

# Breast Cancer Survivors and the Long Term Effects of Breast Cancer Treatment

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Presented by:



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## I. Introduction

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

Shera: Thank you Elise. Good evening everyone. My name is Shera Dubitsky and I am the Director of Clinical Support at Sharsheret. I'd like to welcome all of you to tonight's national teleconference, "Breast Cancer Survivors and the Long Term Effects of Breast Cancer Treatment". Identifying as a survivor is unclear to anyone who has faced a cancer diagnosis. When do you classify yourself as a survivor? At time of diagnosis, or post treatment, one year post treatment, two years later, five years later? If you are living with metastatic breast cancer, do you identify as a breast cancer survivor?

In the Jewish community there is another layer of consideration that contributes to the struggle of identifying as a survivor. Historically, in Jewish history, the term survivor has been connected to those who survived the Holocaust. Embracing survivorship language in light of the Holocaust may be too emotionally laden for some women and their families. Another aspect of Jewish life and Jewish culture is the premium on family. This emphasis on family may elevate some psychosocial anxiety. Questions about growing your family and exploring fertility options may feel overwhelming and stressful. Genetics and hereditary risk vis-a-vis the health risk to the next generation is a burden that some of you may carry. In the Jewish life cycle we celebrate milestones with our family and friends. Upon receiving a diagnosis of cancer you may have asked yourself, "Will I make it to the next milestone?" As I look at the number of registrants for tonight's teleconference, I know that we hit on a very critical topic that addresses the concerns of the long term effects of breast cancer treatment that so many breast cancer survivors face.

Our expert speakers will address these concerns and following the formal presentation we will have time for questions and answers. Before I introduce our first speaker, I want to encourage all of you who have not yet received your personalized survivorship kit to get in touch with us by phone at 866-474-2774 or on our website, [www.sharsheret.org](http://www.sharsheret.org), so that we can tailor your kit to meet your individual needs. The kit includes

resources that address tonight's topic in addition to other concerns that many women face as breast cancer survivors.

Our first speaker is Dr. Helen Coons. Dr. Coons is a Board Certified Clinical Health Psychologist who specializes in women's health and mental health and psychosocial oncology. She is the President and Clinical Director of Women's Mental Health Associates and a Clinical Professor of Psychiatry at Drexel University College of Medicine.

Her practice specializes in improving the well-being of women facing the diagnosis and treatment of breast, gynecological, and other cancer diagnoses. She works with women and couples of all ages before, during, and after cancer treatment, women with early and advanced cancer, as well as individuals who are caring for ill family members with cancer. Dr. Coons brings 30 years of professional work with women with cancer, her personal journey with breast cancer, and her motivation style to engage in presentations. Dr. Coons, the floor is yours.

## **II. Fear of Recurrence and Psychosocial Impacts of Treatment**

Dr. Coons: Thank you very much for your generous introduction and for the opportunity to participate this evening and welcome everyone. I've been asked to spend 10 minutes talking with you about two major areas: one is the fear of recurrence or uncertainty, and the other is a broad range of psychosocial impacts related to breast cancer treatments for survivors. First, I'd like to speak for a few minutes in very general terms about the fear of recurrence, as well as coping with uncertainty for young women with metastatic breast cancer. So often women with early breast cancer express fears of recurrence, while young women with metastatic breast cancer face profound uncertainty. What we know from research is that some individuals report very stable levels of fear following the diagnosis of early breast cancer, while others report quite a bit of variability in their fear level, almost like a wave. And we know that those levels of fear are affected by both individual factors and disease factors.

For some young women with early breast cancer in particular, there are triggers that increase fears of recurrence: finishing the acute types of treatments such as surgery, chemotherapy, and radiation, follow-up visits with your oncology team, as well as follow-up tests, experiencing symptoms that you haven't had before, don't seem to go away, or you don't understand, hearing about others with disease progression or even passing away from breast cancer, or other conditions. Young women with metastatic breast cancer often live in an overwhelming state of uncertainty. They may have had a recurrence and have metastatic disease, or were diagnosed with metastatic disease from the onset. Often

times women with metastatic disease are concerned about how long a given drug will last before there's disease progression, and struggle with feelings of hopelessness or cautious optimism that the treatment could work.

Whether you are a young woman with early breast cancer or a young woman with metastatic breast cancer, it's important to consider your coping options when you're struggling with the fear of recurrence or sitting with profound uncertainty. First, if you're worried about a symptom, or any aspect of your well-being, it's crucial that you take action instead of worrying or ruminating which just create more distress and actually compromises your ability to cope effectively, live well, and be present today. It's important, when you're overwhelmed with fears, to mobilize support and share your feelings with your family, with your friends, or your health care team. It's important to talk with your providers about your concerns, to get accurate information, and to have an appropriate assessment of your symptoms. Please call your oncology team versus staying at home worrying alone about a symptom. If you can't stop worrying about your risk for recurrence or the future, if you're overwhelmed by anxiety, your concentration becomes compromised because you're fearful of recurrence, or even if your mood or relationships are affected, it's vital you ask someone on your oncology team for a referral to a behavior health provider with expertise in psychosocial oncology to help you navigate those fears, and learn to be calmer and more present, even in the context of having waves of anxiety. That was just a brief summary of some of the kinds of issues so many young women with early breast cancer and young women with metastatic disease report around fear of recurrence and uncertainty. I'd like to spend the next five minutes talking about some highlights of psychosocial issues that come up as a result of treatment, both during and following treatment for breast cancer.

I want to remind everyone that data overwhelmingly underscores how resilient women are in coping with breast cancer. Being resilient doesn't mean that coping with early and metastatic breast cancer among young women isn't difficult. In fact, it's highly difficult, stressful, and sometimes overwhelming. You can also be highly resilient. So with that as context, many young women who before diagnosis have plans for work, for relationships, travel, children, or any number of issues in your life, and now face uncertainty and complex decisions, which, at the very minimum, is stressful and frequently overwhelming at the initial diagnosis, with each treatment decision, with your experiences with treatment, and any change in your disease status or treatment protocol.

One of the major psychosocial challenges for young women with either earlier or metastatic breast cancer is feeling off trajectory from your peer group. Now, you may need support from family when you've recently moved away, or started a relationship, or just gotten married. You may need to take breaks from graduate school, or delay jobs or change decisions, or watch your peer group go on to make other decisions when you feel like you're overwhelmed by breast cancer treatment. In addition, many survivors are coping with both acute and long term side effects from surgery, chemotherapy, radiation, and hormones which can affect your trust of your body. It can change your body image and sexual health. Interestingly enough, while many young women with breast cancer are likely to report negative changes in body image and sexual health, they're not always negative changes. Some young women use breast cancer diagnosis and treatment as opportunity to take better care of their health. They're proud that they've gone through such a psychically and emotionally demanding experience.

It's important to recognize that single young women with breast cancer report a strong interest in dating, but are also quite concerned about how to navigate relationships during and after breast cancer treatment. Interestingly, disclosure issues are hard enough under the best of circumstances, but now they're even more complex in the age of social media, when you may have already shared your breast cancer experience online, or in any number of forms. Dating issues are even more complicated for single women with advanced disease. These issues are true for young women with breast cancer who are in heterosexual and/or same sex partner relationships. Another major psychosocial area for young woman with either early or metastatic breast cancer involves changes in sexual desire, satisfaction, and comfort which can be especially challenging for young women who have gone through chemotherapy or prophylactic oophorectomy.

In addition, as our moderator noted, fertility concerns, parenting options, and decisions about adoption are especially complex for young women with early and advanced breast cancer. Many young women who may have not started a family or want more children remain overwhelmed by the very complex issues that result from chemotherapy and pelvic surgery. Fortunately, we have an increasing number of fertility options. But certainly many young women with breast cancer are faced with uncertainty, anxiety, and sadness as they navigate some of the fertility options. Another area of psychosocial impact has to do with changes in communication and emotional intimacy with partners, family, friends, and co-workers. In addition, as our moderator mentioned, there may be very complex concerns about genetic risk for yourself, for children, and for other family members, as well as anxiety about the complex decisions

around prophylactic or prevention options. For many young women both with early and metastatic breast cancer, there are noticeable concerns about how women will care for themselves or their children if their health status becomes more compromised. This is especially true for young single women with advanced breast cancer or young partnered women with advanced breast cancer. Interestingly enough, research helps us know that one of the psychosocial impacts of cancer treatment is also something called benefit findings. In the midst of coping with breast cancer at any stage, as well as its treatment, data repeatedly tells us that almost 90% of women with breast cancer report some kind of positive benefit as a result of this experience. Some of you may have noticed that you feel that your self-esteem, in some ways, has improved as you see yourself navigate such a complex experience. Some of you may give yourself more of a voice in your relationship, at home, at work, and in your community. You may have noticed that your communication has improved or that you've decided to pursue an interest that you're passionate about versus just having a job. Some of you may have taken positive risks such as taking a hike, learning to fly, or starting to run.

Many of you may have noticed that you let go of the small stuff and don't focus on some of the nonsense of life, but instead are more focused on who and what is important to you and your heart. These are just to name a few examples. I could go on and on with a very broad and complex range of psychosocial impacts from breast cancer treatment, lessons of diagnosis, and treatment. I think I'll stop there so we have more time for Dr. Partridge's remarks and plenty of time for all of you to engage in a lively conversation. Thank you.

Shera: Dr. Coons, thank you very much. I think that your overview was probably very validating for many of the women who are on the call with us tonight. I do hope that during the question and answer period that you will be able to address some strategies to deal with some of these psychosocial issues. Thank you very much for that. Our next speaker is Dr. Ann Partridge. Dr. Partridge is the Founder and Director of the Program for Young Women with Breast Cancer and is the Director of the Adult Survivorship Program at the Dana-Farber Cancer Institute. She is an Associate Professor of Medicine at Harvard Medical School. Dr. Partridge completed her residency in Internal Medicine at the hospital at the University of Pennsylvania and went on to complete fellowships in medical oncology and hematology, and she received a Masters in Public Health from the Harvard School of Public Health. She is a medical oncologist focused on the care of women with breast cancer, and she has a particular interest in the psychosocial, behavioral, and communication issues related to breast cancer care and treatment. Dr. Partridge.

### III. Chemobrain, Lymphedema, and Bone Health

Dr. Partridge:Hi. It's a pleasure to be here with you in spirit and virtually tonight, and thank you very much to Sharsheret for sponsoring this teleconference. I just want to echo what our last wonderful speaker said regarding the psychosocial effects of a breast cancer diagnosis and treatment for any patient with breast cancer, but young women in particular. How profound and life changing an experience it can be, and for young women, it's kind of the norm, not an exception. Getting help for that, if you feel like you need it, I think it's really kind of a normal thing. I strongly encourage folks that are having kind of a hard time and/or think they might have a hard time to be proactive about that. What I like to say to my patients is, often women are super women, they do a lot, they're extremely resilient, but they're going through an extra-ordinarily super abnormal time.

To get through it I think everybody needs a little extra support and help, and some need more than others in recognizing that, and taking it, I think, is critical. I won't keep talking about that, but I think that's probably one of the most important things about breast cancer survivorship, particularly for younger women. I'm glad that you led because I think it's just so important that it was prioritized, so that was terrific. I'm going to focus on follow up here from a medical stand point, again, recognizing that much of this can and is framed by the psychosocial, and, to some degree, emotional stuff. I've been asked specifically to focus on cognitive dysfunction, and lymphedema, and things of that sort. When I speak to groups of doctors about this, I actually show them a laundry list, and I say, "Look, this is the potential long term late and medical effects that can happen to patients. It's the physical stuff, most of them don't have everything. In fact, most people will feel whole and kind of get to that new normal psychically and medically."

As we all know, most breast cancer survivors will be long term survivors. Even when they're living with metastatic disease, especially more and more, these days with new therapies, are living with their disease. That's to me the definition of being a survivor. You're living. Of course women in that experience who are on more chronic therapy have a different type of side effect profile to deal with over time, as well as different emotional needs. I just want to frame this: What are the goals of following up with your care team in follow up care? Let's assume that we're not talking about when someone is getting chemotherapy and/or living with metastatic disease, things are a little bit different. I'm going to focus on the kind of the conventional follow up care, for the person who's NED (no evidence of disease), but living with risk.



I'm also not going to focus on the fear of recurrence, as we've just heard so eloquently, but we all know that's a huge issue. The goals of follow up care are, that is, when I see a patient, the main things I am wondering are: is that person at risk of recurrence, and is any symptom that they're telling me about likely related to a recurrence or new primary breast cancer? You may or may not realize that, but when your doctor, or your nurse practitioner, or whoever is caring for you sees you, they're constantly screening for that. Because that's really what they're trained to do, and that's part of their job, and the other big thing we need to screen for is new primary breast cancer, or other cancers they need to think about. For a young woman that's something where we also think about genetic risk.

I know you know, especially in the Ashkenazi Jewish population, where the risks are higher of having a BRCA1 or BRCA2 mutation, which is something that needs to be thought about with you and your care team. If one does have a mutation in BRCA1 or BRCA2, or some other, more rare genetic changes that can exist, then of course counseling and discussion about what one may do to mitigate that risk, to reduce that risk, and/or screen differently is warranted. That's kind of what medical oncologists and the care teams are trained to do. We're pretty good at that, focusing on the same disease coming back if it's going to again, not the common thing. Unfortunately, it does happen. Increasingly, we also need to monitor, prevent, and treat long term and late effects.

What do I mean by long term and late effects? I alluded to them previously. Long term effects are things that happen when you're in the middle of treatment, you wake up from surgery and your under arm was numb, and if it stays that way, that's a long term effect. A late effect is, you woke up after surgery and your arm was okay, two to three years down the line your arm swells. That's lymphedema, generally. That's a late effect. Not something that happened initially, but happened later on. Of course, for the long term and late effects, there are many examples I can go through; people are welcome to ask more questions and I'll focus on the ones that have been ask to focus on. The long term or late effects can be related to the disease itself, or to the treatment. Again, it's not only a medical issue, but it's a psychosocial concern.

There are different kinds of trajectories in the survivorship space where people feel emotionally good, and then they sink right after finishing therapy. Then they may feel better later on as they get further out from their diagnosis and treatment, and then feel worse on an anniversary, or their first mammogram. Lots of different things can trigger somebody feeling badly emotionally in survivorship, as we heard from our speaker. The other huge thing that oncologists, beyond kind of warning people about things that are preventable long term; monitoring, preventing,

treating, is to be available for future medical concerns especially when you're talking about young women, like I'm sure you listeners are. You're young. You're healthy. In your average 30 to 40 year old, we don't worry about bone health normally and especially someone who continues to menstruate through treatment or beyond. That person probably isn't high risk for bone thinning right then, but they may go through premature menopause because they got chemotherapy in the past, and then their bones may be at higher risk.

Fertility is obviously another future medical and emotional concern. When a woman goes through treatment, and then later on has hot flashes because she is going through menopause later, especially when she goes through treatment young and doesn't go through menopause, the answer in the general medical population is: give her some estrogen and then we will taper it off. In the breast cancer survivor that's something that we generally want to avoid. The medical oncology team can be very helpful with that.

Then, finally, what's the other goal of follow up care? Well, there is a big bucket that I think psychosocial falls under. It's really being there to encourage adherence with hormonal therapy if you've been recommended to take that. We now know that with Tamoxifen, five years is good, but 10 years is maybe a little bit better for some women. It's not a no-brainer for all. Optimizing healthy behaviors, we know that exercise, staying or getting slim, and taking care of yourself improves how people do in the long run, at least in observational data. If women aren't told that by their care team, they're less likely to do it. It's hard enough, but at least you have to know about it, and you have to be encouraged to do it. Then we provide updates and support, so when treatments change, when we learn that 10 years was better than five years, when new medical changes come about, if you're not plugged in, at least to some degree, then you may not learn about them. That's our increasing role as medical oncologists. That is what you as patients and/or loved ones need to know.

What should you be expecting in these follow up visits? What are the goals? Like I said, there are a number of potential complications of therapy and treatment. When I think about the potential complications and long term late effects that women can experience, I like to group them as things that are probably mostly due to local therapy. Those things are: pain, numbness in the arm, breast or chest wall area or under the arm, restricted range of motion, cosmetic changes, and then there are more rare things.

The more rare things, people can get include infections, they can have other things happen in the skin or chest wall, and underlying lung. Those

things are more rare and we don't tend to screen for them, but of course we react. I always tell my patients, "If you've got a problem that you think has anything to do with breast cancer or your breast cancer treatment, I want to hear about it first, and then I want to do the triage." I'd rather have you let me know, and let me help you, rather than you worry alone and get bounced around with your primary care or somebody else, unless someone is really far out. Then there are things that are due to the chemotherapy and potential biologic agents if those are received. Those are things that people, if they got chemotherapy, are well familiar with, like the risk of some drugs, neuropathy, secondary heart problems, premature menopause, sexual dysfunction, or bone thinning. Some of those things, the latter things, are due to either chemotherapy or hormonal therapy.

Then of course hormonal therapy, the big things are: menopausal symptoms, and then some of the side effects like hot flashes, and vaginal discharge from Tamoxifen, or bone thinning from aromatase inhibitors. I can go on and on and on. I'm happy to take specific questions about any potential long term or late effects. I think having a healthier awareness of side effects of drugs is important, I think communicating well with your care team what you're experiencing, and asking what's normal, what's not, and most importantly, what's tolerable, and what's not. There are many things we can do to help people if they're suffering, but if we don't ask you and/or you don't tell us, then we can't help. For example, sexual dysfunction is a classic problem which is both medical and emotional. There are studies that have shown that if you intervene, as in figure out what's wrong, and usually there are multiple things wrong, both emotional and medical, then you do a targeted intervention, both emotional and medical, you can improve sexual functioning.

It's not a lost cause, but that's one of those problems that often doctors don't ask because they're afraid they don't know how to handle it. They don't want to open pandora's box. They don't feel like they are schooled in it, or have the resources, so they might not ask, and then the patient might be uncomfortable with asking or bringing it up. I'm saying these things to empower you to say, it's our job as the oncology providers to be able to care for women with breast cancer. We should be able to help them with the side effects and the long term late side effects. That includes sexual dysfunction. We should know who to send them to, so ask. There are a lot of resources available for young survivors about this and I'm sure Sharsheret has some. That's one topic I just wanted to make sure I addressed. I wasn't asked to, but it's really important. I was asked to talk about the long term late effects of lymphedema.

Lymphedema is basically swelling of the arm on the side where surgery was performed under the axillar, or in the chest wall, on the side where

someone had breast and/or axillary surgery. It can occur shortly after surgery. But, very commonly we see it several years out. It's something that very rarely, in the current day, is disabling. When we used to do big surgeries under the arm, we used to see a lot more. Fortunately, breast surgery and particularly with the sentinel node procedure, we see a lot less of severe lymphedema. What we tend to see more of now, is kind of sub-clinical, mild lymphedema. That's mild on the scale when we measure it, but it can be very burdensome for women, and irritating, and feel both medically and cosmetically like a big burden. The risk of it, again, is related to the extent of the axillary surgery. We see it less because we do less axillary surgery, and less aggressive ones. The risk can also be increased if one gets radiation under the axilla and also gets chemotherapy.

Another big offender, in terms of risk of swelling, is gaining weight. This is another good reason not to gain weight. People tend to do better for a lot of reasons, and they tend to have less lymphedema. Prevention of lymphedema may help, so avoiding infection, trauma, burns, and vein puncturing on that side is probably as prudent as avoiding weight gain and encouraging weight loss. Many women choose to wear a compression sleeve, with a glove or gauntlet to squeeze the hand, because if you just wear the arm squeeze, then you end up with swollen hand if you have true lymphedema. From a prevention stand point, a lot of women wear it on a plane, because there are pressure changes. There currently isn't great data to tell us that it absolutely works, but I recommend that women do it if they want to, and see how they feel.

Lymphedema is one of those things that you have to make sure that you don't make the treatment worse than the disease. I've had some patients come in and tell me they were casted for the prevention of lymphedema. I said that feels a little crazy to me, but maybe somebody knew what they were doing. Once someone gets lymphedema, and especially if it's refractory, just swelling, to sleeves then that's something you want to be more aggressive about. There is something called complete decongestive therapy that can be done. Usually you can get to this through physical therapy, if you get this problem. I think the most prudent thing for someone who doesn't live with lymphedema, but is at risk, meaning has had an axillary surgery, is basic common sense compressing. Get the sleeve. Get the gauntlet for either treatment or prevention, some physical therapy can often help. Then, try and stay a good body mass, or try and lose weight if you can, and avoid trauma to that limb.

The really cool thing that we've learned in the last few years is that, in contrast to what we thought for years, which was don't use that arm to lift weight, carry groceries, or to carry your pocket book, we've actually

learned that exercise is probably a good thing for the treatment or prevention of lymphedema. A) It keeps you slim but, B) in a couple of studies that were done where women wore sleeves, this is an important note, women wore sleeves, and then they participated in exercise programs with people who knew what they were doing. They were moderated, they were monitored, they were graduated, (meaning, gradual weight lifting with the upper extremity), where women were wearing sleeves, compared to a control group, the women who exercised, again, very gradual, low weights, wearing sleeves, had fewer developments of lymphedema. Those who had lymphedema had fewer exacerbations, fewer flare ups, among the women who have lymphedema. What I take that to mean is that it's good to exercise, but do it gingerly. There is a group called the American Society of Sports Medicine, I think it's ASSM. They have a website and they have guidelines for exercise for women after breast cancer. Maybe someone at Sharsheret could send it out to all the people on the call, because you can go to their website and you can look at the guidelines. You can also find people in your area who are trained to deal with breast cancer survivors, particularly with regards to the lymphedema risk and exercise after breast cancer.

I strongly recommend that. Because I keep talking about exercise and the people say, "How do I do it? I'm not sure how to get started? And what's safe?", and this is really a good way to start. Even if you're somewhere where you don't have someone in your area, you could bring the guidelines to somebody, a trainer and say, "Take a look at this. Can you help me with this?", if you need some help yourself or you can read it yourself.

I'm going to switch gears a little bit, but I'm going to stay on the theme. We're talking about recovery and/or the teachable moment. You weren't taking care of yourself, maybe, before, but then you have a diagnosis of cancer, you've said I'm going to take advantage of this and try and change some things. We gave you chemotherapy because you need it for your high risk breast cancer, or you have enough risk to warrant it, and now you're tired. You are going to the doctor, and the doctor is someone like me, very well intentioned, and is saying, "Go out and exercise. It will make you feel better." And you are saying to me, "I can't get off the couch. How are you expecting me to exercise?"

Fatigue is extremely common and very related is chemobrain, so I put them together. It's not so clear that they can be separated. In fact, there's some biologic information that suggests these days that they are related biologically. That certain cytokines in our body that are increased in people with fatigue are also increased in people with chemobrain. Most people with fatigue have some chemobrain if they got chemo, and most

people with chemobrain have fatigue. They seem to be very related and they're very common after a treatment with chemotherapy. Increasingly, we are suspecting that there may be some cognitive changes with some of the hormonal therapies many women complain about, as well.

The good news is they don't tend to be severe, and, particularly for chemobrain, they tend to get better over time. What I always like to do though, especially when it comes to the fatigue aspect, is make sure that nothing else is going on. Just because you got breast cancer, and you got chemotherapy, doesn't mean you can't have other things happen to you during that time that may be related but may not. You had surgery and if you have pain, and you're not sleeping at night from that pain, that is going to make you tired and that may make you not function quite as well, either mentally or physically. If you're not eating well and your nutrition is not good, same thing. Hypothyroidism is a common disease in all women in our society, and there's no reason why because you have breast cancer, you're not also at risk for that.

Sometimes if people are really tired I'll check their thyroid and just make sure I'm not missing something. I have diagnosed a number of hypothyroidism cases for women and you treat them with the thyroid medication and they're made better. Anemia, low red cells, low blood count, can make people tired and it's certainly not helping get oxygen to your brain. Insomnia, which can be due to those things, as well as hot flashes, anxiety, distress, and disruption, can really take a toll on a person's physical and cognitive functioning in the morning and beyond. That's something that we also address and there are many programs now for sleep, and actually one of the biggest things that can help with sleep is, again I'm going into psychosocial, is cognitive behavioral therapy. We can slap drugs on you, but that's a temporary fix. There are good psychological things that can help people to make their sleep better and more restorative, and they can also be less fatigued and have less cognitive dysfunction, subsequently.

Finally, depression can make people feel terrible emotionally, make people tired, and can be associated with chemobrain type features, and cognitive problems, as well as inactivity. That's why I do recommend exercise as the first line of defense for fatigue, once someone is able to get off the couch if they're really exhausted. Inactivity can really contribute to this and these things are a vicious cycle.

There are lots of things, and I alluded to some of them, so one is for chemobrain and fatigue exercise, behavioral and psychotherapy, and complementary therapies can work for some women. We definitely recommend trying them. When I say complementary therapy here I mean

things like relaxation, Reiki, and mindfulness massage. Ingesting things, I'm not as much of a huge fan of, the data does not suggest that any particular thing works, to be honest with you, but I think as long it's not harmful, it's okay to try.

For fatigue, we just studied psycho-stimulants like Ritalin, and it actually doesn't seem to work very well, so I don't recommend that as rule, but sometimes we will try it. Because we want to try everything when someone is profoundly tired and sometimes it can work. Then, for chemobrain in particular, there's increasing evidence that when people feel they're having cognitive problems, paying attention to it, and actually exercising your brain, can help. Doing crossword puzzles, doing things that force you to memorize a poem, practicing using your brain and, I know that sounds a little silly, but exercising that brain muscle, just like you would try and get your body back in shape physically, has been associated with improvements of chemobrain. Finally, reassurance, and trying to mitigate any anxiety a person might feel if they have chemobrain.

Because, of course, if you add anxiety on the "What does this mean that I can't remember this word?" I can't remember words all the time, but, because I didn't get chemo, I don't stress about it that much, and I think adding anxiety onto it makes things worse and you're bound to forget more words, or have more troubles. Another thing is to accommodate oneself, so I tell my patients, "Okay, you were a high functioning multitasker. You're still high functioning, but maybe it's time not to multitask for a little while. Take care of yourself. Take one thing at a time. Smell the roses a little bit more. Make a list. Check them off. Don't be afraid to look back at that list. Give yourself a little extra time to get through stuff if you're having a hard time," would be what I recommend. I'll be interested to hear if our other speaker has any other suggestions during Q & A.

Finally, the other area I was asked to talk about was bone health. I've alluded to it. This is something that we increasingly think about with our survivors, and basically all women with breast cancer. In post-menopausal women, their bones are thinning anyway, generally, and we give them aromatase inhibitors. In pre-menopausal women, we give chemotherapy which reduces bone mass by virtue of often shocking the ovaries, if not making them permanently dysfunctional. Then we also give treatment that suppresses the ovaries, which again thins the bones. Tamoxifen, actually in young women, if you still have mutual functioning, can actually thin bones as well, and so we think about bone health in all young women. If a person is not having regular menses and is at high risk for osteoporosis or osteopenia, meaning your mother had it, you're very thin, you don't do weight bearing exercise, it's reasonable to get a baseline bone marrow density. Women who are on ovarian suppression

or an aromatase inhibitor should absolutely follow up with bone marrow density. If you have low bone marrow density then treatment is very reasonable, and we don't know when to start this very personal decision. We can use the bisphosphonates that can be used to help strengthen the bones. More importantly, we know prevention can help. So, weight bearing exercise, having a diet that is high in calcium, (we don't recommend calcium supplementation anymore for prevention very much because there is some concern that calcium supplementation may hurt people's hearts in the long run), and vitamin D, we want to make sure our vitamin D levels are okay, we are not sure that it helps from a breast cancer treatment stand point, but it helps for the bones. These are all things that women can do to help their bone strength. Avoiding cigarette smoking and minimization of alcohol are two other big things that are both good for your bones and obviously good for your overall health in general.

I will stop there. My final comment is all of this stuff I have talked about is just a snap shot of things that women can kind of do to help themselves, and a snap shot of problems people can encounter that can be helped as you live beyond your breast cancer diagnosis. It's really important that you feel empowered to bring your concerns to your doctor, make lists whether you have chemobrain or not, not just about your questions, but about what's worrying you and what you should expect next.

I actually think that it's important that we all, and there's a mandate to do this, start giving people, all patients with cancer and women with breast cancer specifically, recommendations at the end of care. The early active care to say here's what you've got, here's what you went through, and here's what you need to do moving forward. We call that a treatment summary and survivorship care plan, and there are other names for that. I'm telling you all about that, if you haven't heard of it already, because it's kind of a roadmap for your future. We can't tell the future, but we can at least say what we think you should do to optimize your future health. It's also a roadmap for your other care providers, because your medical oncologist isn't going to do all of this, your primary care can do your bone stuff, and there are other people who can help.

They don't need to do it all, but you kind of need to know what to expect, so I would start demanding from your oncologist, don't tell them I sent you, things like a treatment summary and survivorship care plan. If you can't get one from your oncologist there are different resources where you can get things like that on the web. I will stop there but I'm happy to answer your questions about any of that.

Shera: Dr. Partridge, thank you so much, and I want to share with you that we actually have a care plan in our Thriving Again survivorship kit. As Dr.



Partridge mentioned, I encourage you to bring that care plan to your treatment team and have them fill out the medical portion of the care plan. As Dr. Coons has mentioned, in this care plan we also have questions and areas to fill out that address the psychosocial aspects. I would encourage you to fill that part out as well. Dr. Partridge, thank you. I think one of the big takeaways is the importance of knowing your body, trusting your gut feelings, and most importantly, recognizing that you are very much a part of your treatment team, and you need to make sure that you have open lines of communication with your doctors so that these symptoms and concerns can be addressed.

Dr. Partridge: I couldn't agree more, and I think again that speaks to the psychosocial too. People need to feel comfortable with their care. They need to feel safe from both an emotional and a medical stand point, that they are getting what they need.

#### **IV. Question & Answer**

Shera: Thank you. We now have time for questions and answers. You can ask your question by pressing \*1. We ask that you keep your questions broad in nature so that all of those joining us tonight can benefit from the discussion. We've already had questions coming in. Dr. Coons, what has your research found that perhaps offers two or three strategies to address some of the psychosocial concerns that you have identified?

Dr. Coons: Actually not my research, but several of our colleagues nationally have outstanding research with large groups of women with early breast cancer, that point to several areas. First taking a very active look at mobilizing support, this is very important. It's a long term finding and research on health, health outcomes, and health quality of life. We invite young women with breast cancer, to be very specific, on seeking contact, deepening your connections, and creating community. I call that the three C's. For example, we have repeated data that help understand that emotional support improves practical problem solving, emotional support, and feeling less alone and isolated. Going through breast cancer treatment, whether you have earlier or advanced disease, as a young woman, is not something that we want you to do alone.

Many of you have heard the expression "it takes a community or a village to raise a child," well it takes a community or a village to support women going through breast cancer as well. One crucial evidence based strategy is to certainly mobilize support from individuals in your life who can be there for you. At some times different individuals will be there in different ways, whether practically, emotionally, or spiritually, or financially, for example. Another major area is the overwhelming data that Dr. Partridge

alluded to. It has to do with the benefits of exercise for women especially with hormone positive breast cancer, really any woman with breast cancer, almost at any stage unless you have very, very advanced disease, three to five times a week. The data underscores the benefit of aerobic exercise on reducing anxiety, improving concentration and focus, and improving sexual energy and body image. Improving all the biomedical outcomes like bone health and heart, and those kind of things, but also our sleep. That's probably the third area that I want to mention specifically. We know that stabilizing sleep is essential to our well-being. Sleep is one of the biggest drivers of our energy and of our emotional wellbeing, including mood and anxiety. Sleep affects our weight metabolism and it affects our cognitive skills among many, many other indices. It's very important that if somebody is not sleeping, and doesn't have a good sleep quantity or quality, that they talk to their oncology team, and they may very much benefit from excellent cognitive behavior techniques that Dr. Partridge alluded to that can be highly effective in shifting and re-stabilizing your sleep cycle.

It's very hard to navigate these complex decisions when you're not well rested. Disease and treatment compromises your energy, so it's crucial for all the reasons we have noted that you are sleeping well. Finally, I will mention some of the research on some of the benefits of compartmentalizing your experience with your breast cancer and its treatment. For example, taking the best care of yourself whether it's to see your doctors, or to adhere to your medications, or if you are not, to talk to your oncology team, maintain good weight and get exercise, limit your alcohol and certainly not smoking, and taking good care of your relationships. At the same time, finding time to kind of not be just be a cancer patient. All of the women on this call are daughters, or sisters, or mothers, or professionals, or workers, or athletes, or artists, or musicians, or whatever the example. To understand, or recognize, that while we might have cancer, cancer doesn't have to have us.

The compartmentalization of the experience is a very helpful coping strategy and it also gives individuals with cancer the kind of time out and more resilience to cope with kinds of challenges that are so common for both women with early and advanced disease.

Shera: Thank you, Dr. Coons. Dr. Partridge we have a couple of questions about lymphedema specifically, so I'll pair these two together. How many years after surgery does the survivor need to wear a lymphedema sleeve on an airplane flight, and the second question that came in: is there such a thing as a lymphedema specialist?

Dr. Partridge: The first answer is lymphedema occurs because you have had surgery under the arm that has disrupted the lymphatic channels. The channels, the roadways as an analogy, that allow fluid that is normal in all tissues of your body to drain out of that limb. When that channel is disrupted it's pretty much disrupted forever, and so you're at risk forever. And so, when you say how long does one need to wear the sleeve, you don't need to wear the sleeve," but if you choose to wear the sleeve for prevention then you're going to be, probably, wearing it forever. On the flipside, if you choose to try it for the first couple of years, or as long as you want to, and then you say, "I'm kind of done with this, I'm going to take a wait and watch approach," that's okay too. It's okay at some point to say, I haven't gotten lymphedema yet, I'm tired of wearing the sleeve, we are not even sure whether the sleeve prevents lymphedema, the data does not necessarily support that. I think it's okay to wear it, but I think it's also okay to say, "I'm going to hold off and I will use it if I need it," and do more of that kind of treatment and symptom management, as opposed to a prevention use of a sleeve, especially when someone is pretty far out, but there's no cut point.

The second question which was about lymphedema specialists, there are people out there who call themselves lymphedema specialists because they have decided to devote extra effort and expertise to learning how to deliver good lymphedema focused physical therapy. There are lymphedema specialists out there, and there is actually a lymphedema society that you can find online. They probably could direct you to people who focus on this. Your healthcare provider could also likely direct you to local physical therapy folks that focus on lymphedema. If they take care of a lot of breast cancer patients, they will know who the good folks are.

Shera: Thank you. We received actually several questions about the impact of treatment on the heart. Can you briefly address that Dr. Partridge?

Dr. Coons: Sure. Very briefly, certain treatments like anthracyclines, Adriamycin, Doxorubicine, as well as Trastuzumab or Herceptin, in particular, can affect the heart. The other thing that can affect the heart, although increasingly less, is radiation. All these things can affect the heart, especially if you had left side radiation, but with newer techniques, we think it's less. We try very hard to avoid the doses of Adriamycin or Epirubicin that would affect the heart. We don't go above certain amounts so that the total a person gets is the right total at the right time. They're not at a high risk of having heart damage (at least overt heart damage) right after the chemotherapy but of course some people still may, and that's the concern obviously whenever we give any of those therapies. We weigh that into risks of chemotherapy. Are they justified when you consider the risk of the cancer?

Trastuzumab or Herceptin, is one of those things that we see increasingly less cardiotoxicity; we don't pair with certain drugs, we are more aware of it, and we can monitor it. The nice thing about the Trastuzumab related cardiotoxicity, that is for the women with HER2 positive breast cancer, that it seems to be very reversible. For some that can be very devastating and the cardiac complications this cancer cause, while rare, are extraordinarily serious. It's something that we take very seriously in the sense that we don't give the chemotherapy, unless we think the risks are far outweighed by the benefits, and then, of course, we have a very low threshold for looking into symptoms that might be related to cardiac problems, like shortness of breath, chest pains, and the like.

Shera: Thank you. Dr. Coons, is it helpful for survivors if they become more active in the breast cancer community, or can continuing to remain engaged in the cancer community trigger fears and anxieties?

Dr. Coons: That's a very interesting question. I don't know of data that speaks too definitively one way or the other. I can tell you from decades of clinical experience that there are some individuals who find that being actively engaged in advocacy around breast cancer research and care, healthcare policies, and actively involved in supporting the well-being of other women going through similar experiences, is grounding, is empowering, is profoundly meaningful. There are other individuals for whom that is either overwhelming, or they want to limit the focus of their energy on breast cancer to getting themselves well. They need to focus on other parts of life, and may contribute quietly to an organization, or may quietly support another woman in her community or family, but are less inclined to be extensively involved with an organization around advocacy, education, or support.

Dr. Partridge may know of some data. I have not seen anything that I would consider excellent data.

Shera: The second part is about whether or not it can be more of a trigger for anxiety?

Dr. Coons: I think we are all aware that many young women with early and advanced disease find October triggers a host of feelings ranging from connectiveness and empowerment, to feeling absolutely overwhelmed by the amount of media that in many ways has been very helpful for breast cancer survivorship issues and the advances and treatments, and for other individuals is simply too much. It's certainly that the time of the year when a particular focus can be difficult, but quite frankly we have done an amazing job in some communities, certainly not all, and especially rural or underserved communities, where there's less information. There could be

triggers any time of the year, and so part of it is just individuals understanding what their triggers are and again seeking support from their healthcare team, from individuals in their life, whether it's other women with breast cancer or individuals in their family, and friends.

Shera: Thank you. Dr. Partridge, we received several questions about your recommendation of not taking calcium supplements, can you expand on that briefly and maybe suggest some other options?

Dr. Partridge: I brought that up purposely and I knew it would be provocative. There was a recent US Preventative Services Task Force report that looked at the use of calcium supplementation for the prevention of fractures and osteoporosis. Basically they reviewed all the evidence and decided that for prevention it was not a good idea because it's associated with concern about increase in the risk of heart attacks. It's not clearly preventative. We do recommend it for people for treatment who have definitive bone loss, as a rule. In terms of what women should do who are at risk, I asked my own primary care physician this, I've kind of grilled our osteoporosis doctors, and right now the common recommendation is try to get your calcium from food. There's a little bit of wiggle we're doing right now, and vitamin D supplementation appears to be okay, and that's good for the bones.

Shera: We have a question here. Dr. Coons, how do I distinguish between what is normal post cancer anxiety, as compared to anxiety that suggests I need to seek the help of the healthcare professional, and what are some of the signs I should look for?

Dr. Coons: It's an excellent question. There is a degree of anxiety that almost all women coping with early and metastatic breast cancer would get. That we consider a normal reaction to a very complicated and scary experience. Then there's the fine line of when the level of anxiety that an individual might experience is affecting her functioning, for example unable to sleep, or loss of appetite, or eating down feelings of anxiety, or drinking down feelings of anxiety, finding that someone is very irritable, or withdrawing from a relationship, feeling intrusive thoughts of cancer, what the future might hold, fears, and concerns are interfering with concentration, and focus, whether at home or at work. When one's quality of wellbeing, either emotionally or cognitively, relationally, is affected, or even physically, finding that your stomach always hurts, you have a chronic headache once you have been diagnosed, but it's more stress related. Those are indications that you really want to reach out, and you want to ask your oncology treatment team for a referral to a behavior health provider with specific expertise and credentials and experience in providing care to women with psychosocial issues during and following

cancer treatment. This is the time you want to get a referral to a reputable mental health provider who has expertise specifically to help you navigate your experience with breast cancer.

Shera: Thank you Dr. Coons. We have one final question and that is for Dr. Partridge. Any research in the pipeline regarding survivorship that you think is particularly promising, that we should keep an eye on? Part two, what are the best ways for survivors to keep on top of emerging research without feeling more anxious than empowered?

Dr. Partridge: I'll answer the first question by saying there's a lot going on. Not as much as I would like, but a lot, and there's a lot of things looking at the health behavior things, like how much does exercise add prospectively, or looking at whether aspirin might help, these are all questions that we want to find out about. There's a lot of data that suggest that aspirin, at least observationally, when we look at large groups over time, and look back and say, they took aspirin that seemed to help in terms of breast cancer risk and recurrence. We need to look at it prospectively. These are things that we want to hear about in the future but we don't have the data yet. I think in terms of other survivorship concerns, the other place where there's a growing number of studies, is managing side effects. Neuropathy treatment is evolving and there are a lot of things that are looking into how to treat neuropathy, and there's a new drug called Duloxetine, it's been showing to be effective against neuropathy.

How to stay engaged with those kinds of things? I think doing what you're doing, being a part of things like Sharsheret, the teleconferences. I know Sharsheret and other advocacy groups have blast emails. I look at those emails, and if there's anything really critical to the average breast cancer survivor, an advocacy group, like Sharsheret, is going to pick it up. I recommend staying engaged like that and I'm sure that the message is positive. I think you can be anxious if you think that every single thing applies to you. I think if you feel that way that it may be time to go out and seek some help as we've just heard. I just want to add from the emotional stand point I think it's normal to be anxious to some degree. You were just diagnosed and had your carpet ripped out from under your feet. Even if you are someone who is living with knowing you have breast cancer mutation BRCA 1 or BRCA2, it is still an anxiety provoking thing to get breast cancer and have to deal with it, and worrying about what these treatments might do. That's all normal. But it's how you manage it and it's not a failure at all to actually need some extra help. Actually I think it's quite normal, even if you are not completely dysfunctional, to get some extra help, whether it's informational or supportive; you need to get help if you have the signs and symptoms you just heard about. I think also it's a

pretty good thing to get some extra help, either educational or some cognitive therapy, to kind of wrap your head around this.

Dr. Coons: May I respond to that? This is Dr. Coons.

Dr. Partridge: Of course.

Dr. Coons: That's an extremely important point that mental health providers whether they are psychologists, social workers, or psychiatrists who are trained in psychosocial oncology, we don't want to just see individuals when they are highly symptomatic. The data does tell us that women are really impressively resilient at coping with both early and advanced disease. There's only a subset, probably around 25%, to that who actually need treatment for, or meet a diagnostic level of depression or anxiety. That doesn't mean that there aren't times when you feel sad or down. There are so many indications, however, for coming into someone with expertise in psychosocial oncology to help improve your body image, navigate complex decision making, or work on sexual health.

I'm always happy when an oncologist refers patients early so we can help patients prepare for invasive medical procedures. We have decades of data about the benefit of coping strategies to improve outcomes with procedures, to actively prevent sexual sequeli, to improve communication, to talk about different ways to have difficult conversations with current or future partners, with children, or other family members, where sometimes communication can be complicated for any number of reasons, for difficult conversations about treatment selection, for concerns about preventive strategies, for self-esteem, for transitions, and learning about a philosophy of wellbeing as you navigate any part of this treatment experience. I couldn't agree more with Dr. Partridge: you don't have to meet clinical levels of anxiety and depression to benefit greatly, and instead of viewing that kind of reaching out as selfish, it is actually quite self-respectful.

## V. Conclusion

Shera: Thank you to all of you and to our speakers for that enriching question and answer discussion. You should have received an evaluation in your email so please take a moment to complete the survey. All of our programs and support are driven by the feedback we have received from you. We are committed to staying relevant by enhancing our programs to reflect the growing and changing needs of the women and families of our Sharsheret community. Sharsheret's expertise is in young women and Jewish families, but our 12 national programs are open to all men and women regardless of background. I'd like to thank, again, our speakers for sharing their expertise with us tonight, and to recognize that our program

was made possible with the support by the Cooperative Agreement DP11-111 from the Centers for Disease Control and Prevention, and we would like to express our gratitude to them for recognizing and supporting the needs of breast cancer survivors.

Finally, I would like to thank all of you for participating in tonight's program, feel free to continue the discussion by reaching out to us by phone, again, 866-474-2774, or on our website, [www.sharsheret.org](http://www.sharsheret.org), and if you would like a peer supporter to speak to about your individual survivorship questions and concerns, please call the Sharsheret office and we will be happy to connect you.

Have a good night and we look forward to hearing from you.

## VI. Speakers' Biographies

**Shera Dubitsky, M.Ed., MA**, is the Director of Clinical Support at Sharsheret. She 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.

**Helen L. Coons, Ph.D., ABPP**, is the President and Clinical Director of Women's Mental Health Associates in Philadelphia. Dr. Coons is a Clinical Psychologist and Board Certified Clinical Health Psychologist who specializes in behavioral medicine, women's health and mental health, and psychosocial oncology. Dr. Coons received her Ph.D. in Clinical Psychology from Temple University after interning at the Duke University Medical Center. She is also a Clinical Professor of Psychiatry at Drexel University College of Medicine, and has an allied health appointment in the Department of Psychiatry at Pennsylvania Hospital.

**Ann Partridge, MD, MPH**, is the Founder and Director of the Program for Young Women with Breast Cancer and Director of the Adult Survivorship Program at the Dana Farber Cancer Institute. Dr. Partridge is an Associate Professor of Medicine at Harvard Medical School. She completed her residency in internal medicine at the Hospital of the University of Pennsylvania and went on to complete fellowships in medical oncology and hematology and she received a Master's in Public Health from Harvard School of Public Health. She is a medical oncologist who focuses on the care of women with breast cancer, and she has a particular interest in psychosocial behavioral, and communication issues in breast cancer care and treatment.



## VII. 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 30,000 breast cancer inquiries, involved more than 3,000 peer supporters, and presented over 250 educational programs nationwide. 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

## **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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