

How Do We Care For Our Children?

Issues For Women and Men Facing Breast Cancer

**Transcript of the Symposium Presented at
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Symposium Presented By:

**Sharsheret: Linking Young Jewish Women in Their
Fight Against Breast Cancer
and
MSKCC Post-Treatment Resource Program**

Symposium Sponsors:

**American Cancer Society
North Jersey Affiliate of the
Susan G. Komen Breast Cancer Foundation
Cancer Care
Gilda's Club
Hats of Hope**

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I. Introduction

Linda Roberts: Welcome to this very special evening. My name is Linda Roberts and I am a social worker at the Post-Treatment Resource Program here at Memorial Sloan-Kettering Cancer Center.

For those of you who are new to our program, the Post-Treatment Resource Program offers education, counseling, advocacy, and practical services for patients and their families to help in adjustment after cancer treatment. We are a community program that is open to both Memorial patients, as well as to others treated anywhere in the surrounding areas.

Tonight we have the privilege of hosting this community event with the participation of the American Cancer Society, Cancer Care, Gilda's Club, and the Susan G. Komen Foundation. These fine organizations all provide education and support to help patients and their children in their adjustment to cancer.

We are proud to have partnered tonight with Sharsheret, a rather new agency which has been built and nourished by Rochelle Shoretz. Ms. Shoretz is an attorney who has served as a law clerk in 1999 to United States Supreme Court Justice Ruth Bader Ginsburg. After her diagnosis of breast cancer and while still in treatment, she founded Sharsheret, an organization to help young women with breast cancer find support and resources to cope during this difficult time.

I am pleased to turn the podium over to Rochelle who will guide us through tonight's special program.

Rochelle Shoretz: Thank you for joining Sharsheret and Memorial Sloan-Kettering Cancer Center's Post-Treatment Resource Program as we present *How Do We Care for Our Children: Issues for Women and Men Facing Breast Cancer*.

I'd like to thank all of our sponsors listed on your program for their generous support of this important symposium: the North Jersey affiliate of the Susan G. Komen Breast Cancer Foundation, the American Cancer Society, Cancer Care, Gilda's Club, and Hats of Hope. And I'd like to express my gratitude to the Post-Treatment Resource Program, and particularly Linda Roberts, with whom it has been a pleasure to organize tonight's event.

The collaborative efforts of all of these important organizations enables Sharsheret to address significant issues for young women and men, their family members, and the health care professionals who care for them.

When I was diagnosed with breast cancer a little over one year ago, I was overwhelmed with concerns. What type of surgery should I opt for? What course of treatment should I choose? Will I lose my hair? Will I live? But by far, the most painful and difficult question I asked myself repeatedly was, “How am I going to help my children through this?”

Diagnosed at age 28, I was raising two young sons, then ages five and three. And though books and websites offered a host of useful medical advice, I felt overwhelmed every time I considered the impact of cancer on my children. A team of health care professionals worked diligently on my medical care, but not one offered resources to assist me or my husband in the care of our children.

In the midst of chemotherapy, I founded Sharsheret, which is Hebrew for chain, a national not-for-profit organization providing support and information to young Jewish women fighting breast cancer.

My motives in founding Sharsheret were, in part, selfish. I wanted to find other young women with whom I could address the challenges of raising children through cancer-- how to tell my boys I needed surgery, how to prepare them for the loss of my hair, how to unburden them from the weight of a frightening diagnosis.

Sharsheret’s national efforts are now three-fold. First, we pair young women with volunteers who can share their personal experiences. Second, we educate cancer organizations about the issues specific to young women and Jewish women who are fighting breast cancer. And third, we present educational events like tonight’s symposium on subjects of interest to the women who phone in for support.

Sharsheret’s Link Program pairs women one-to-one to discuss a host of issues: the results of their genetics test, how to explain chemotherapy to a young child, or how to cope with the spiritual crisis that can accompany a traumatic diagnosis.

Women who call Sharsheret receive a welcome packet, resource information, and a Link with whom they are paired to discuss the issues important to them. The Links we make are tailored to address those concerns, and callers are free to speak to as many women as they need under circumstances of confidentiality that they establish themselves.

In just 15 months, we have received over 1200 phone calls from, among others, women and family members affected by breast cancer. And by far, the single most frequent concern raised by those with children is the subject of tonight’s symposium: “How do I care for my children?”

Many of the materials you've received tonight and much that you've probably read on the subject indicate that sharing developmentally appropriate information about cancer with our children helps them feel secure and informed. It seems only logical. But for many families, those conversations are difficult to begin. The questions children ask can be unsettling, and the questions children don't ask, perhaps even more so.

So in addition to the obvious anxieties with which parents struggle when coping with a new diagnosis, parents often grapple with feelings of guilt that they are not doing enough to address the needs of their children. Those needs evolve through surgery, treatment, and then post-treatment.

When I was first diagnosed, my oldest son wanted to know whether cancer was contagious, whether I rode in an ambulance to receive chemotherapy, and whether I would leave the family because he and his brother had not done enough to help me feel better.

Now that I've completed treatment, my son wants to know whether I will get cancer again, why I got cancer in the first place, and whether other mommies get cancer, too. New questions and new concerns seem to surface at moments that continually catch me off guard: in the car, on a walk, while preparing for bed. In addressing the needs of my children, I often view myself as a player in the mole games you find at amusement parks. I hit one mole only to find two or three new ones have appeared.

Our aim tonight is to present some of the concerns that stand in the way of open communication with children, to discuss the needs of a child at the time of a parent's diagnosis and through treatment, as well as the needs of a child whose parent has completed treatment.

Our focus this evening is on breast cancer and the particular impact of this disease on children - whether it's receiving a hug from your young one when you've just returned from a mastectomy, discussions about body image with your teenage daughter, or conversations about genetic testing with your adult children.

The subject is enormous when we consider children of different ages, with parents who have undergone different treatments and face different prognoses. And we know that we've bitten off more than we can possibly chew in a two-hour discussion.

Our hope is that the presentations tonight will answer some of your questions, raise new ones, and generate discussion about the significant effects of breast cancer on our children.

Our first speaker tonight will be Rosalind Kleban of Memorial Sloan-Kettering Cancer Center. Ms. Kleban is the administrator-supervisor for psychosocial programs and leads support groups for women dealing with all stages of breast cancer. She brings to our discussion a wealth of experience speaking with and supporting young mothers facing breast cancer, and will address the concerns that may stand in the way of open communication.

Please join me in welcoming Rosalind Kleban.

II. Concerns That Stand in the Way of Open Communication with Children

Rosalind Kleban: Thank you, Rochelle. And I'd also like to thank Rochelle and all the other people here from Sharsheret who are truly filling in a niche that has been sorely needed in working with breast cancer patients. I think -- and I met Rochelle when she was a newly-diagnosed patient, maybe treatment one or two, talk about beginning this organization and what is that -- two years ago Rochelle?--

Rochelle Shoretz: Not even.

Rosalind Kleban: -- that the organization has become so entrenched and so vast and has filled an important place and does some very important things.

A diagnosis of cancer of any kind -- of breast cancer -- is just an overwhelming, dislocating, traumatic event for anybody. And I think when it happens to young people, it's been my experience, that it's even more difficult because what people expect is that it happens when you're 55 and older or 75 and older.

So every young patient feels isolated, feels alone, feels that there's nobody else, except -- their neighborhood is telling them so and so's aunt and so and so's grandmother and everybody's great aunt has had breast cancer and do not worry.

But when you're 33 years old and the only thing you're hearing is older people, it's not very comforting and it's a little bit more frightening. As Rochelle points out, you have to face all of these extra questions on your own.

And I think the biggest question -- well, one of the biggest questions because another program that Sharsheret did was one on infertility, which certainly is of extreme importance to young women.

But additionally, one of the most important things, and what I hear from patients all the time is, "What do I tell my children? What do I do about my children?" I just know in interviewing a new patient, all I have to do is ask them, do you have children? And it's like putting my foot on a spigot. They cry immediately. The thought of the children and what's going to happen to the children and how do I handle the children. That is something that is overwhelming to all patients.

Now, I really wish we had a much more intimate space here, but we'll have to do with this. I'm going to start with a disclaimer. And what we're going to do here is talk about all the things that are good to do. All of the things that research or experience has told us we ought to do. Maybe this is the best thing to do. But,

truly everybody facing a diagnosis of cancer, facing a diagnosis of breast cancer, has to do the best they can.

This is one of the most difficult moments in life. I have seen people who were living good, strong, satisfying lives -- as I think you were, Rochelle. Things were going well for you, with family and career. And this just shatters a person's sense of self, a sense of security, a sense of wholeness, the entire world looks different to that person. And here we, as professionals, are now going to dance in and tell that person how to live their life and how to go about dealing with things.

I think I'd like to be a little bit more humble than that. And I think to put out to patients who are dealing with more than is tolerable for anybody, that now we have another thing that you need to do. And by the way, I want to point out that you're doing it wrong. So now we're going to add guilt to this. I think that we do people a disservice.

So what I would like to do here tonight is to just throw things out to you guys. You're all intelligent, well-meaning, competent people. Take what you can use and discard what you can't use now.

The other thing is that all of this is an evolving process. There may be things that you will hear tonight that seem undoable to you. But maybe two, three months down the line, you will remember what you heard and it will seem more sensible. It will also seem like something that you can approach.

We once had Phyllis Newman here. Raise your hand if you've ever heard of Phyllis Newman. Oh good, thank you, because a younger crowd is not going to have heard of Phyllis Newman. I used to talk about Loretta Young. Well, I've stopped that. I think you have to have the over 80 crowd for Loretta Young.

Phyllis Newman was here once to talk about her cancer. This is many, many years ago. Probably 20 years ago she had cancer, a tremendous amount of chemotherapy. Then some years after that, she had another mastectomy. So she's had bilateral mastectomies.

And the women asked her -- and her husband was in the audience looking up at her so adoringly, just -- this is of no consequence, but people asked her if she had reconstruction and she said, no, she's so terrified of surgery, that if she had the nerve to do surgery, she would do something about her face. That would be the first thing. The breasts would be secondary.

And then somebody asked her how she handled her children at the time because they were young children. And her answer was "Poorly." She handled them

poorly. She did the very best she could. In retrospect, she's sorry she did a lot of things. She's sorry she didn't do a lot of things. But the truth is, she did the very best she could.

And so I think that's what I would like all of you guys to take away from our evening tonight. Take the information that we're going to talk about and then you're going to do the very best you can.

The other piece of the disclaimer is: you know your family. We don't know your family. We're going to give you some information. We're going to give you some -- the other -- my colleagues are going to give you some tips about how to do it, what to say. You are the final person. You are the final judge of what's doable.

I have been asked to speak about what hinders people from talking to their children. It's interesting. It's just sort of like a knee-jerk reaction. I meet some people. They've already told their children. They've told everybody. And then there are some people who feel relatively strongly that their children don't need to know.

It's interesting that there's very little research actually done on why people -- parents are reluctant to talk to their children. But I think I've learned about why that is. The way I learn about most things having to do with breast cancer, and that's from you guys. Everything I know about how you cope with this and how things -- how you feel about it and how you deal with it comes from the patient.

What I heard from people is, "I need to protect my child." What is it to be a parent than the need and the desire to protect your child? You protect them from harm. You protect them from hurt. And giving information like this is going to be extraordinarily painful, extraordinarily hurtful, and you certainly are not going to do it.

We have, I think, a lot of myths about what will happen if we should tell children. We're going to damage the child. The child will be unable to cope. The child's world will be shattered.

And you have to ask yourself, where really does that come from, that notion that the child's world is going to be shattered, they will be unable to go along. When I think about that, I think we all have to think about what happens to the person when they're told that they have breast cancer. It is the most damaging, shattering, difficult information that you're ever going to hear in your life.

One patient puts it in a way that just feels right to me and that she says it just brings her to her knees. The fear and the terror is overwhelming. Now, she's 38 and it does that to her. Her thought of what it's going to do to her 4-year-old, her

6-year-old, and her 10-year-old if she's having trouble getting up in the morning and dealing with it, how possibly can her child? So it seems just intuitive that you need to protect your children from this kind of news.

I think another piece of what stops us from talking to our children is in a way what stops us from talking to anybody. I think when women are first diagnosed with breast cancer, you're somewhere on a continuum of dread to hope. And you're on that continuum and you slide back and forth and slide back and forth. And I think women work very, very, very hard to maintain some kind of optimism. "I'm going to do it. I'm going to beat it."

Then you tell your next-door neighbor "I've been diagnosed with breast cancer." And you get a face from that person, "Oh, my god." And on that face is your death, is your burial. Women do all sorts of things to avoid that. I understand that. You're fighting your own battle. You're fighting your own battle to maintain some optimism, to maintain some coping mechanism. And that can all be wiped out by the next-door neighbor who then, of course, immediately tells you about all the people on the block who have died of breast cancer.

So the thought of telling your child, who is going to have what you believe is going to be an intense, fearful, negative reaction, is just going to stir up in you all of the terrible feelings that you have about this -- rightful feelings. I mean, feelings that are just absolutely normal to have.

But, at that diagnosis phase certainly at the beginning or throughout, people are so vulnerable and so fragile and sort of holding onto a very slim thread there. And that kind of devastating -- what you believe will be a devastatingly difficult response that you're going to get from children is really more than you can tolerate at the time.

And if that's so, then you needn't tell your child. If that's the case, then you need to wait if you -- with time, maybe some time you're going to feel strong about it. Some time that you're going to feel able to do it. When you're feeling so devastated and fragile, that is not the time to do it regardless of what we are going to tell you. You're really hanging on to a very fragile thread. And the child's terror is just going to mirror your own and that may be too much at the time.

Now, while protection is good -- I mean, I'm a parent too. What else would you want to do but protect your child? I believe in many ways it's just simply impossible.

There's this wonderful article. I'm sorry we didn't have a chance to reproduce and send out. But, they quote Dr. Wendy Harpum [ph], who is a physician who

has four children -- three children and has struggled with -- she had leukemia -- has leukemia for many years. And so she has written extensively on her experience in working with children.

And I believe the whole thing can be summarized in this one quote. "The greatest gift one can give to children is not protection from stress, change, or loss, but the confidence and tools to cope with and grow with all that life offers, both the good and the bad." The truth is, we can't protect our children as much as we'd like from the realities of what happens in life.

I believe that it is impossible to protect our children because children take the temperature of the room. Their entire world is mom and dad and the family. That is their entire world. When something changes in that world, they sense it. They know that something is going on.

People tell me that they don't talk about it in front of the child. But what happens is the child is entering the room, you see them, you change the subject. The child has heard. You'll hear from my colleagues about all the different and better ways to approach talking to children.

But when children are left in the dark, they really do know that something is going on in the house. They know that it's not to be talked about because it hasn't been talked about. So they are left to conjure up in their minds what is going on. And generally speaking, they think of some pretty awful stuff and they have nobody to go to.

If when the family sits down and one talks about it, whatever are their fears and their terrors, they have adults, they have their parents, they have aunts and uncles that they can talk with about what's going on. In some ways by telling our children what is going on, we are protecting them from these unknown horrors that are rambling around in their mind and they have no place to go with it.

So here we are talking about 35-year-olds who are having an impossible time coping with this, which is something we expect across the board, an impossible thing to cope with. But, we have all of these services, hopefully, in place to help people deal with it.

Now we need to think about that 5-year-old, the 10-year-old, the 14-year-old who has an idea that something terrible is going on in the family and is left to cope with it all by himself. So by speaking about it openly that, in a way, is a protection because that serves to give our children coping mechanisms.

Rochelle mentioned one of the things that's the biggest fear in dealing with children and that is her boys thought perhaps they had done something wrong,

which is why she might go away. I don't think there's a child in this country who hasn't wished ill to their parent. You punish them. Something happened. Then you come down with -- something goes on and they think it's their fault. Something has happened in the house. They see mommy crying. It must be something that they wished on mom or that they were bad last year or got bad reports from school. And so what mom is suffering from is their bad behavior.

I think when it's all thought out, the best protection for our children is to include them in what's going on, to answer their questions, to be open and honest with them. I think probably one of the most important things is to assure children that there will always be somebody there to care for them, to love them, to take care of them.

I think the other thing that probably is very helpful with children is it helps eliminate some problems in the future. And I think that we'll spend more time on that later.

When children are not told what's going on, it really removes one of the most important things parents and children need to have with each other, and that is trust. So on the one hand, while we think that we're protecting them, we're creating an atmosphere where they feel that they cannot be trusting of the people most important in their life.

So when they find out later about all that was going on and then when they're in college and call home and say, how are things, mom, and you say, fine -- well, maybe fine. You know, that's what you said last time, "Things are fine."

To create an atmosphere where there is not a great deal of trust in the family makes it much more difficult for the child. I think by telling the child you also give them the idea that they can cope, that they are strong, that they can deal with it, and that the family together can deal with it.

I think that there are some people who feel, "I don't have to tell my child. It will be over in six months." Then there are other patients where it's not going to be over in six months. I know we're going to talk about how to talk about children during treatment and how to talk to children after treatment.

But then there are patients where there is no end to treatment, where there's going to be continuous treatment. That child needs to be in on what is going on because that patient is now dealing with a chronic illness. That is an illness that we cannot say treatment will be over in six months or treatment will be over in nine months. This is a chronic illness, and this is something that is going to affect the family sometimes a lot, sometimes a little. Sometimes a lot. Sometimes a little. The child needs to know what's going on.

And I said that I was going to talk about a conversation I recently had with a patient -- who will go unnamed -- who felt that talking to her child -- because this person has advanced disease -- that the child would worry that this is the worst case scenario. And in fact, this is the worst case scenario. Well, in fact, it's not the worst case scenario. So the truth is that the worst case scenario is when the doctor tells you that we have come to an end and we have no more that we can do. People who have stage four disease have many, many, many, many years to live. It is a chronic illness. So that is not the worst case scenario.

The worst case scenario for a child is two-fold. One is when they lose a parent and when a person is close to that point, I think most people -- most parents feel that that really does necessitate a discussion with the child.

But the other most difficult thing for a child is the thought that there will be nobody there to take care of them. It's even more than the loss of a parent. The thought that a child will have that if my mom is in danger and if I lose my mom, who is going to take care of me. That child needs and deserves -- if we're going to protect that child -- to be constantly reassured that that child will never be alone. That child will be cared for. That child will be loved. That child will be taken to Girl Scouts and Cub Scouts and class trips. That is the most important thing that a child has to know.

I'm going to end by telling everybody my fruit story. Those patients of Sloan-Kettering know about my fruit story.

Everybody's worried about telling a child that you have cancer. We all know that is absolutely the worst possible thing that you can say. What is the first thing that people think about when you use the word "cancer?" And that is death.

But the word "cancer" is a very -- in some ways a very meaningless word. I compare it to fruit. The word "cancer" is the same thing as the word "fruit." There is a watermelon and there is a kiwi. Breast cancer is not the watermelon of cancers. Breast cancer is much more treatable, much more curable, much more amenable to dozens upon dozens upon dozens of chemotherapy agents to different procedures.

The child who is terrified of cancer has to be able to understand that you're not dealing with cancer. You're dealing with breast cancer and there really is a difference. There is a difference to newly diagnosed patients, and there's a difference with stage four breast cancer because stage four breast cancer is a chronic illness and goes on for years. I don't know that we could say this with many, many other cancers. And I think, not only will children learn from that, but

I think patients learn from that because we all respond to one thing, and that's the word "cancer," and there's nothing more devastating than that.

But slowly, I think that we have to educate ourselves to understand that this is not -- this is not the pumpkin in the fruit basket. That this is a doable disease. This is a treatable disease. The vast majority of our patients live long, healthy, normal lives. And people who have to deal with it in an ongoing basis also live good, fruitful
-- I'm sorry I used that word -- good functioning lives.

I think we'll have time for questions afterwards? Okay. Thank you.

Rochelle Shoretz: Thank you, Ros. I'd like to remind you all that we'll be taking questions for all our panelists after their presentations. So please jot your questions down on the cards you received earlier this evening and there are some additional cards in the back.

Our next speaker will be Peggy Anne Murphy, the program coordinator of the children's program at Cancer Care. Ms. Murphy counsels children who have a significant family member with cancer and will address tonight the needs of children at the time of a parent's diagnosis and through treatment.

Please help me welcome Peggy Ann Murphy.

III. The Needs of Children Coping with a Parent's Diagnosis and Treatment

Peggy Anne Murphy: Good evening everyone.

Before I begin, I just want to comment on what Rosalind had said about being humble. I think a lot of times as mental health professionals, we deal with people who have cancer and come across very harsh, as if we know all the answers. And I hope that throughout tonight, what you'll hear us say is that you're really the experts. Cancer does not have the power to take away the fact that you know your children the best and that you have a history and strengths. And any information that we give you, you have to tailor to what's best for your family. So I like your comment about being humble.

I also have to add that there will be some repetition -- hopefully, not too much, but there are some important points to emphasize.

As Rochelle said, I direct services at Cancer Care for children and their families, children who have cancer, children who have a parent or a significant family member who has cancer. We are a non-profit agency founded in 1944. Our main office is in Chelsea, but we have offices around the Tri-State area, and we talk to people around the country.

We offer support groups, one-on-one counseling, telephone counseling, telephone support groups, internet groups. And a large part of what we do that I'm not sure if everyone is aware of is we offer financial assistance towards costs related to treatment. And that's namely child care and transportation monies. And if you have any questions about that, you can see me later. But that's an important part of what we do. And everything we do is free of charge, if I didn't say that.

Any work that we do with children, the whole purpose is to keep children on developmental track. And as I said, all of the information that we're going to give you is really important to tailor it to your family. The information I'm going to talk about, it applies to the time of diagnosis, but also through the treatment process. So that if you're sitting there and you're thinking, well, we didn't talk about this. As Rosalind also said, it is an ongoing process. Your understanding of your disease and your family's understanding evolves over time. You can always go back. You can always repeat things. You can always give information you hadn't given before if it makes sense to do so.

A cancer diagnosis, as I was saying, can't take away the fact that you're the expert. And we receive a lot of phone calls from people saying, I don't know

what to do about my children. And in my work with parents, I try to remind them of all the good things and all the strengths and all the things that they are doing right with their children.

I have an important quote that I want you to take note of. It's, "Whatever is human is mentionable. And whatever is mentionable is manageable." And I don't know if anyone has heard that quote before, but that comes from Mr. Rogers, who is a very -- was a very wise theoretical person. And it's important to remember that because this is manageable. I mean, I think everyone here believes that or we wouldn't be here tonight.

And cancer doesn't, as you know, happen to one person, it happens to an entire family and a community. As Rosalind was saying about children taking the temperature in a room, children keenly feel a cancer diagnosis. The mood in the house has changed. Routines have shifted, and the person with cancer may not be as available to them.

Another important thing to think about is the Chinese language symbol for crisis. I don't know if anyone's ever seen this symbol. But what it means is opportunity and danger. Hopefully, this experience will be an opportunity for your family to model that this is how we problem solve. This is how we manage a difficult situation together.

The literature that's written about working with families dealing with cancer talks about the first 100 days as being the most stressful. And that includes both a new diagnosis and a recurrence.

And you obviously can guess why that timeframe is most stressful. Everything is in upheaval. There's so many unknowns. As Rochelle was talking about when she was speaking: Will I lose my hair? Will I be able to work? Will my health insurance cover treatment? And how will I manage my children? You're really in the eye of the storm when you're in the initial phase of the medical information.

And then about the three-month mark or so, a routine starts to establish. Everything is not as foreign. But it's such a short period of time that many decisions need to be made. And it's hard because there's so many things you don't understand in the beginning that are crystallized as treatment ensues. And yet, you have to make decisions. You have to interview physicians and medical teams, and you have to talk to your kids. And as I was saying a little earlier, your understanding of the diagnosis and what it means to your family and their understanding will evolve.

I was starting to say that at the three-month mark, you start to get a glimpse of a routine. One of the challenges that I think everyone in the audience is faced with

and that we're faced with as social workers is the fact that being a patient is a full-time job. And so is being a parent. And neither role goes away. The role of patient, hopefully, goes away. But at the time, it's all-consuming. And it's sometimes hard to have room for your child.

It's a very tough time to give information to your children when you're feeling kind of fragile. And I agree with what Rosalind said, if you're feeling incredibly fragile, you may not be the person to give the initial information. But, it's hard. You're scared. You're vulnerable. This is not the time you would ordinarily choose to give such important information.

But your children need the information. And one of the most important reasons is to keep them from needlessly worrying. As Rosalind was mentioning and anyone out in the audience who has an imagination knows this, that if you don't give information, it's very, very scary. The things that they may fill in the gaps with may be worse. And children need to have control in the way that adults need to have control, particularly in a situation that really highlights that we're not in control here.

By giving the information to your children, you validate their experience, which is extremely important because it's a crazy making experience, particularly if you don't know what's going on. And at a minimum, what children need to know is the name of the disease -- we're talking tonight about breast cancer -- where it is in the body, and preferably before treatment starts, before there are physical changes.

It's tricky to talk about this because we're talking about an intimate part of the body and many people would not opt to talk to their children about their breasts, quite frankly.

An important point that I think needs to be emphasized is not using euphemisms. They lead to a lot of confusion and anxiety. And it's particularly the word "illness" and "sickness." When you're talking about little children, when they think of illness or sickness, they're thinking of colds. And doing the math, that leads to catching colds and spreading. And cancer doesn't work that way. So it's important to use the word "cancer." And again, if we're using the word, we're saying we can manage this. You can talk to me about it.

Developmentally speaking, it's important -- and you know this -- that children think that what they do, there's a cause and effect. And as both Rochelle and Rosalind were talking about -- if I was mad at mom, I caused her cancer. Or because I'm not doing well in school, I caused her cancer. Very important to look at the fact that a child's world is real small, probably until they get into late adolescence.

So in a second, I'm going to talk to you a little bit more about that. But, children need clear, age-appropriate information. Not information that's overwhelming.

A few years ago I had a client who was a physicist and literally gave her daughter information that you would have to go for about 18 years worth of schooling to understand. And it was very frightening and confusing and I didn't understand what she was talking about and neither did the kid. I don't care how bright your child is. Your child is a child. And one of the things you want to do is ask them what they know about cancer. Have they heard the word? What do they think it means?

Also important to answer questions that are asked and not to over give information. When we're talking about preschoolers, we talk about a boo boo called cancer. And saying that the boo boo is called breast cancer and that the doctor is going to give mommy very strong medicine and you did nothing to cause this.

For school-age children, you might want to talk more about some changes they've seen in the family. "Do you know that mom's been at the doctors a lot? That we've been upset? This is why." And again, this is where the cancer is, name the treatment that's being offered. There are different types of cancer, as Rosalind was pointing out, which is important. That it isn't all one disease. It behaves in many different ways. There are good cells and bad cells.

With children who are eight and over, they may want even more specific information. And if you're comfortable with that, they may want to actually see the body part, see the breast. And you have to make a decision whether that makes good sense. But, they're real curious about bodies. They have a lot of clinical information -- questions.

One thing I often ask parents is, "Does the child want to speak to the doctor or meet the medical team?" I've known 4-year-olds who have met oncologists and said, "You better be taking good care of my mommy." They're on notice. And it sometimes helps for them to be able to ask other questions that maybe you couldn't answer.

One thing about older children that you need to be careful with is the fact that developmentally speaking, they're individuating from you. They're trying to separate and do their own thing. And they may have some feelings about the fact that they're more needed at home now. The baby's sick. Or perhaps to administer some medical care.

One thing that I would caution people about is always to error on the side of finding another adult if you can. Do not have a child function as an adult. And I'm thinking about things like administering Nupigen or Epigen. Sometimes you don't have a choice and you need a child to learn.

But it's important to find out from your child if this is more anxiety-provoking than it is helpful. And if there's any other way you can get a nurse to come in or hire help. Important to be aware of age-appropriate tasks. Can a child do something else? Can they bring you water? Can they remind you to take medication if they need to have more of a medical role?

With older children -- and with all children -- you need to reiterate "What do you think? Do you understand what I'm telling you?" Often times when we tell parents to have conversations with their children, the child can tolerate only so much information and then the child goes out and says, "Okay, that's nice. I want to go play." And that's normal. Children can only take this information in small doses, as some of us adults do.

Some of the points that are really important to stress and to continue to stress throughout treatment is that no matter what they thought or did, they did not cause the cancer. Children need to know that they're important, that they're involved, that they're part of the family. They need to be reassured about the reactions of the adults around them.

They need to maintain age-appropriate activities. It's okay to be a kid. It's important to be a kid. They need to know that they can have their own thoughts and feelings about the cancer diagnosis. That they might be really angry. They might feel guilty. They might feel confused. They might feel everything at once, which is normal and common. And while we're saying it's okay, it doesn't feel okay. But that needs to be validated.

As we were saying earlier, you cannot catch cancer. And obviously, I'm not dealing with the genetic issue here, but that cancer's not spread the way the common cold is.

They need to know that they'll be consistently cared for. Very important that if you can have the same caregiver care for the kids. Important that if you can keep the kids in your home, to not send them out to other relatives, if at all possible.

They need to know that they'll be disciplined, that there are still rules in the family. That we're not running amuck because of this diagnosis or treatment. That if the other parent is well -- and it's important if the other parent is healthy,

that they've gone to the doctor and that they're feeling okay and they're going to take care of you.

Community is extremely important. I hope everyone knows that and certainly, we value that because we're here this evening. But to involve as many people in your child's life as possible who care about your child. Whether that's the Rabbi, teachers, parents, the friends, guidance counselors, people who run activities -- anyone who has an interaction with your child needs to know because you need them to be on the lookout for your child to see if there are any behavior changes or just to provide support.

And some of the things that we get concerned about with kids are their grade changes. And people often talk about grades slipping. But it's important to keep an eye on the kid whose grades are perfect and feels that they must be perfect so that mommy will get well. You know, all the magical thinking we all do.

Irritability, mood change. A child who's normally very outgoing becomes kind of reticent or vice versa. Very important throughout the entire process to talk about any physical change that mom's going through. For instance, having surgery. "The doctor says I won't be able to drive for a while, so and so will take you to your activities." Or not being able to lift things. Or not being able to use a certain arm and having to baby it.

Very important to prepare and anticipate for children. Any sights or smells that are going to be different. Will a visiting nurse be coming in? Will there be drains? What does that mean? For how long? Anything that you can think of they need to know.

A very important piece here for anyone going through treatment is the fact that it's cumulative. How you're feeling when you first start treatment may not be how you're feeling throughout the course of chemotherapy or radiation. It's exhausting. And it's the type of exhaustion that people describe as being a tired that is like none other. That you can sleep for eight hours and wake up exhausted, that you're not replenished.

And I know of so many people who tell me that all they could do was take a shower and they're wiped out. Really hard to deal with an angry 10-year-old who doesn't know why you're not taking them to soccer practice and you're just laying there. Hard to explain it. Hard to concretize it. Important to keep talking about that and reminding your children that you're sorry. You know it's frustrating. That you're not doing this deliberately. That it's the affect of the medicine and that it's hard when your body is not predictable, which a lot of people report to us, the fact that you try to make plans and that you may or may not feel well enough to go through with them.

Parent may feel crabby. They may not be able to have friends over because you're immunosuppressed. Or you may not be able to go to a school function because you're immunosuppressed. That's really hard when your child is counting on you to sit in the audience. Can someone else attend? Can you make it up to the child? Can you keep talking about the fact that this is upsetting and not how you want this to go?

Keep checking in. Keep checking in. And it's hard because "Are you the same mommy?" comes up over and over again. It comes up in the work that I do with kids during play therapy. What does the new mommy look like? And what are we going to be like as a family?

Some of the things that I talk to families about are having activity baskets. If you're not able to go to an activity, are there quieter types of things that you can do together. A journal as a family. And you can either buy a notebook or make a book together and date it and this is how I felt today and this is how you felt today. Or work on projects together. Watch videos. Have your child read stories to you. Be creative. And I think a lot of people experience the diagnosis and the treatment is needing to be more creative in terms of what they do with their kids.

And basically, I'm going to end with the point that we're talking about your child at this moment. That everything that we're aiming for here is that one day your 5-year-old, your 7-year-old, your 12-year-old will be a functioning, independent adult. And that's the point. Even though these conversations are so difficult, you're thinking about the big picture.

That's all I have to say formally. Thank you.

Rochelle Shoretz: Thank you, Peggy.

Our next speaker, Ingrid Whitaker, will continue the conversation as she addresses the needs of a child whose parent has completed treatment. Ms. Whitaker works with children and teens with a parent fighting cancer as the program manager of Noogieland, a children's program at Gilda's Club New York City.

Please join me in welcoming Ingrid Whitaker.

IV. The Needs of Children Whose Parents Have Completed Treatment

Ingrid Whitaker: I guess I'll start with a panel disclaimer that I'm going to be repeating some of the things that the panel has already said. And I think that speaks to the fact that many of these themes carry over throughout treatment and beyond treatment. And that many of these things are inter-linked. So if you feel like you've missed your opportunity to begin, you still have many opportunities to begin to speak with your children about things.

When I was nine years old, my 11-year-old brother died on the operating room table during open-heart surgery to correct a series of chronic heart problems. When I was 29 years old, my mother was diagnosed with stage three breast cancer. Now I'm a social worker at Gilda's Club New York City who works with children whose lives have been affected by cancer.

My life has enabled me to understand first-hand the grief that a child feels from a loss that changes the family forever. I also have struggled with and celebrated many of the phases that come with being the daughter of a mother with cancer.

Working with the children at Gilda's Club has provided me with the privilege of being with these special children at a unique and fragile time in their lives. It is my hope that I can share with you today some of the things that I have learned over the years, and perhaps provide some guidance to help you and your families manage the post-treatment experience.

It's probable that many of you sitting here today have already been through some combination of treatment consisting of surgery, chemotherapy, and/or radiation. The treatment regime has probably left you with both physical and emotional changes. Some of the physical changes may be permanent, such as the loss of a breast; or temporary, such as fatigue, memory loss, or hair loss.

And then there's the emotional impact of the disease on you and then the impact on your family. Post-treatment. By definition, that sounds like it should be the end of treatment, and therefore, the end of the challenging part of cancer. This notion is one that can leave many women and their families confused as they enter and begin to live through the post-treatment phase.

Many cancer survivors find the post-treatment phase to be interestingly one of the more challenging phases to manage. Why is this the case? In many ways, I believe that expectations play a role in the confusion and turmoil.

When you go into treatment, there seems to be lots of information about the potential side effects and what to expect. As Peggy Murphy was saying, the first 100 days what to expect. You and your family prepare yourselves for the road that lies ahead. Your friends extend themselves in any way possible so that they are able to help you and your family move through this process as quickly as possible.

You go through your treatments sometimes feeling better and sometimes feeling worse, but always expecting not to feel well and appreciating if you actually happen to feel better than expected. You're busy running from appointment to appointment to get well.

And then one day, it all comes to an end. The treatments stop. The appointments slow down. And along with it, the friends no longer think they are needed and you, and particularly your family, are ready to just get back to normal. And this is not to say that your family will never get back to normal. It will just probably be a new normal, which may take some getting used to.

What I want to share with you today is what I would call the nitty-gritty of the post-treatment experience, perhaps highlighting some of the darker corners of this phase for you and your family.

I want to let you know some of the possible hurdles that lie ahead so that you and your family can look out for them and be more prepared for them if they happen. Now, I say if because everyone's experience is different. That is always important to remember.

I will also share some of the stories of the children that I have worked with whose family members have had various types of cancers and whose situations had all types of outcomes. Yet interestingly, I have often found that the needs throughout seem to be quite similar.

In addition, I want to remind you like the rest of the panel has, that you are the experts of your family and you know your children best. What I share with you today may or may not be particular to your family. Trust yourself and your sense of judgment. You have your own styles and traditions and you have to do what is right for your family. At Gilda's Club, we feel that the members are the experts in their experience.

Now, that doesn't mean that the experts don't need some suggestions of possible options to help them, but it does mean that you know best what feels right for you and your children.

In preparing for this presentation, I went to the experts, the children at Gilda's Club, and I let them know that I would be speaking to parents about how to help their children when cancer happens. I asked the children what they thought would be most helpful for your children. Their message to you was this: Tell the truth, keep talking, and let us be a part of things. Now, these messages may sound quite simple, but anyone going through this knows how hard this can become.

There are a variety of factors that can complicate these three needs from being met. Yet, I have seen time and time again the impact of whether these needs are met or not in a family.

Telling the truth. That sounds easy enough. We always ask for our children to be honest, so why can't we? The reality is that the truth both during and after cancer may be hard to manage and painful to imagine. When thinking about telling the truth post-treatment, you may feel that your children have been through enough already and why should you burden them with more information?

Or perhaps you withheld a lot of information during your treatment and now it seems like too much of a challenge or unnecessary to share the information now. Or perhaps your children seem like they are ready to move on and get back to normal and all of their behavior seems to suggest that they no longer want to even think about cancer, let alone talk about it. Maybe you're unsure what to share since you yourself don't know exactly what lies ahead, what the future may hold.

Or finally, perhaps you are fully aware that your prognosis is not good and that just seems too painful to burden your children with already. You wonder why you should share something that may just upset your children more since you have been through enough already due to your cancer.

Your guilt, your sadness, your anxiety can feel overwhelming. However, whether your prognosis is good or bad, the children need to be told the truth whatever the outcome. They need to be able to prepare for what lies ahead just as you need to be able to prepare.

Some of you may be asking, "If my prognosis is good, what do I possibly need to prepare them for?" Well, having been through the treatment process with you, your children have seen lots of changes in their lives. Their daily routine has probably been changed. The family roles and responsibilities have probably shifted. And they probably have lots of thoughts and feelings about all of this.

There's a tremendous readjustment for both you and your children. You both need the space and permission to grieve the life that has been changed and lost

and to come to terms with the new life that's ahead of both of you. Your children may still have some leftover disappointments, anger, or sadness about what has happened over the past few months or year. It is important to find a way to forgive each other and forgive yourself.

At the same time, there may be a tremendous expectation and urgency that now everything will just go back to normal again. And for a variety of reasons, that may not be the case. Even if your prognosis is good, the after effects of treatment can leave you fatigued and unable to jump back into your role as super mom.

Children need to be told the truth about what to expect over the next few months or year. They need to be prepared for things such as, "How long will it take for mommy to stop having to take naps or for daddy to stop having to do so many mommy things?"

And you as a parent need to be prepared to continue to ask for help and to continue to delegate when necessary and possible. After all, one of the ultimate expressions of love is recognizing your limits and putting your child's welfare first.

Although you and your children may desperately want it to all go back to normal, they will do better when they are more aware of what is coming. Sometimes their needs may not be met and it's helpful to teach your children how to express their feelings about this. Encourage them to express themselves. It may be painful, but it is vital.

This will help to teach your children how to cope with life's challenges and disappointments. In addition, even though you are now out of treatment, you'll probably still have follow-up doctor's visits and blood tests, or you may even require further treatment. Tell them about any additional surgeries, medicines, and how they may affect you if it affects them.

Perhaps you will have additional side effects, such as more hair loss, greater fatigue, or even sun sensitivity that could affect vacations. You need to keep your children informed now so that they are aware of what is happening. Otherwise, something as simple as a Band-Aid that is suddenly on mommy's arm for a routine blood test could send panic into a child who has now learned some of the telltale signs of hospital visits. And this child may fear the return of cancer. Without adequate explanations, what their powerful imagination creates can be much more devastating than your actual reality.

Now, when I say tell the truth, that means tell them enough, but not everything. They need to have answers for the changes that they see affect their lives and their world. And they need to know it in age appropriate language. Telling the

truth to the child continues to build trust and allows the child to trust their sense of the world. Hearing the answers from you allows them to have correct, undistorted information, unlike what they may hear from some of their friends.

As many people have often said, and even said here today, yet many don't always want to believe, children always know. They always know. They may not know exactly what is going on, but they know that something is going on. And when you share the truth with them, you allow them to trust their sense of reality.

There's no question that one of the greatest challenges for family's post-treatment is living with the uncertainty of recurrence. Like you, your children may be afraid that the cancer will return. It's important to give your children the best and most honest answer that you can when possible.

Sometimes that answer may even be as simple as, "I don't know." If there is not a likelihood of recurrence, perhaps you can say something such as, "If it comes back, we will deal with it. For now, I am planning to never need chemo again."

On the other hand, if there is a possibility of recurrence, the child needs to be forewarned. If they are told that everything is fine and it comes back, then they have to deal with huge disappointment and perhaps greater fear. Use these moments to allow you and your children to face the fears together.

Despite how challenging it may feel, it is always important to approach the topics honestly and to praise your children for having shared their feelings and concerns for you. Children are resilient and their response is not shaped as much by what the change is, but rather by how it is presented and how prepared they feel.

One of the most painful possibilities of cancer is if your prognosis is not good. If that is the case, you need to let your children know. While this may seem tremendously cruel and unnecessary at the time, they need and deserve to know the truth. And though it may be tempting, try not to make promises that you may not be able to keep.

I'm reminded of a 10-year-old boy that I worked with whose father had pancreatic cancer. The family made sure that the boy knew that the father was going to die, but of course, did not know how soon. The father ended up dying within a year of diagnosis, which is an unfortunate reality of this particular type of cancer.

However, all along, the father had told the boy that he would live to see him graduate from high school. No matter how sick the father got, and even when the father required hospice, this 10-year-old boy kept holding on to the promise of his father seeing him graduate from high school.

The father did all he could to stay around as long as possible, but eventually, his body let go. The boy could not understand how this could have happened. My heart breaks for this family. And though I completely understand the wish, hope, and need that filled this promise for everyone involved, it was very hard for the boy to understand how it was not so.

Children can at times be very concrete. And if you promise to be there for something, it will be hard for them to understand how it did not occur. It's helpful to be careful about how you say things to your child. Perhaps saying "My doctors and I are doing everything I can to help me be here with you as long as possible" is all the reassurance that you can give them at the time.

When deciding how to share a bad prognosis, the status of your current medical condition coupled with any spiritual beliefs that you may have will help to inform you about how to choose to talk to your kids. One of the hardest things for a parent to come to terms with is that as hard as you can try, you can't protect your children from change, loss and pain. But, you can help them deal with these facts of life in a healthy and healing way. And like you, your children also deserve a chance to say goodbye and to continue to find ways to cope.

One of the girls I worked with at Gilda's Club was the one who said, "Let us be a part of things." She's a 10-year-old who started coming to Gilda's Club right after her father died from melanoma. In an effort to protect her and her 6-year-old sister, her parents decided not to tell the kids that their father was sick with cancer.

Once he got too sick to be able to come home, the mother finally shared that the father was sick, but didn't want the children to see him as sick as he was in the hospital. The father died in the hospital and the children were shocked. In an effort to protect them, understandably, the children were consequently unable to process the severity of the illness and were, therefore, unable to say goodbye.

The 10-year-old still speaks about how much she wished she would have known. She continues to talk about all the things she would have said and done differently had she known the truth. She understands that her mother and father were only trying to take care of her, but she is sad for what she can never redo. Her 6-year-old sister continues to use her time at Gilda's Club to process through her grief through activities.

Every week during Small Talk, the arts and crafts base support group for children, the 6-year-old uses the play dough to make her father's grave with a white cross on it. And then she makes flowers around the grave, one for each of the family members that are left behind. Each week I ask her to tell me what she

has made and she quietly shares her thoughts about the grave and missing her father and the prayers that she says for her father. Through her play, she is working through her grief.

And the parents in both of my stories are loving parents who were doing the best they could and honestly doing what they thought was right. They did not realize the impact of some of their choices. And fortunately, their children are talking about it now and processing through it in various ways both at Gilda's Club and with their families.

When helping your children to deal with end of life issues, it is important to validate their fears, anxiety and grief. They need to know that what they are feeling is normal and understandable. In addition, they need to know that no matter what happens, they will be taken care of, that there is a plan.

If things seem to feel really sad and heavy all the time at home, sometimes it may be helpful to encourage the child to remember some of the good things in the past and present. Allowing the child to express the sadness and also at times to be aware of the good times will help the child to learn that both realities can be true in life.

And now, moving to the second piece of advice, keep talking. Again, something that sounds easy enough but can be quite difficult, painful, and challenging. As your children go through the post-treatment process, some of their anxieties may continue to surface. They may have to ask you the same questions over and over as they continue to process through their emotions. Always be as straightforward as possible and let them know that you will keep them informed of any changes.

Perhaps other emotions will be prevalent for your children that may be challenging to manage and difficult to respond to. If they are angry, let them know that being angry is understandable and okay. Besides encouraging them to talk about their angry feelings, you can also help them to get physical and to exert some of their aggression through activities that they enjoy.

If your children are sad, they may be grieving all the losses and changes and yet, they may also not know why they are sad. It may be difficult for them to verbalize. Give your children permission to grieve. Let them be sad. It is also helpful, of course, to cuddle and comfort your children, giving them a place of security and safety.

Laughter is also something that time and time again has been shown to be helpful, and even healing. Encourage your kids to laugh and have fun. Let them know that it's okay to still live and be playful despite what may be going on.

If you're unsure about how to talk with your children about any of these issues, the first thing to remember is that it is never too late. There are various ways to begin to help children to open up. When asking questions, it's always best to ask them open-ended questions, or what we can call "fishing questions," such as, "What do you think could happen?" Or "What is your worst fear?" Or perhaps, "How do you feel when I go to get check-ups?"

Another tool that can also be used is the "three wishes game," which a lot of the kids at Gilda's Club love, which is a safe way to see what is on your child's mind. And, of course, keep in mind that these wishes can understandably change from time to time.

Family meetings are also a helpful way to bring the family together to keep talking. These meetings create a forum for sharing information and updates, but also create an environment for cooperation, mutual respect, and understanding. It helps a child to feel included and important in the family. Family meetings embody the third piece of advice by letting your children feel like a part of things.

When done regularly, not just when the family is in crisis, these meetings can keep tensions from running too high. When it is only done in crisis, it sets a different tone for the meeting and can raise the anxiety level of the children and for you. It's important to try to keep it as a part of the family routine on a regular basis.

In addition, though you may feel as if you have few reserves as you try to move back into your life, try to re-establish routines. Getting back into routines can go a long way to helping a child to feel secure. Dinner times, bath times, bed routines, all provide a sense of security and help to re-establish intimacy again.

It's also important to be sure to set aside private time for each child on a regular basis. The two of you can use this time to talk, relax, or do fun things. Spending this time together helps them to feel loved and cherished. Also be prepared that your children will most likely share some of their more intimate feelings when they are one-on-one with you. Those can be very precious times.

It's also helpful, as others have said, to keep other significant people in the child's life as up-to-date as possible about any additional information that's going on to provide additional support to your child. Teachers in the school, religious personnel, extended family are all additional people that your child can turn to for support.

You may want to encourage your child to share things with his friends, not needing to keep them all to himself. Help your children to build community. Help your children to build a community of support.

The 10-year-old boy that I spoke about earlier, his mother asked me to come to speak to his class when his father started receiving hospice and the questions were too difficult and too much for the boy to handle. I went to the school and together, the boy, his mother and I helped to educate his friends and answer some of their questions. We didn't have all the answers for their questions, but we did begin to open up the lines of communication and to create an awareness for his classmates of what this boy was managing. That in itself was a helpful step for this boy.

Another option for a place to talk is through support communities such as Gilda's Club. At Gilda's Club, we feel that when cancer happens, it happens to the whole family. Everyone is affected in different ways and everyone needs their own place for support.

For adults, we have weekly support groups and we also have workshops that meet on a daily basis such as yoga, meditation, or art classes. These workshops help to teach people skills to manage their experience and to provide an outlet of sorts for them.

And on Tuesday nights while the children's parents are in their own support groups, the children can come together with other children whose lives have been affected by cancer in the play land called Noogieland. In Noogieland, the kids can play with other children whose lives have been affected by cancer, but they can also participate in Small Talk, which is a support group for children ages 3 to 12. In Small Talk, the children can come together and lean on each other in a way that is helpful to them and to feel empowered by being able to share their information with each other.

Time and time again, kids tell me how much they love coming to Gilda's Club. Not only because it's fun to play in the play land, but also because they know that they are in a room with other children who understand what it's like to have cancer in their family. It's a connection that means so much to these children. It helps them to have their experience normalized. At Gilda's Club they know they can lean on each other and help each other when they need to.

The post-treatment phase can be filled with challenges, but it can also be a time for new understanding, closeness, and appreciation for life. One thing that I have learned through my experience with my mother and her cancer is that at times, we will have wonderfully heightened moments of real connection, sometimes huge misses in communication, and sometimes we just coast along in neutral.

But, it is the talking and the coming together that is the glue that holds us together in the end. So from the mouths of my experts, I leave you with their powerful words: “Tell the truth, keep talking, and let your children be a part of things.”

Rochelle Shoretz: Thank you, Ingrid. And thank you to all of the panelists for sharing their insights on this important subject.

Now we’d like to open up for questions from all of you. I invite you to submit the questions you may have for our guest speakers on the cards we’ve circulated, and there are extras in the back. Pass them to the volunteers you will find roaming around the audience.

As we collect your questions, I’d like to welcome Shera Dubitsky to our panel. Ms. Dubitsky is a psychologist who has conducted research on intervention with children whose parent has been diagnosed with cancer. When Shera was 13 years old, her mother was diagnosed with breast cancer and lost her battle six years later.

I’d actually like to start with you, Shera, as I wait for some questions to come up. And I invite you to share with us your perspectives and reactions to tonight’s presentations as the daughter of someone who fought breast cancer.

V. Reflections From an Adult Child of a Breast Cancer Patient

Shera Dubitsky: Thank you. Listening to the panel today, it really brought back for me those six years of my life. And I really relived so many memories and everything that they touched on magically applied to me personally. What I just wanted to do was share with you some of the memories that I had based on the discussion this evening.

The first thing that came to me was the discussion of gifts and gifts to our children. And that the gifts that we as parents can give to the children are very powerful. But, on the flip side of that, that I think it's important for children to know that they are also capable of giving gifts. And that's something that I live with as an adult that I can feel proud that my mom was able to acknowledge the gifts that I gave to her as well. And that we shouldn't underestimate either side of that.

And just as Rosalind was saying that we should do the best as parents that you can do. But, I think that as important as that is, we should also recognize that there may just be things that you can't do.

And one memory that came to mind was that I had gotten into an argument with my mom and I was feeling furious and angry. And I stormed out of the house. And as I was storming out of the house, I was cursing and yelling. And there was a crescendo of that, and as soon as I left, the guilt came on. And I felt guilty. And after some time, I was able to return and it was clear that I felt guilty about my anger.

So being a good mom, she told me that it was okay for me to feel guilty -- to feel angry, and that I shouldn't feel guilty about it. But then that left me in confusion because it was hard to feel angry at somebody who was being so nice to me. So I think that that was a no-win situation for her. But, I also think that that was an okay interaction.

I also wanted to talk about the importance of laughter and touch that was also brought on. And that again, memories that I have are that we had a lot of laughter in our household during that time. And it was a big relief for me when I was able to see my parents laughing even in very difficult times, that I knew that I would be able to laugh again.

And again, looking back now, that was a tremendous tool. And again, Rosalind talked about that. That's been a tremendous tool for me in terms of coping with

things in my own life today and has shown that I've been able to get through things and that I too can be a survivor.

And we didn't really talk so much about this, but I really want to say that sometimes the words are not available. And that touch is incredibly powerful as well.

And I wanted to share a very inspiring story at a time that it seemed the most despair in terms of our family. And that is when my mom was dying and she was in the hospital, she -- between the cancer and the medication, she was very much out of it. And I remember it being in the middle of the night, I went to the hospital to sit with her, to be there with for her and to provide comfort, which as a 19-year-old is a bizarre place to be.

But that at one point, I was leaning over her bed and out of nowhere, she took her hand and she placed it on my cheek. And I don't know where that came from. But that touch -- that simple touch is something that when I go through things in my life today, I feel the warmth of my mother's hand on my cheek. And that touch is consistent throughout my life with my mother that I remember the touches.

So sometimes, I think as the women spoke about, the words are hard to come to. And sometimes a touch is okay and enough.

I also want to say also another inspiring story for me in a time that was difficult was that during the time of saying goodbye -- I think that Ingrid was talking about -- that the courage that came out in our family was again, very strong. And I share this for a reason. That my mom had brought us into the room together and she had said to my father in front of the children, "We had a very wonderful life together and you've made me very happy and I would want you to have that for the rest of your life. And I'm saying that in front of the children because I never want the children to feel that you've betrayed me."

And that was an act of courage. But again, it goes back -- the reason why I'm bringing this up is actually not as a painful memory, but in fact, as an inspiration that I believe that my mom and my father gave me the tools to live by and the courage and the trust that they did speak to me truthfully and we did have open dialogue. I think to a fault. I think that in fact sometimes they gave me too much information and I really would caution to find out what the child really wants to know. But, I do feel that I grew up being able to trust and being able to have courage and being able to know that I can live on.

And I want to just leave off with this one last thought, that this year was a significant year for me because I was 19 when my mom passed away and it's

been 19 years since my mom passed away. So there's been a turning point in my life that I actually have lived longer without her than with her.

And at a time where I really had to think about things again, I want to say that in those 19 years that I've lived without her, she has been a part of my every single day because of these tools and because of the courage and because of the laughter, that she has continued to parent me even in this time that she hasn't been around. And I really would not underestimate the power of what you can still give to your children in the most darkest of times.

VI. Questions and Answer Session

Rochelle Shoretz: Thank you so much, Shera.

I'd like to start the question and answer period by touching a little bit on something Shera just mentioned and something that one of the other panelists mentioned as well.

And that is the concept of too much information. One thing that we've heard some conflicting information on in the past has been whether or not a child should see a parent's scars. And that goes along the lines of what is too much in terms of sharing with your child.

What are the expert opinions on the subject? For any of the panelists, feel free to --

Rosalind Kleban: I think one of the ways in which we always approach this is, how did the family run prior to the diagnosis of breast cancer? Is this a family where mom generally walked around without clothing on where she was perfectly comfortable when the children came into her room before she was dressed?

There's a problem there because now what is she going to do? Is she going to hide? Is she going to change the culture of the family? That becomes difficult because in including your children, you want things to stay the way they were to include the child in what's happening.

However, it may be too much for a parent to share that kind of thing with a child. And if it's too much for the parent to do that, therefore it can't be done. If a child asks and it's okay and the child really does want to see it, and it's okay with the parent, then we would suggest then that it's okay. If the child asks and it is not okay with the parent, then it can't be done because the bottom line is it has to be something that's comfortable with mom -- for the person going through this.

And that comes with a very reasonable explanation. There are things that are private. And everybody has an opportunity and a right to have privacy. And on this issue, you could describe what it's like. You could draw a picture. But, if mom can't do this, then it can't be done. And I think the child can understand that.

If the child doesn't ask to see, well, he's telling you something. He or she is telling you that they don't want to see. So I think it's something that there's no rule about it. I think it can be worked out.

Peggy, would you like to say --

Peggy Anne Murphy: I can't do a better job.

Rochelle Shoretz: Along those same lines then -- a question came from the audience -- How do I help my daughter love her body as she develops into a woman? How can I help her not fear her breasts? Ingrid, I think you might be in the best position to talk about the post-treatment discussions one has with growing children and particularly daughters.

Ingrid Whitaker: I think that that's also a discussion that mothers and daughters struggle with whether there's breast cancer in the family or not, is the child's image of self. And that's something in today's society that we are constantly dealing with.

I know with the teenagers that I work with a constant discussion is their body image and what to do. And I know that there's one teen that I have whose mother has just gone through breast cancer and the teen has her own concerns in terms of that and has had a lot of open dialogue with her mother about the possibilities and the what ifs and things like that.

And, I think that it's something that we're -- it's really about an ongoing discussion with the mother and the child in terms of where they are, what their feelings are about their body. And also asking if, as I said during the presentation, that it's -- asking the child what their thoughts are and how do they feel about things, but not asking more than what the child may already want -- not asking more than what the child has not asked for.

Rochelle Shoretz: Peggy, for you: How can you assist a child who adamantly refuses to hear about, let alone discuss a mother's illness?

And I'm going to add to that the flip side of that. What do we do about parents who adamantly refuse for whatever possibly legitimate reasons, who just can't have these conversations? Are there other resources? Are there other approaches besides for the conversations that we all seem to agree are important? Are there any other options?

Peggy Anne Murphy: Your second part of the question I have a little more of a struggle with in terms of the parent issue.

I think a child who is so adamantly opposed to hearing about information you have to be respectful with that child. And keep reiterating the fact that I'm here.

And if you want to talk at some point, you can talk to me -- or if not me, someone else in the family.

Or, I guess, try to explore why they are so afraid of information. What is it that's so upsetting? It's kind of a balance between respecting someone's right to say, "I can't handle it and I need space" versus the parent thinking that you do need some information to cope.

Parents who are -- the second part of that, Rochelle, about parents?.

Rochelle Shoretz: Parents who just can't have these conversations. We've spoken a lot tonight about methods to open dialogue and the importance of raising certain issues with your child. But there are, and I know for Sharsheret callers in particular, there are some women and men who really are not in the best position to have these conversations. What else can we do for those children?

Peggy Anne Murphy: In my capacity at Cancer Care, I might invite the parents to come in and keep talking about why it's so difficult. Do they need someone else to be there when they give the information? What are they resistant to? It's a process I would keep exploring, why they're having such a tough time and what they're afraid will happen.

And also the issue that you don't want a child to hear about it from someone else. I had a client a couple of years ago who came home to an answering machine message. Her parents had decided not to tell her about the breast cancer and Aunt Sally said, "Gee, I'm so sorry to hear that you have breast cancer." So it was out.

So continually educating and explaining to parents that you want to be the person, or if not the person with cancer, you as a family want to control the information. You don't want the child hearing about it in other ways. It's complicated.

Rochelle Shoretz: For you, Ros: Is there ever a time or situation to conceal a diagnosis or a prognosis from a child? And then, sort of a tangent question, but still related, how does one approach the risk of cancer for our own children? Is that something to discuss? Is that something to hold back on?

Rosalind Kleban: I suppose there's always the possibility of all kinds of things, but I haven't run into a situation where I felt that the children should not hear about what was happening in the family. In the words of the children themselves what they said was they wanted to be included. They wanted honesty and they

wanted to be kept in the loop. So I can't think of the situation where children shouldn't be told.

And, Rochelle, what was the second part?

Rochelle Shoretz: The second part is how much information do we share with our children about their own chances of developing breast cancer?

Rosalind Kleban: Well, outside of the new developments of people who are tested for the BRCA gene, we just don't have an answer to that question. The answer that we do have is that --

Female Speaker: [indiscernible].

Rosalind Kleban: No, children are not tested. It's just the -- do you know the in's and out's of the testing? It's the --

Rochelle Shoretz: The parent is tested.

Rosalind Kleban: The parent is tested. And then I think probably when the child becomes an appropriate age, they become part -- at least here at Sloan, we have a surveillance clinic that takes care of people who are at that kind of high risk. And at that point, there are all kinds of options.

Rochelle Shoretz: Adult daughters, obviously, can be tested.

Rosalind Kleban: Adult daughters; right.

The issue -- and I think a lot of what we've been talking about here, particularly when we say we want to tell the truth, we don't know the risks that our children are at. What we can bring to our children -- which is a positive thing -- is the fact that they need to be aware. They have to constantly be aware. That's the responsibility of every woman. The biggest risk for breast cancer is being a woman and every woman has to be extraordinarily vigilant.

A patient I have who had breast cancer 10 years ago, she has a daughter and two sisters. And she said the way she coped with the notion that she felt guilty in bringing this to the family, she was able to turn that around and tell herself that what she was bringing to her family was an awareness. That these were people who couldn't possibly say, "Oh, this year I'm going to skip the mammogram." They couldn't be cavalier about their healthcare. They had to be extremely vigilant so that I think what we all struggle with is how to accommodate ourselves to the unknown and to being out of control of certain things. And the absolute truth is we have no information about the risks our children are at.

Shera Dubitsky: I'd like to just add something to that because something that I've had to deal with from my early 20's was when I used to go for physicals, let's say with a new physician, I always had to fill out that questionnaire. And inevitably, that question always came up about your family history. And that's an emotional time for a daughter or any child -- but certainly, for a daughter that that's something that is always highlighted whenever you go for a physical. And I've had to go for mammograms at a very early age. And they're much more hyper vigilant when you have history in your family.

And that's something that -- not for the younger children, but certainly for your teenage daughter if you are having open discussions, that I think that you should prepare them for because it can be scary to go for a mammogram and for any other person, it would not have been given a second look. But, because you have that history, they're going to want you in for a follow-up. And so that they should be reassured that that doesn't necessarily mean that there's anything, but that it's just them being more cautious because of your history.

Rochelle Shoretz: Shera, this next question is for you: In families with more than one child, please talk about the roles which emerge post-diagnosis. How does an oldest child typically react versus the youngest? And perhaps you can share your own experience.

Shera Dubitsky: Okay. That is very -- and there are also gender differences as well. Because in our family, I'm the middle of three children. I have two brothers. And by far, my brothers were much more silent than I was. My younger brother was 10 and my older brother was 16. And my older brother, it was not something that he discussed with us. And that as a younger sibling to him, it was scary to me to see that my brother was so withdrawn. And that was yet another dynamic in the family because you often look to your older sibling to model how you're supposed to react.

So I knew internally that I was experiencing things. And yet, my older brother was reacting as if nothing was going on. So that was yet another dynamic for our family. And then my little brother was, I don't know, just like frenetic as usual in his life.

So I think that one of the things that my parents said to us was that each one of us was going to be dealing with this differently and that we shouldn't judge how the other was so that clearly, I should not have been seen as the hysterical female that I later on was seen as.

But, I think that it's important to communicate to all of your children that each of you are going to respond differently and each of you can approach your parents independently as you see fit to get your needs met.

Rochelle Shoretz: Thank you.

Ingrid Whitaker: I also think it's important to reiterate what I think Peggy was saying which is that a lot of times the -- I see with the children I work with that older kids tend to want to take on the role -- become parentified children and take on a lot more and they don't -- I see it a lot of the times in Noogieland that they don't even let -- they take care of the younger sisters and brothers and don't even really give themselves a chance ever to really be a child. And it's important to watch out for that role as well, which is a very easy thing to get into in the family.

Rochelle Shoretz: Peggy, I'm delighted actually to see a number of healthcare professionals here with us this evening. How can the professionals caring for breast cancer patients help those patients address the needs of their children? What resources might they make available? What kinds of conversations should they be having with their patients?

Peggy Anne Murphy: I guess one of the most important things is to ask how your children are doing. For 10 years, I worked at an oncology unit in a hospital and sometimes that information isn't always so -- I don't want to say pressing, but the medical aspects of the care sometimes take over. So asking the questions -- what was the -- I missed --

Rochelle Shoretz: What resources might you make available? What kinds of conversations should healthcare professionals be having with patients?

Peggy Anne Murphy: Healthcare professionals should also keep asking how the kids are doing. How have your children been doing throughout your treatment? How are they doing in school? What do they think about how you're feeling? How are things going at home? Do they need to talk to someone? It would be good to know if that particular unit is there a social worker who could talk to the kids. Should they go to a place like Gilda's Club or Cancer Care for support services? What information have you given your children? I don't know that a lot of medical people actually ask that question. What do your children know?

Rochelle Shoretz: Ros.

Rosalind Kleban: Our nurse could speak for herself, but I will speak for Fran.

At Sloan, one of our nurses has worked extensively on what we as health professionals can do to inform parents in what they can, in turn, do to help their children. And friends of the presentation for oncology nursing -- right ONS?

Female Speaker: Uh-huh.

Rosalind Kleban: What's the S?

Female Speaker: Society.

Rosalind Kleban: Thank you. Oncology Nursing Society -- for other healthcare professionals dealing with breast cancer patients in trying to teach the other nurses what needs to be done to take care of the breast cancer patient in terms of how to talk to children because I think it is neglected.

I mean, we as healthcare professionals, and certainly the nurses -- the nurses are geared to take care of a specific thing. And this is a little bit out of the realm. And so I think that that was a tremendous service to sort of highlight what is needed because a lot more attention is needed to this area.

Rochelle Shoretz: Good point. Ros, this next question is for you as well.

We talked a lot about chronic illness. One question that comes in from the audience. Is it not important to tell children that it is a terminal disease, not chronic? Perhaps a child might confuse the two. And the same for an older child. Is it not important to tell them that they may have to learn to take care of themselves?

Rosalind Kleban: Well, that's a very -- that's an important question and an interesting question, and in many ways a very philosophical question. And it sort of also speaks to when we talk about telling the truth.

The question that I have to follow that up with is, what is the truth? In all of these support groups I run at the Breast Center, which are many. I have a support group for young women with metastatic disease, as well as a support group for -- I don't know how to call it. They're not old women. They're regular women.

Rochelle Shoretz: Older women. Not old women, older women.

Rosalind Kleban: Older women. Thank you. I guess -- right, older women. And then, of course, a support group for newly diagnosed patients.

And we always talk about, "Are the doctors telling us the truth?" Now, I know here at Sloan, doctors pride themselves on telling the truth. But what is the

truth? I think if this is the truth, the doctors get this close because between here and here, we don't know. I don't know. The patient doesn't know. And Dr. Norton doesn't know. They don't know between here and here. They just don't know.

So when we talk about telling the truth, the truth is we don't know. I really believe that a doctor, a nurse -- actually, the patient herself and the family members know when death is really imminent. I think that that becomes obvious. That is not something we have to sit down and talk about.

But when a person is diagnosed with a stage four disease or metastatic disease, that is not a terminal condition. It may at some point be. But when that bone scan comes back with a positive finding, that also does not say that this is a terminal illness. We at the Breast Center call it a chronic illness. All of our physicians call it a chronic illness. Can it become a terminal illness? Yes. Of course, it can become a terminal illness. But am I going to tell a child I have a terminal illness when it may become terminal 8 years from now, 12 years from now?

I have women in my group who were diagnosed at stage four. I'm thinking of one in particular who was diagnosed with stage four disease in 1987. What was she going to tell the people around her who would be waiting now -- what is that 16 years for her to die?

So when we talk about telling the truth, we have to figure out, what is the truth? I think the truth is somebody diagnosed with advanced disease or then the person who was early stage and is now diagnosed. The absolute truth is that this person has a chronic illness. And chronic illnesses change. And if something changes within several years, that needs to be reopened and re-discussed, and as you say, the lines of communication should always be open. Then if you're always talking to your children, then if there is a change that makes this more dire, then the children will be in on it. But, to begin with to call it a terminal illness, that is not the way we approach this illness and I don't believe that it's accurate.

Rochelle Shoretz: Ingrid, once treatment has been completed, how proactive should a parent be in discussing cancer with the child? Should a parent wait for the child to raise the subject or raise the subject periodically?

And along with that question, one from the audience, what to do about a woman who is diagnosed before a child is born. How much information do you raise after the fact?

Ingrid Whitaker: Okay. I think that it really depends on a variety of factors in terms of how much you share after the treatment. It depends what you're managing after the treatment. What sort of -- is everything done? Do you not have any more follow-up visits? No more treatments to go through? Everything's done?

Then I think it depends on where the child is, what sort of behaviors you see your child demonstrating. Are you seeing problems in school? Are you seeing emotional upheavals? Are they angry? Are they sad? Because as we were saying here today, a lot of the emotional impact of cancer can really impact the family after the treatment because you're so busy during treatment doing things that it often doesn't catch up to you until afterwards. And what we often see with parents and with children is that the depression can set in afterwards just because you have time to finally sit with what's gone on and process through some of your emotions.

So I think it really depends what the child is -- what sort of behaviors are going on with the child. And if the child has questions, then I would encourage the parent if they are able to try to be able to answer them as much as possible because what I see a lot with parents is they keep coming to me and saying that the child keeps having the same question over and over again. And no matter what they say, it seems that as they process through different levels -- the children and the parents -- that similar questions and things still keep coming up as your child goes through different developmental stages.

In terms of if the child is unborn when the mother has cancer. I actually have somebody at Gilda's Club, a co-worker of mine who has ovarian cancer and who actually adopted her daughter. And her daughter didn't understand why her mommy loved working at Gilda's Club so much and spending so much time at Gilda's Club. And her mommy told her that she likes to help people. And her daughter, who's six years old, didn't understand how her mommy could understand about cancer.

And it became a discussion about why her -- because actually, the mother had not told her because it had been very far before this daughter was brought into her life. And the mother had -- it's now become a part of their discussion and a part of the daughter's understanding that this is in mommy's past and right now, mommy is fine and we are where we are and we're going to see where things -- and we are where we are and we will keep talking is basically where things are with that family.

Rochelle Shoretz: Thank you. Shera, what should parents tell others -- family members, school officials, friends about discussing cancer with their children? We have in the audience a school psychologist who's wondering what kind of

information she needs to help balance the needs of the child with the needs of the parent that she's working with.

Shera Dubitsky: So in terms of if the school psychologist was given information should she be passing it along?

Rochelle Shoretz: Correct. And just generally how and I guess even more broadly, what do we communicate to those around us about how to talk to our children?

Shera Dubitsky: Well, I think it's very important that the schools be alerted to what's going on. Because inevitably, whether your child is talking about it or not talking about it, it's affecting the child. And so the school or the teachers may be seeing certain behaviors that are different or an escalation in certain behaviors. I think it's important in fairness to your child that the school be alerted so that they can now make a connection between their behavior and that there's something really going on within this child's life.

I think that in speaking to the workers or in speaking to the people who are close, that I think it is fair to say this is what we've discussed with our child. And that we feel most comfortable that information is coming from us as the parents. Unless otherwise stated, I think somebody had mentioned that maybe it can't come from the parents. Maybe the parents aren't feeling that they're in a space to give that information.

But I think it's very important as professionals that we really respect the space that the parents are in and try to encourage them to give the information. Because I think it would be good if it came from the parents themselves. But that certainly, they should have the information as the first step. And the second step should be how much of that information do you as a parent feel comfortable imparting
-- for the worker to be imparting to the child, but not to violate that.

Rochelle Shoretz: Ros, I think we have time for one more question. What are the some of the signs parents might look for that indicate a child may need the help of a professional in addressing concerns about breast cancer? We've spoken a lot tonight about information that parents must pass on. But what happens when a parent realizes that this may, in fact, be a conversation beyond the scope of that which they're able to address themselves?

Rosalind Kleban: I'm going to answer very briefly and turn that over to Ingrid, who works directly with children. But, I think that when looking at your children, you want to see how well they're doing compared to the way they were operating prior to the diagnosis. I mean, there are a few areas that children have to

perform in at school. It's how they do in school. How they do with their friends. How they do at home. And if any of those things are disturbed in any major way, and you think it's beyond your ability to discuss this, I think that's the time to seek a professional.

I would always worry about the average child who becomes perfect. That's a bad sign. I mean, because that child -- either has felt guilty and thinks that they were responsible for what's gone on. Or is taking it upon themselves to cure you and is going -- by their perfect behavior, they're going to see to it that you're well. That's a bad sign and that needs to be looked at.

But, Ingrid, I think you work directly with children. What would you add?

Ingrid Whitaker: I think that if the parent feels that it's too much for them to handle, as we've said, that it's always helpful to have somebody else and not to feel like you have to take it all on as a parent in addition to what you're managing on your own and that turning to other places for support are helpful. Whether it's through someplace at the synagogue or support communities that are -- there are so many support communities that are around to support people living with cancer that are available to people.

The only other thing that I would say -- behavior that I would look for is if any child is talking about hurting themselves and starts to say that on a more regular basis, then that starts to become a sign immediately if the child talks about a plan and is thinking about things. This is when you want to get your child help immediately outside the family. And that would be the one sign that I would say to be aware of. Yes?

Female Speaker: I usually tell my patients to look at whatever developmental stage your child is at. If your child just recently learned finally how to sleep alone in their own room, and they start coming back into your room; if a child just recently was toilet-trained and they start having accidents again; that kind of regression in behavior for whatever developmental stage they were at baseline is also a very concrete something to look for.

Ingrid Whitaker: I agree. And I see a lot of times -- I think it's very -- a certain amount of regression in some ways is to be expected. And I encourage parents that I work with not to shame their child about the regression and not to -- and to maybe just ask what they -- I've noticed that this has started to happen. What do you think is going on? And approach it with a curiosity and try to see what the child thinks about for themselves and what reason does the child give so then you can work from their frame of reference and move forward with the child.

VII. Closing Remarks

Rochelle Shoretz: There are obviously so many more questions that we could address. And as we close tonight's session, I'd like to thank our panelists for beginning this conversation with us: Rosalind Kleban, Peggy Anne Murphy, Ingrid Whitaker, Shera Dubitsky.

I'd also like to thank, once again, the sponsors of tonight's event: the North Jersey Affiliate of the Susan G. Komen Breast Cancer Foundation, American Cancer Society, Cancer Care, Gilda's Club, and Hats of Hope. And I'd like to thank all of you for your participation this evening.

A transcript of this event will be posted on Sharsheret's website, www.sharsheret.org. And just a few of the many resources that parents and professionals can use in addressing the needs of children were presented here this evening: books published by the American Cancer Society, a video produced by Englewood Hospital in conjunction with the Susan G. Komen Foundation, children's programs at Gilda's Club and Cancer Care.

And I'd like to highlight as well Sharsheret's Link Program where young mothers can call in to be paired with others who have already addressed some of the child-rearing issues we began to address together this evening.

Thank you all for joining us in this important discussion.

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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