Thank you.

Jennifer: Thank you, Ms. Shoretz. Wow, tonight’s panel was full of information, and I am certain many of you have questions for our speakers. Now I would like to open up to discussion. You can ask questions of all of our speakers, and we will try to get to as many of the questions as possible. I do ask that you keep your questions general and broad, so that all of our participants can benefit from the discussion.

V. Questions and Answers

Jennifer: Dr. Puckett, the first question is for you. You spoke a lot about relationships during treatment, but would you discuss how these relationships change post-treatment, during the survivorship years?

Dr. Puckett: Yes. I think most people just really relish the opportunity to get back to life in as normal a fashion as possible. That is going to look different for everybody. Sometimes, people don't want to have life just as it was before; they want opportunities to have a new normal, and to help create them. Sometimes they have some remaining physical challenges that make it impossible to have life just as it was. If you move forward in the survivorship phase in relationships with people keeping the lines of communication open, negotiating together, planning together, then I think it can be successful, whatever shape it takes.

Jennifer: Thank you. Our next question is for Ms. Shoretz. I'm struggling with the idea of even speaking with my children about my diagnosis. Have you heard from other women who have chosen not to disclose this to their children?

Ms. Shoretz: That's an interesting question from a Sharsheret perspective. At Sharsheret, we really have heard from women who are at either end of the spectrum. We've got those women who are very open with their children, really eager to bring them along in the journey, and explain everything that's going on in the context of the family, as Dr. Puckett described-really just sharing from day one.

There are others who are more reticent. Sometimes it could be that they live in a community in which the discussion of cancer is still not open and shared. Those who are afraid that their children might not be ready to understand all that's going on, and from a developmental standpoint, are really holding back.

The nice thing about Sharsheret is that the resources we have are available to really help women at either end of those spectrums and address the needs of young children. They're on our website, www.sharsheret.org. The Busy Box program that we have for parents who have young children addresses the needs on either end.

I don't think there's a right way or a wrong way. I agree with Dr. Puckett that children do have a sense of what is happening. I think also parents have a great sense of what their children need at any given time. Our effort at the organization is to help parents wherever they are in their journey, and the resources we have can help parents on either end.

Dr. Weiss: As an oncologist in practice for almost 25 years, this is an issue I encounter all the time. I would just say a few things that I think are helpful. One is that your children will take their cue from you. They're going to be watching you and seeing how you are responding to and dealing with things, and whispering and hiding and taking private phone calls and all that. As Dr. Puckett was saying, if it looks like something's wrong, it's going to cause some anxiety and worry, and they're going to blame themselves. That's not a good outcome.

Another thing that's really important to keep in mind is that as parents, we're teaching our children all the time how to deal with life. If you choose to hide things from your kids, of course it depends on the kids' age, then you're teaching your children to hide things from you. I think you have to find the right time and the right place and the right message to share, depending on the ages of your children, and their intellectual and emotional capacity. You may have more than one kid, and you have to make different judgments for each kid. I just want to make it clear that it is an opportunity to teach them something very important about life. Again, if you can share things, you're teaching them to do the same when they're going to go through times of life when you want them to share with you. Just keep that in mind.

Ms. Shoretz: I think also that anybody who is interested in learning more about this particular topic, talking to your children about cancer, talking to your children about survivorship, should definitely check out the teleconferences we have available on our website. We've done whole teleconferences on this subject alone. It's obviously a very complicated and very important subject. There's more resources to be found on the website, and certainly in our Family Focus program.

Jennifer: Fantastic, thank you so much. This next question is going to go to Dr. Weiss. This is a question about dating and disclosure. I'm dating someone, but not yet sexually intimate. How can I communicate to this partner that I've had breast surgery and some of my fears associated with that?

Dr. Weiss: You know, as Rochelle said, it is a very delicate thing for anybody; sharing things about your body, how it works, and an illness that may be impacting them, and how they might be relating to you, how they might touch to you, how they might see you, what you look like, how your body is going to function, particularly when you're intimate together.

I think that the best sex and intimacy happens in the context of a good relationship. Really developing a friendship first and reading cues along the way, finding somebody who has the capacity to understand that no one is perfect, and that you have so many gifts. I think you've heard from

all of us that we don't want to let this define you. There are so many things about you that are so much bigger, more important, more revealing, and more predictive of who you are, who you're going to be, and how you're going to be with them, than the fact that you may be missing one breast, both breasts, part of one breast or have a scar that you may or may not see.

I do think it's really important to, as Rochelle said, prepare for this. Decide what you feel comfortable sharing. Really pick some talking points. Get comfortable saying them, so that when you do come to say it, you project and express a level of comfort, confidence, or resolution about it. They're going to take their cue from you. I would take it one step at a time, but really stick to what you feel comfortable sharing at that particular time.

Ms. Shoretz: I've actually changed the script a few times. It's trial and error. What I used to tell people I dated is very different from what I tell people I date now. I've changed-in the level of comfort I have with my own diagnosis, with the way my body looks after treatment and after surgery. It has been many years since my first diagnosis. I was diagnosed when I was 28 years old. The way I thought about my body as a 30-something-year-old is very different than the way I feel about my body as a 40-something-year-old.

I think it's okay to say it out loud and change it up; figure out what feels right and what you can say with confidence and with comfort. I also think that understanding what you look good in and what you feel good in, in terms of clothes, and what you might end up sleeping in, is very important. It's a whole package. It's what you were talking about before, but it's also the way you feel when you're together with someone. The more you prepare yourself, the more you will be prepared for that conversation that you need to have with someone.

The one thing I would caution against is the element of surprise. No one wants to be surprised by a breast cancer diagnosis. I think it's very difficult to maintain a relationship of trust if you hide pieces of your past from someone. I've heard people say, "Well, if someone truly loves me, they'll love me whether or not I've had cancer." That's 100 percent true, but can you say the same of, "If somebody truly loves me, doesn't it matter if I had some really significant experience, but I didn't share it with them?" As much as cancer doesn't define you, it is a significant part of the journey. I think building an element of trust into the beginning of a relationship is very important as well.

Dr. Weiss: At BreastCancer.org, we have an enormous community where people connect with each other, and discuss sexuality and meeting new people; what to say, and possible scripts. There's a million examples there.

People are very funny, and you can really learn a lot and have a lot of laughs, and arm yourself with some good new ideas.

Jennifer: Thank you both for that insight. All of our resources will be available in the transcript, and we'll make sure that we share those with our listeners this evening. The next question goes to Dr. Puckett. I am done with my treatment, and don't feel up to speaking about my breast cancer diagnosis or journey any longer. How can I communicate this with my loved ones, and yet be sensitive to the fact that they still may need to process this themselves?

Dr. Puckett: That's a good question and a challenging one. I really encourage the loved ones of anybody who has been through cancer treatment to follow the lead of that person. If you're the survivor, I think you have the right to call the shots on this. Not to say that your family or loved ones don't still have a need to process and talk about it, but if you don't want them to do that with you, if you want to just move on, then perhaps you can help them find other resources for processing-support groups, a counselor, friends they have. There are a lot of options out there for people to deal with this.

Hopefully, the survivor and their loved ones could talk about this. Rather than say, "I'm never talking about it again, and that's it," say, "Well, here's why I'm ready to move on, and here's what it feels like when we bring it up again and again. It takes me back there, and I don't want to go back there." Whatever it is to you, hopefully with some frank discussion and dialogue about this, you all can come to a mutual understanding where everybody can get their needs met. You can have your chance to move on, without having to keep thinking about it. They can have a chance to still get their needs met, even if it's with somebody other than you to process it.

Ms. Shoretz: I have a great anecdote that goes along with what Dr. Puckett was just recommending. It wasn't three months after I had finished chemotherapy or radiation, and a friend – not a close friend, but a colleague – met me at the post office. I was standing in line with my son at the time. She saw me waiting in line and came over. She said, "How are you?" and I said, "I'm fine." She said, "No, really, how are you?" It's that sort of "How are you" that you get when people are asking you to give more information. I said, "No, really, I'm fine. In fact, I finished treatment, so you don't really even have to ask me that anymore in that way." I tried to make light of it. She pushed back and said, "Can't I ask you how you are?" I said, "You can, but when you ask me in that way, you remind me that I had cancer, and I know you don't mean to do that."

It was a difficult thing for me to say to her, and in some ways, I think it was a difficult thing for her to hear, but she understood what I meant. From

there on in, she didn't ask me the double, "How are you?" It was just the single, "How are you?" It was an acknowledgement between the two of us that the cancer journey was, for me at that point, done. She didn't need to ask after my cancer well-being; she could just be asking after my healthy person well-being. It was a very interesting learning process for the both of us.

Dr. Puckett: I think that's beautiful, and I really admire your straightforward communication with her, even though it was hard. That's what needed to happen, and it was a victory. Congratulations, that's beautifully done.

Jennifer: Along similar lines, this question is for Ms. Shoretz. You spoke a little bit about disclosure to partners earlier, but what is a good way to handle disclosure to a significant other's family?

Ms. Shoretz: That's interesting. I'm wondering if I ever had the opportunity. I don't think I've made it that far in the relationships I've had; no, I'm just kidding. I think that it depends on the nature of the relationship you have with a partner's family. Sometimes it can be an opportunity to bond, where you're talking about your life, what you've been through and important milestones in your life, which could include health milestones.

Other times, it may not be a comfortable conversation and you'd prefer if your partner shared that information with their family. I think it goes back to what we discussed before, about shaping the information and the conversation. Obviously, if you're the person who has the conversation with the family member, you're the person who's controlling the flow of information. The fewer voices there are in the conversation, the easier it is to make sure that the information is transmitted correctly and accurately.

That being said, I think ultimately it depends on the relationship that you have with your partner's family members. If they're asking genetics-related questions, sometimes that can be a conversation that would be helpful to have alongside a genetic counselor, or a health care practitioner. If it's just sort of a background question like, "Can you tell me about what it was like to have cancer?", sometimes those conversations can be bonding more than anything.

I think that question is a hard one to answer on one leg, because there are so many different circumstances. Obviously, controlling the information you share with others, be it family members, friends, or colleagues gives you that much more of an opportunity to make sure that the information is accurate and told in a way which feels comfortable for you.

Dr. Weiss: One of the things I learned in my own breast cancer experience, and also as a physician, is that you can't control the world. Part of being diagnosed

is losing control of your own health and your body and your life, and all kinds of things. When it comes to the information, we are in the information age. People have access and people talk. With all the social media outlets, things can be shared so fast. It's really hard to protect your privacy. It can consume a lot of energy if you really want and expect to control everything.

Really, it's beyond your grasp. You do have to rise up and be like the mother lion, and protect your privacy as best you can. There are going to be people who are so intrusive, and it's really more about them than you. It's their anxiety, not yours, and it's an imposition and an intrusion upon your situation. You might have to have a little plan on how to manage them. It may be that you've got your agents in place that can communicate to them or let them know that you're not interested in talking to them about it. Or you always have caller ID and just don't talk to them on the phone. Find an asynchronous form of communication, like e-mail, to communicate with them when someone's upsetting or prying, trying to get too close.

I just want to say something else about the breast cancer genetic information and sharing. I had a family history of breast cancer, although there's a whole other arm of the family where there's an unexplained pattern. In one family that I'm a part of, everyone has different philosophies, a different style, and different readiness, just like Dr. Puckett and Rochelle were saying. It's also true that genetic information is a puzzle. It is true that sharing with somebody in an anonymous way is very helpful when it comes to figuring out the puzzle that may be going on in your family. Knowing what your genes are can help you make really important decisions to do some procedures, not to, when to, how much to-everything.

There is a pressure people feel about sharing that information. It has a major impact on other people and denial can be an enormous barrier. It can be a real challenge. You want to respect privacy, but at the same time, you want to fit the pieces of the puzzle together so that the people who choose to know can know what they need to know.

Ms. Shoretz: I think that is a really important point. In fact, one of the most frequently addressed and most critical pieces of information that survivors that we surveyed for the Thriving Again program wanted to understand, was "How do I communicate with my family members, my friends, my colleagues, et cetera, about genetics, particularly in the Jewish community, when the incidence of the BRCA mutation is that much higher?" I want to foreshadow that we will be having a Sharsheret teleconference addressing just that genetics piece, communicating genetics information to family members, at a later date, I think within the next couple of months.

That again, in and of itself, is a whole topic of conversation that we could spend another hour on. We also have a program at Sharsheret called Genetics for Life, and anybody who is interested in having a conversation about talking to family members about family history is more than welcome to participate in that program as well.

Jennifer: Thank you. We have a lot of questions on communication this evening. This one is for Dr. Puckett. The caller would like to discuss how their needs and experiences have changed throughout their survivorship years, but their friends and family are not willing or interested in having the conversation about their breast cancer experience any longer. How can they address their concerns and process this? Where can they go for long-term support as a survivor?

Dr. Puckett: I want to make sure that I understand the question. In this case, the survivor still wants to be able to process with the loved ones, but the loved ones don't want to talk about it anymore?

Jennifer: Correct.

Dr. Puckett: Again, communication is going to have a lot to do with the nature of the relationship. People get exhausted from going through this journey. It's understandable that, especially if talking about it again brings up old memories of what it was like going through treatment, people wouldn't want to talk about it.

I'm not sure if the survivor is looking primarily for another outlet, if she can't talk with the family in the way that she wants, or if she's looking for ways to facilitate conversation with them. In either case, there are support groups available that she could be part of, or just connecting more informally with friends. There are certainly counselors and therapists who can help both the individual survivor process those feelings and help a family come to terms with communicating about them, as well as help with the decision whether or not they are going to communicate about this and how, if they're not on the same page about it.

It would be interesting to understand more about their needs-why the survivor still feels the need to talk about it, why the family really doesn't want to talk about it and what their underlying intentions and goals really are. Ideally, if somebody could help that family facilitate that, it might take a few conversations to really gain some clarity. It could help them all feel closer together, just from understanding each other's perspective.

My guess is, maybe they're not at a level of understanding of the other's perspective that they might be if they got some help figuring it out.

Jennifer: Great. I'm actually going to turn the next question to Dr. Weiss. You spoke earlier about devices and creams, et cetera, to combat physical changes. Where can I find information about the devices and creams?

Dr. Weiss: There are a lot of sources of information about various ways to make the vagina wetter and more resilient or more elastic to accommodate sexual activity. In terms of making it wetter, if the vagina is dry, you can use a lubricant to wet it. There are all different kinds. People have different brands that they like. There's a whole section on BreastCancer.org about them. Specifically, there is a whole section in the book, "Living Well Beyond Breast Cancer." You have to try different things, and you can choose one that's more watery or more viscous, depending on what you need. You end up having to apply it throughout the time that you are sexually engaged.

One product that people like is by Lelo. They also make very modernistic designs of vibrators and dildos and things like that. That is sort of a medium viscosity. You put it on yourself and you put it on the man. You really use a generous amount of it. You make sure that the foreplay is more, that you really attend to it, in a way that maybe you hadn't before. The vagina on its own is capable of doing a lot of tricks. Again, it's supposed to get wet. It's supposed to get longer and wider and fluffier when it's stimulated. If you can sort of work on getting in the mood, setting the stage, making sure that there's enough lubrication, that you're not worried about something, you're feeling good about yourself, all that. You might have a partner who's got rough hands. Make sure that they're soft, that they've used lubricant there. Alcohol is a very bad thing to be drinking before you have a sexual encounter because it makes it harder for you to respond to sexual stimulation. It also makes it much harder and longer for a man to finish. It ends up putting the vagina through a lot more stress and strain than if you are not drinking alcohol.

Replens is a product that is a lubricant, but it also kind of hangs on the wall of the vagina and helps to maintain some wetness beyond most lubricants. Your doctor might talk to you about the possibility of using vaginal-only estrogen cream intermittently, in small amounts, if you feel that enhanced foreplay or lubricants are not effective in preparing the vagina to get ready for sex.

I think it's a really good idea, before you get sexually active again, to go to your gynecologist and ask him or her, "What does my vagina look like? Does it look like it's shorter than before? Does it look fragile? When you examine me, do I have bleeding? How about the outside, the vulva? In those folds, is the tissue really delicate and thin and tender?" The outside is like a bumper for the thrusting that happens when the penis comes into the vagina. The outside has to be ready, too.

It's also important to know that chemotherapy is like a very harsh antibiotic. Just like when you're on antibiotics for a long time, you can get a yeast infection, you can also get infections during and after chemotherapy until your body's pH acid/base balance is back in order. You do have to worry about hygiene of the vulva when you are in the shower gently clean with a very mild soap, a lot of warm water, not hot; sort of open up the skin folds. When the vagina's not as moist, it kind of gets stuck together. It kind of gets glued to itself. Make sure that you take care of business down there.

Jennifer: I'm sorry to interrupt you, we have a couple more questions. I just want to get to a really important one that we have before we run out of time this evening. This one is for Dr. Puckett, and it kind of goes back to the communication that was very important and people were very interested about. We have several questions regarding children. If they choose to share the diagnosis with friends and family, how do they prepare their children for questions they may face from other people-friends, people at school, et cetera?

Dr. Puckett: How the parents can prepare their kids for being questioned by other people?

Jennifer: Yes.

Dr. Puckett: Maybe their teachers or friends at school have heard it from their parents, or something like that?

Jennifer: Yes.

Dr. Puckett: I think it's helpful. The survivor is going to have a pretty good idea of who is going to talk, hopefully; how the word might get around. They know their own community. If they think there's any significant chance that their kids are going to hear about this from somebody else, hopefully they're going to have those conversations at home first and prepare the kids, let them know the basics. Based on their age, you tell them less or more, depending on what they're ready to hear. I think you can practice conversations. You can say, "You know, Rachel, your teacher does know about this," or, "My best friend is your friend Joan's mother, and they did tell her, so she might tell Joan, so Joan might ask a question. Do you want to think together about what that's going to feel like if you hear that, and how you could respond?"

I don't think there's anything wrong with practicing and role-playing. Practice responding to other people asking those questions. They can choose, just like we were saying about the adults. You can choose whether or not to talk about something. The kids can, too. You can help

them try on different options for size. How they decide to respond may depend on their relationship with that other person asking the questions.

I think helping them prepare is really important. You don't want them to be blindsided. They may feel ashamed, afraid, or confused. The more preparation the better, I think.

VI. Conclusion

Jennifer: Thank you, Dr. Puckett. We are actually nearing the conclusion of our teleconference. I would like to thank everyone for participating this evening. We have so much information from Dr. Weiss, Dr. Puckett, and Ms. Shoretz, that it's almost hard to absorb it all. The good news is that we will have the transcript posted online at www.sharsheret.org, and that will be available to you in case you want to look back and read a little bit more about some of the things you may have missed this evening, or share it with a friend or your health care professionals.

We'll also be sending you an e-mail about completing a survey. We would really appreciate it if you took the time to fill it out. Your feedback is very helpful to us in building our programming. I think tonight, more than anything, we all recognized that survivorship is challenging, and it can bring with it just as many questions and concerns as the breast cancer diagnosis itself can. The good news is that there is support. You can receive more information, resources, and your tailored survivorship kit that addresses many of the issues that we spoke about this evening by contacting Sharsheret. You can find us on Facebook and on our website, at Sharsheret.org, or you can contact us toll free at 866.474.2774.

We would love to connect with all of you. Thank you again to all of our speakers, and we are wishing you all continued blessings on this journey, and every journey. Good night.

VI. Speaker's Biographies

Dr. Katherine Puckett is a Licensed Clinical Social Worker and the National Director of Mind-Body Medicine at Cancer Treatment Centers of America at Midwestern Regional Medical Center. She earned a Ph.D. from the University of Chicago and a master's degree in social work from Loyola University. Her mind-body medicine program is designed to help empower patients and caregivers so they are able to maintain or regain a sense of control, a sense of hope and a sense of effectiveness in the midst of living with cancer. Comprised of highly trained, licensed psychotherapists, the Department of Mind-Body Medicine offers a wide range of therapeutic and supportive services including individual and family counseling, educational groups providing training and practice in stress reduction techniques, and support groups. In taking advantage of these offerings, many patients report greater peace of mind and relaxation and improved communication with family members.

Rochelle Shoretz, Esq., Founder and Executive Director, is a two-time breast cancer survivor who founded Sharsheret after her own diagnosis at age 28. Rochelle served as a law clerk in 1999 to U.S. Supreme Court Justice Ruth Bader Ginsburg. A member of the Federal Advisory Committee on Breast Cancer in Young Women, Rochelle speaks to audiences across the country and serves as a resource for major media on issues related to breast cancer in young women and Jewish families.

Jennifer Thompson, MSW, is the Survivorship Program Supervisor at Sharsheret. Jennifer is a graduate of Columbia University School of Social work and has vast experience in cancer advocacy, public policy, analysis, and legislative initiatives. Prior to joining Sharsheret, Jennifer served as a Senior Advisor to Mayor Michael Bloomberg and Director of Advocacy for the American Lung Association. Jennifer spearheads and oversees the development of "Thriving Again", Sharsheret's new culturally-relevant support and education program for young Jewish breast cancer survivors and their families.

Marisa Weiss, M.D. is the founder, president, and guiding force behind Breastcancer.org, the world's most utilized online resource for medical and personal expert information on breast health and breast cancer — reaching 27 million people globally over the past 10 years. A breast cancer oncologist with more than 20 years of active practice in the Philadelphia region, Dr. Weiss is regarded as a visionary advocate for her innovative and steadfast approach to informing and empowering individuals to protect their breast health and overcome the challenges of breast cancer. Dr. Weiss currently practices at Lankenau Medical Center, part of the Main Line Health Hospitals of the Thomas Jefferson University Health System in the Philadelphia area, where she serves as director of breast radiation oncology and director of breast health outreach. She also served on the National Cancer Institute Director's Consumer Liaison Group from 2000 to 2007. Dr. Weiss is the author of four critically acclaimed books on breast cancer and breast health, published by Random House: *Living Beyond Breast Cancer*

and *Living Well Beyond Breast Cancer*, coauthored with her mother, Ellen Weiss (1998, 2010); *Taking Care of Your “Girls:” A Breast Health Guide for Girls, Teens, and In-Betweens*, coauthored with her daughter, Isabel Friedman (2008); and *7 Minutes!: How to Get the Most from Your Doctor Visit* (2007). As a renowned leader in the field of breast cancer, Dr. Weiss is frequently called on by both print and broadcast media and has been a repeat guest on ABC’s *Good Morning America*, NBC’s *TODAY*, CNN’s medical features, and *The Dr. Oz Show*. After attending the University of Pennsylvania for her undergraduate studies, medical school, residency, and laboratory research fellowship, Dr. Weiss became an assistant professor in Penn’s Department of Radiation Oncology. In 1992, she established her clinical practice in the Main Line Health System.

VII. About Sharsheret

Sharsheret, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer at every stage—before, during, and after diagnosis. 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 25,000 cancer inquiries, involved more than 1,750 peer supporters, and presented over 250 educational programs nationwide. 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. 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 and Sharsheret is the beneficiary of funding from the federal government.

Sharsheret offers the following national programs:

- *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
- *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
- *Sharsheret Supports*, developing local support groups and programs
- *Ovarian Cancer Program*, tailored resources and support for young Jewish women and families facing ovarian cancer
- *Thriving Again*, providing individualized support, education, and survivorship navigation for young breast cancer survivors

VIII. Disclaimer

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

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