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## Managing Your Complex Emotions and Anxieties About Breast Cancer

November 9, 2007

David Sachs, MD

### ELYSE S. CAPLAN, MA:

Thanks to everyone who is joining us today. We welcome you to Living Beyond Breast Cancer's teleconference, "Managing Your Complex Emotions and Anxieties About Breast Cancer." Today's program will focus on understanding how breast cancer can be a traumatic experience and some of the implications for its recovery.

I want to acknowledge everyone for stopping in the midst of their day to join us. My name is Elyse Caplan. I'm the education director at Living Beyond Breast Cancer, and I will serve as the moderator for today's program, which many of you know is interactive in nature. Like all of Living Beyond Breast Cancer's teleconferences, you will have the opportunity to ask your own questions following our speaker presentation, so please stay tuned.

Some of the things you will learn about today are: coping with your complex feelings after diagnosis or completing treatment; how traumatic experiences in your life can affect your feelings and your behavior; coping with emotional difficulties during treatment or around anniversary or holiday time, and how those difficulties may trigger particular feelings; and when seeking professional help or medication might be important for you to think about.

As many of you know, Living Beyond Breast Cancer offers a variety of educational programs for women and families affected by breast cancer. We hope you'll take advantage of some of our other programs, such as our physical conferences. . . . Visiting our website [<http://lbbc.org/>] will help you get the information you need.

Also, if anyone needs to leave today's program early, we offer audio replay online for 30 days following today's program and, at a later date, a transcript will also be posted. Feel free to share this information with others who couldn't dial in today.

As I mentioned, the format today will be approximately a 30-minute presentation by Dr. David Sachs, our speaker. Then you will have the opportunity to ask questions. We do ask that, if you choose to ask a question, you keep it as broad as possible and get to your question quickly so that we can reach more of you on the line and allow our speaker to answer you in an efficient manner. Evaluations will be e-mailed to you after today's program; please keep in mind that your feedback is very important to us in designing our future programs. We sincerely read each and every one, and we hope you'll take a few minutes to complete the form online.

I'd like to tell you a bit about today's featured speaker, Dr. David Sachs, and then I will turn the program over to him. Dr. Sachs is a training and supervising analyst at the Philadelphia Center for Psychoanalysis and a clinical professor of psychiatry at Drexel University Medical School. He practices psychiatry and psychoanalysis in Bala Cynwyd, Pa., and has spent more than 40 years teaching, writing and treating patients.

Dr. Sachs has served on many committees of the local chapter of the American Psychoanalytic Association, its national organization and those of the International Psychoanalytic Association. He also served as editor of the *Journal of the Philadelphia Association for Psychoanalysis* and has served on the editorial board of *Psychoanalytic Quarterly*. One of Dr. Sachs's major interests is the relationship between traumatic events and later psychological problems.

Dr. Sachs has had prostate cancer, and his wife was treated for breast cancer 20 years ago. His daughter, Jean Sachs, is Living Beyond Breast Cancer's executive director. Please welcome Dr. David Sachs.

### DAVID SACHS, MD:

Thank you very much. It's a great privilege for me to be able to participate in this teleconference. It's my first one, and I am inexperienced at doing so, so I have prepared my remarks. I'm going to read them so I get into the conversation all of the points I want to make.

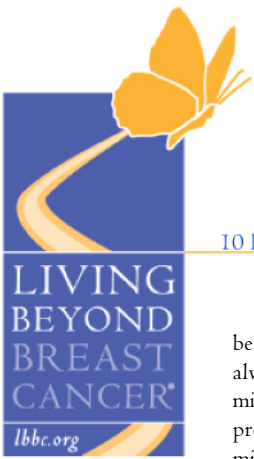
My paper – I would call it that – is called "Breast Cancer As a Traumatic Experience: Implications for Recovery." My clinical experience convinces me that there are many, many ways in which women experience learning that they have breast cancer. And there are many different paths through the difficulties imposed on them by the treatment protocols that they are asked to follow.

In these opening comments, I want to discuss one of the most common reactions to the diagnosis and one of the paths followed by many women to deal with the rigors of treatment. I've chosen it for special attention because the patient's responses are often misunderstood and cause her to be deprived of some of the emotional support she needs.

Later, there will be ample opportunity for questions that are stimulated by these ideas, as well as questions about alternate responses to the diagnosis and alternate ways of dealing with the emotions aroused during treatment.

There is widespread agreement among patients and professionals that the initial diagnosis of breast cancer is a traumatic experience for many women. One way of understanding the reason for this is to consider how they receive the news that they have breast cancer. Almost always it is a doctor who has the responsibility to be the messenger of the bad news. He or she has been trained to do so in an objective and unemotional manner.

Further, the office setting is one where it is difficult for the patient to have an emotional reaction. Often the doctor uses this opportunity to describe the next steps that need to be taken. The patient's numb silence in response is due to



being overwhelmed by the news – often, not always, but mostly. But it can easily be misconstrued by the doctor as an invitation to proceed with his recommendations in the misguided belief that the patient is capable of absorbing all of the information.

It is an unusual doctor who understands the patient's lack of response as the reaction to the traumatic news and gives the patient time to experience it in terms of its emotional significance. Many women say they have no idea what the doctor told them after hearing the diagnosis. If accompanied by a friend who is able to absorb the information, they're surprised to learn that the doctor was clear about all of the details. As a result, women frequently recommend to each other that they should not go to the doctor alone when they are expecting a report on a mammogram or a biopsy.

I'm not suggesting that the doctor is unsympathetic to the patient, even though some are so accustomed to delivering the news that they themselves become numb to its traumatic significance. However, I am suggesting that many doctors do not provide the time to allow the patient to react to the news emotionally at the time it is delivered.

I'll repeat that last sentence. However, I am suggesting that many doctors do not provide the time to allow the patient to react to the news emotionally at the time it is delivered. They may even believe that their calm and unemotional manner represents the best model for the patient to follow.

The traumatized patient's problems are compounded by the fact that the emotional implications of trauma are often misinterpreted by those who support the victim of cancer. For example, if she demonstrates a calm and determined stoicism from the time of the diagnosis through the treatment, her responses usually are considered appropriate rather than being due to a post-traumatic withdrawal and numbness. Of course, being an unemotional patient facilitates getting through the treatment requirements, but it is at the cost of restricting the expression of underlying feelings. As I will describe later, these feelings will make their appearance after treatment is ended.

Before opening the teleconference discussion to questions and comments, I want to describe briefly the unavoidable emotional responses to a traumatic event so that the patient and her support system can recognize the process of emotional recovery and facilitate its expression.

Trauma is not just having a bad experience. Instead, it is a special kind of bad experience in which the victim is shocked and surprised by an event that creates a feeling of intense fright. These intense feelings, stimulated by the life-or-death quality of the threat, shatter the victim's normal expectations and shake her confidence and her sense of reality. At the moment the trauma occurs, the victim feels overwhelmed and numb, and cannot integrate the events attending the experience of fright into a coherent story of what has just happened.

The intensity of the emotions evoked fragments of the mental representation of the events and disorders her sense of time. Common descriptions by the victim of her emotional response at the time of a traumatic experience and afterward include feeling numb, paralysis, the sense of being out of her body and so forth. The victim often describes herself as "just going through the motions." It's easy to mistake this flat and unexpressive emotional tone as dealing logically and practically with the bad news. Nothing could be further from the truth about the victim's actual emotional state.

The post-traumatic period can continue for hours or days, during which time the victim must cope with all of the realities of her current life and follow the medical requirements of dealing with cancer. Meanwhile, the psychological work of allowing herself to experience the fear and terror that was obliterated by the numbing and disorganizing effect of the diagnosis is postponed in favor of coping moment by moment.

As she is pushed and pulled by old and new demands, the patient often describes herself as going through the motions of doing what has to be done in a mechanical fashion. Abreacting or expressing the emotions that were not felt at the time of the trauma and constructing a coherent story that places the fact that she has cancer into the perspective of her own life often does not occur. Because her numbness and mechanical coping are usually understood by the support system as a remarkable emotional strength in the face of the bad news, the absence of emotional reactions is accepted as normal.

For example, her doctors are inclined to praise her for being a cooperative, even an ideal patient because she does not become emotional as she is studied further, and treatments are recommended. The emotions that would be appropriate to the fact that she has cancer and must undergo difficult treatments are suppressed because they would make it more difficult for her to cooperate with her care. In this sense, her emotional numbness enables her to cope very well, at the price of deferring her emotional reactions. These feelings await expression until later, when an event that is relatively trivial in comparison to the diagnosis of cancer itself triggers a strong emotional reaction.

For example, if the patient has accepted the need for surgery and chemotherapy in a calm and relatively emotionless manner bursts into tears when the first sign of hair loss appears on her comb, that should be viewed by her husband or companions as entirely understandable. Unfortunately, her husband or friends may believe that this is the perfect time to mimic the calm and logical doctor who first conveyed the news of cancer and say something like, "Oh, honey, you knew this would happen. It's not the end of the world." If neither person realizes that she is reacting to the hair loss as she did not react to the diagnosis of cancer, the patient may experience her husband as cold and unfeeling – mechanical himself. In turn, he may feel that his sincere effort to help – just being practical, is what he might think – was misunderstood and feel rejected. An understanding of the paradoxical nature of the emotional responses to trauma would help both parties understand each other.

This series of misinterpretations of the patient's emotional state is common because the emotional responses to trauma create a paradoxical outward appearance that invites being misunderstood by others. The patient appears to be calm and in control because of the effect of trauma. If you are highly distraught and emotional at the time of diagnosis and during treatment, such reactions would in fact be appropriate to the news, but would be quickly suppressed by those around her because it would make it easier for them to help her get through the treatment. People would urge her to "get a grip," understand that the doctors are only trying to help, that her behavior only makes matters worse, and so forth. Because such unemotional, calm and logical behavior does have an adaptive advantage for the patient, for the treating team and for her support system, the mistaken idea takes firm root that there is no deep distress.



Paradoxically, it is also easy to observe that people who care about the patient do have the opportunity to react emotionally at the time of the initial diagnosis of cancer and during treatment. This is easily understood if we consider that it is not they who have been traumatized. They do not have to suppress their emotions in order to cope. The caretakers often report that they cannot believe how realistic the victim of cancer is, and they freely admit that they are falling apart. In fact, it is common, at least in my experience, to hear that a complete role reversal occurs in which the patient becomes a support system for her family and friends. Adding to the out-of-phase responses is a silent expectation placed on the patient to handle all of the stresses of treatment in the same calm and logical way as her caretakers wish her to do, as I illustrated previously with the hair loss example.

The patient's support system often tries to suppress emotional responses to minor irritations in the mistaken belief that becoming immediately calm will be helpful. A second example may be useful here. A patient who has handled the nausea of chemotherapy, the shock of hair loss, the disruption of her family life and so forth with relative equanimity may break down completely when she notices that her skin bruises easily. This physical insult is trivial in comparison to the other discomforts, but it triggers the unexpressed anguish at realizing that her body has been damaged by the treatment.

It is typical of the post-traumatic state to become upset by trivial stimuli that represent the trauma itself. At this moment, people in the support system often bend every effort to suppress this reaction because they fear that the patient will "fall apart." If they understood that this is a typical and necessary aspect of the recovery from trauma, they would accept the emotional outburst and allow it to run its course. The idea of encouraging a strong and positive attitude, valuable as it is when needed, becomes systematically over-emphasized at the expense of not allowing the patient to be emotionally overreactive to trivial stimuli.

As a consequence of not expressing the terror during treatment, the patient may have many paradoxical reactions at the completion of therapy that are actually part of the normal recovery from a traumatic event. Although we are familiar with this with soldiers who have been traumatized in terrible wartime situations, it is unusual for the same tolerance we give to soldiers to be given to patients recovering from cancer.

For example, if a soldier who returns from combat has difficulty adjusting to civilian life and becomes hypersensitive to trivial frustrations, people have learned to accept this as part of the recovery process. In contrast, if the victim of cancer feels somewhat withdrawn and sad when treatment is complete, this can easily be viewed as dangerous and inappropriate because the supporting friends believe that she should now be happy and enthusiastic and just resume her life. If this were understood as a delayed mourning for the damage done to her body and her sense of having a safe and dependable future, such reactions would be considered a normal response to having had cancer.

The cancer patient knows that her life will be filled with repeated follow-up exams and other reminders that she was very ill. Although she would like to believe she's cured, she knows that it is too soon to tell. A period of delayed sadness then is entirely appropriate. Well-meaning friends often do not recognize that these feelings are appropriate to what happened and redouble their efforts to get the patient back to her lifestyle that she had before cancer. This can cause the patient to feel misunderstood and even sadder that she is not allowed to feel the loss of her health. The patient must first work through her feelings that she will not return to exactly the same life as she had before and needs time to readjust.

In short, trauma causes the emotional reaction of the victim to be expressed in a delayed way. This is the well-known "double time" of trauma. Initially, the full reaction of terror does not occur. Later, trivial stimuli that remind the victim of the trauma enable the feelings that were never consciously experienced due to the numbing effect of trauma to find delayed expression.

It is not true, of course, that all women are traumatized by the news that they have breast cancer, and the story of the traumatic experience with breast cancer, therefore, does not apply to everyone. Some have been expecting to get the diagnosis due to a family history of breast cancer. Some have had previous mammograms that were suspicious, and they're really expecting the bad news sooner or later. Some are old enough to know from many friends who have had breast cancer and cannot claim to be unaware that it might strike them, so they don't experience the diagnosis and the immediate circumstances surrounding it as traumatic.

In these instances, the news that is traumatic for many women is just very bad news for them, and they do not experience the overwhelming terror and numbness I just described. And, therefore, they don't have the double time of trauma. I mention this for the sake of completeness and to extend the range of issues open for discussion today, even though my experience does indicate that the news of having cancer is traumatic for most women.

My overall hope is that the woman who is traumatized by discovering that she has cancer understands enough about her own responses to help others recognize and accept these reactions that are due to the paradoxical effect of trauma. At the same time, I hope that those who are in a position to support the traumatized victim become sensitive to the special needs of the traumatized woman. For those who are not traumatized, their responses are not paradoxical, and they are in a position to inform others of their needs without being misunderstood.

This brings my prepared remarks to a conclusion, and I want to thank people for listening and to comment that it's an odd experience to read a paper to my computer screen and not to a live audience. It makes it a little odd to know what's getting across and what isn't, but we'll soon see what's getting across when we hear the questions. Thank you very much for giving me the opportunity to present these ideas. It's been a great honor to do so, and I look forward to the questions.

**ELYSE S. CAPLAN, MA:**

Dr. Sachs, thank you so much. We're glad that you were willing to have your maiden voyage as a teleconference speaker with us at Living Beyond Breast Cancer. Before moving into the question-and-answer session, I want to acknowledge that I'm sure the concepts and ideas that you presented resonated with many of the women on our call today.

Your way of expressing the impact of breast cancer on a woman's life from the emotional standpoint and psychological standpoint is quite unique, and not many people frame the experience of breast cancer through the eyes of a trauma and a traumatic experience. We sincerely appreciate your level of expertise in being able to look at anxiety and emotion and the whole breast cancer experience from a very for-instance angle. I'm hopeful that the women who will be asking questions might have more information that they want to sort of tease you with.



I would like to remind everyone to please limit your questions to one so we can get to as many people as possible. If you have another question, you can get back into the queue, and keep your questions more brief, and then we can satisfy the largest number of women.

**OPERATOR:**

Thank you. Your first question comes from Casselberry, Fla.

**CALLER:**

My thing with managing the emotions is the insensitivity – which he covered very nicely – of the doctor. How do you communicate to your doctor and keep him sensitive to you?

**ELYSE S. CAPLAN, MA:**

That's a great question.

**DAVID SACHS, MD:**

A very good question. Of course, all questions are good because they always are concerned with something important to the questioner, and this is a particularly important one. There is no general answer to the question of how to make doctors sensitive to concerns that you have if they don't start out being sensitive. However, I think it is important to be able to raise your concerns with your doctor and to find time to do that.

If the doctor is not interested in that, of course, you may be up against an impossible situation to change his habitual responses. Tell the doctor, "I need some more time to discuss this with you. Can you make time available for me to talk about this matter? I know you can't do it at this appointment, but can we have some opportunity to talk, because I have things I need to talk about. I haven't had a chance to integrate into my understanding of my treatment and my condition everything I need to know."

If you view the doctor as having difficulty in terms of the pressures on him or her with finding time, and he or she is really caught up at the time you have your question with the pressures of a schedule, sometimes it helps to simply acknowledge that. They feel that you understand them a little bit, and then perhaps they can extend the same courtesy to you.

**ELYSE S. CAPLAN, MA:**

Thank you for those thoughts, Dr. Sachs. If we can move on to the next question?

**OPERATOR:**

Your next question comes from Austin, Texas.

**CALLER:**

I was just about in tears because you were describing me – the whole thing: the trauma, being strong for everyone else, and my family not understanding. Mine is more of a comment than a question. I look back six years ago on my diagnosis, and I remember when I told friends. They said, "Oh, you're so lucky because all you have is a lumpectomy. Let me tell you about my friends. They had this horrible thing happen to them. They had to have a double mastectomy, blah, blah, blah."

People can be so insensitive. They really can, and I think the public needs to be educated that cancer is cancer, and it's always bad, no matter whether their friend or neighbor had it worse than you. You need their shoulder to cry on if they're really your friend. They shouldn't try to tell you that just because someone else had it worse – it doesn't make you feel any better.

**ELYSE S. CAPLAN, MA:**

You brought up a really important point. Many people listening probably are shaking their heads in agreement that they've had experiences similar to that. Just acknowledging it – and I'll let Dr. Sachs talk about that – is probably the most helpful, and not trying to fix it with words. I'd love to hear Dr. Sachs' comments.

**DAVID SACHS, MD:**

I agree that one of the most common reactions people have to difficulties is to say, "Oh, you think you had it bad? Well, let me tell you a story." That misses the entire point. I've used this kind of trivial example with people. If you're waiting at a bus stop, and it's freezing cold and you're shivering, the fact that the person next to you is shivering doesn't make you warmer.

It's a complete insensitivity to try to distract your attention from the difficulty that you're having so that you can worry about somebody else. They're compounding your problem. Not only are they imposing on you a lack of sympathy, but they're also suggesting to you that you ought to be sympathetic to somebody else when you're in the least appropriate position to do that.

I'm not sure it's suitable for everybody – I don't have a great deal of patience for people who act that way – but I tell them, "That's really not very helpful to me to know about somebody else at this time, because I have very big problems also,

and a lumpectomy is no trivial matter, because cancer is serious business." You can try to force them to pay attention to the seriousness of your own complaint.

**ELYSE S. CAPLAN, MA:**

That's a great point, and I think the language that you used, Dr. Sachs, is really helpful for people. Thank you.

**OPERATOR:**

Your next question comes from Sunnyvale, Calif.

**CALLER:**

Everything Dr. Sachs said resonated with me, and I've been a very strong, independent matriarch leader of my family. I have four daughters, and I reacted just as the doctor described, being numb and very matter-of-fact and get-down-to-business and "This is what it's going to be, and I'm going to have a lumpectomy," and then I had a mastectomy.

I'm in treatment now, so to family and friends, I appear as strong as I've always been, but in reality, I need my family and husband to step up and be there and take the leadership and give me the kind of loving support I need. But, I've set this model, and they just can't seem to break out of that mold, and I don't know what to say or do to make this change. I really need the support now.

**DAVID SACHS, MD:**

That is exactly why I've been so interested in this topic. People really don't understand the paradoxical position that a person who has cancer or any serious event that is traumatic – they don't understand the position that that person is in. The person is in a position where it is necessary for them to be strong, because if they break down and cry and seem overwhelmed, they're going to provoke from people around them a very critical attitude, which will not help them, because they're going to want them not to cause any trouble. They're going to want them to buck up and get through it.

That avenue of expressing those emotions at that time – that you're going through the treatment and having to run a household with four kids and so on – that's not an easy time to become emotional, but it is a time when the victim can explain what they're doing and try to tell people: "I'm getting through this, but don't think I feel great. I feel terrible inside, but I've got a lot to do. I've got to keep the household running. I've got to



get through the therapy. I have to deal with whatever the side effects are, and don't mistake this for not being upset within. And, at some time when I am able to express those feelings and allow them to come to the surface, then you can be supportive to me for that. Meanwhile, don't be confused by what I'm doing."

I don't know if you will always find a receptive audience for that. No one knows that, but most people don't think of doing that — they don't think of explaining it to somebody. They think that they should know. I agree with you in your point that when you don't explain it to somebody, you're training them to believe that you are capable of dealing with this without any help and without any support. You have to disabuse them of that, and the only way you can do that is by trying to explain your inner self to them. I don't think it is possible to just display it emotionally. I think it requires a certain amount of effort to find the words to express the paradoxical nature of your own situation. On the one hand, you've got to be strong. On the other hand, you've got plenty of grief inside.

**ELYSE S. CAPLAN, MA:**

That's such wonderful, practical information and advice, and I hope that's been helpful to you and some of the others on today's call.

**OPERATOR:**

Your next question comes from Springville, Mo.

**CALLER:**

My question is regarding the delayed response you have to a trivial event. Could you offer tips for us? A quick example: When I go back to the oncology office and I just have to have a blood draw, it's like my body knows that it's coming, and the veins just suck up tremendously. It's like, "Don't get another needle near me," just because, I'm sure, of the trauma of the whole experience. Any tips that you might have would be greatly appreciated.

**DAVID SACHS, MD:**

That is an interesting example. You're quite right that what's happening is that you're having so much anxiety that you're having a fear reaction, and your peripheral blood vessels are constricting, which is what's getting you ready to run away from the office, which you can't do. That's a very good example of an emotional reaction that appears in a delayed way. What can you do to prevent it? That's an interesting question.

I have to struggle with this a little bit, but I think you don't want to focus your attention on the experience of having your blood drawn as a terrible experience. You have to be able to interpret that experience to yourself as something that is reminding you of all of the terrible things you've gone through and, in that way, take away the emotional pressure of this event. The event, after all, is a symbolic event.

Let me give you an analogy to people I've worked with who have had a traumatic experience from a wartime situation. If you had a veteran who had been in the jungle of Vietnam and heard rifle shots and was very traumatized by that, and he comes back, and he is in a hot and humid place, and a car backfires on the street outside, he is liable to dive under the table because the whole experience of Vietnam comes flashing back.

In a certain sense, a post-traumatic experience is a flashback experience, and what you want to try to do is rob the experience of having your blood drawn of its symbolic value. It is really just having your blood drawn, and you have to find a way to explain to yourself that it is no longer all of the things that you have not reacted to before piled together into that one experience.

What you're doing in that situation — I may be going on too long here, but it's a little complicated to explain — is trying to rob something of its symbolic value. I'll have more to say about that if people bring up questions that regard anniversary reactions and similar matters, but I hope that's helpful to you.

**ELYSE S. CAPLAN, MA:**

Dr. Sachs, why don't you take another minute or two and expand on that, because I'm certain that other people would like to hear a little bit more about that.

**DAVID SACHS, MD:**

Post-traumatic reactions are extremely common. We just don't recognize them as such in ordinary life. Many of us have had traumatic experiences, and we set up ways to keep ourselves from being reminded of those traumatic experiences, because those experiences are so terribly frightening. We are protecting ourselves from being frightened, and because the experience itself is never going to recur exactly as it occurred the first time, you are safe from that happening. Even a recurrence of cancer is not the same thing as the very first traumatic experience of cancer.

People protect themselves from being reminded of the trauma, but this causes them to displace into things that they don't think they're going to be confronted with. They displace onto unsuspecting things, things they don't expect, so things that are very far removed from the original experience then become reminders of that experience. One then has to do the work of saying, "Oh, having my blood drawn is just having my blood drawn. That's all it really is. It does not really mean that I'm going to have cancer treatment again. It does not really mean I'm having surgery again, etc."

Similarly, you could say that having cancer is analogous to the unexpected death of somebody close to you, because it's a death of part of yourself. It's an injury to a part of your own body, and in that sense, it's similar to a death. We all know that if somebody close to you dies, you do begin to recover from it. Then you meet someone on the street who doesn't know about the fact that the person died, so they ask, "How is So-and-So?" And, you say, "Oh, that person died a month ago," and you're not expecting to cry. But suddenly, in the presence of this person, you start crying. You're crying because you are now responding to the full effect of that person's death, and this person triggers that response. That doesn't mean you're going to cry every time you see that person again; you would get over it.

What I'm saying is, in the post-traumatic period, you're working through the reminders of the bad experience of having had cancer and its treatment, and you should allow yourself to do that and to make sure that those reminders do not become equivalent to the original experience.

**ELYSE S. CAPLAN, MA:**

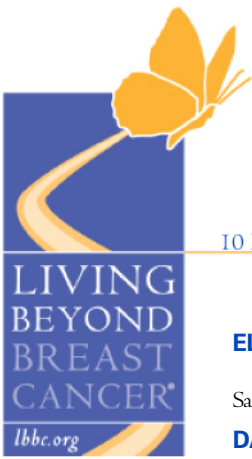
That was perfect. Thank you so much. The way you summed it up at the end is a good take-home message for our listeners and all of the women out there today.

**OPERATOR:**

Your next question comes from Arlington Heights, Ill.

**CALLER:**

Hi. I've had breast cancer twice, and I'm also a social worker. This is the very best description of what women emotionally go through, and I say that from a patient and a professional standpoint. I was going to ask you to talk more about the anniversary reaction, which you've already done, so, I'll just leave let another questioner ask.



**ELYSE S. CAPLAN, MA:**

Thanks very much for your comments. Dr. Sachs?

**DAVID SACHS, MD:**

I just want to say one thing. Anniversary reactions are an interesting subspecies of this entire topic, and they are a little different. People, as we all know, tend to have anniversary reactions about happy things. Some people ritualize certain happy occasions, and they have a celebration on those occasions, and then they're reminded of that. They make the date of that occasion very important to them. That works pretty well for happy occasions.

People who have had cancer also tend to try to get rid of it from their everyday life by memorializing it in an anniversary reaction. They say, "Oh, I had my diagnosis on Sept. 27 three years ago," so that's the date. They emphasize the date in their own mind, so they put a great deal of emphasis on that date. Of course, they're hoping that by putting the emphasis on that date, they won't think about it any other time.

That's exactly the wrong thing to do, in my opinion. In my opinion, the thing to do is to allow yourselves to know you have cancer whenever anything reminds you of cancer so that you don't memorialize it and create the potential for a major reaction and a major breakdown when everything comes together around an anniversary reaction. I'll use a personal example here. My father died many, many years ago, and somebody asked me what the date was when he died. And I said, "You know what, I can't think of it right now. I know it was in January, but I'm not sure what the date was." I said, "I don't really keep the date very much in mind, because I think of him often. And, when you think of somebody often, you don't really need the anniversary to remind yourself of somebody you loved."

I think that makes the point that I'm trying to make. There's nothing wrong with remembering that you had breast cancer in September four years ago, but I wouldn't make a big deal out of the precise date and time and circumstances, because I think it can lead to paradoxical reactions that you don't really need to suffer from.

**ELYSE S. CAPLAN, MA:**

That's an interesting point, Dr. Sachs. You probably would have a group of women shaking their heads, saying, "Absolutely, I agree with you. I can't remember the date. I don't want to remember the date, actually. I want to block it out

of my mind," and I also think there are women who hold on to that date because it has different kinds of significant meaning for them – they're marking that date. . . . There's a range of things that we all feel, and I think your points make us pause and think very differently about our own experiences. I appreciate that.

**OPERATOR:**

Your next question comes from Metairie, La.

**CALLER:**

I want to thank Dr. Sachs so much, because I, too, was one of those patients who was very strong, very calm, went through my treatment just perfectly. It was not until after my treatment was completed – since February of this year – that I kind of broke down and kept having emotional bouts. I decided to talk with my doctor, and he said, "If it disrupts your life, then maybe we would put you on a mild antidepressant," and it wasn't like I was depressed. I just had overwhelming emotions all of the time.

So I have done this, and it's really helped me. I've been on it for about three weeks, but I guess my question would be, do some women – mostly I'm just thankful that he has told us about this trauma, how it can affect you, and it certainly helps me think I'm not crazy, to know the emotions that you have might happen a year-and-a-half later. I guess that's it. Thank you.

**DAVID SACHS, MD:**

That's an excellent point, and I think you are a very good self-observer. I'm not anti-antidepressants. Sometimes they're useful, and in your case, they seem to be. At the same time, you were very perceptive about yourself. You said you didn't actually feel depressed. You were having a different set of reactions, and those also are typical of post-traumatic reactions. If you had understood this, you might have been able to benefit yourself psychologically without the need for an antidepressant, but I don't object to the fact that you got it, because you didn't know this at the time, and, therefore, you didn't try it.

These are typical post-traumatic reactions. There's an interesting analogy that some of you may be curious about. Postpartum depression is a relatively common phenomenon. It's not universal by any sense of the word, but it's not uncommon. Some women go through pregnancy tremendously, confidently, and optimistic about how wonderful it's going to be to have a baby. Then the joys of motherhood are somewhat not present every day

of the week when you have a child who keeps you up at night, and there can be other problems, and these women sometimes fall into depression. Some of those depressions – not all of them, because there are hormonal problems and other reasons for postpartum depression – are post-traumatic reactions in which the person is having a reaction because of the disappointment after their unusually high expectations.

It's not exactly the same as the pregnancy being traumatic, but it is an indication that delayed reactions are not uncommon. I'm not trying to claim that the pregnancy is a traumatic experience, but I am trying to emphasize that very powerful experiences that are disappointing can have delayed reactions later.

**ELYSE S. CAPLAN, MA:**

Thank you, and we wish you the best moving forward.

**OPERATOR:**

Your next question comes from Hot Springs, Ark.

**CALLER:**

My question builds on some of the previous questions. What is the incidence of an actual post-traumatic stress disorder? I know I'm not the only one – when I drive by the doctor's office, I feel nauseated and scared and go through all those feelings that had to be buried because I was told, "You're a strong person. You're going to come through this."

When I try to explain to my doctors what I'm feeling, they tell me, "Well, you shouldn't be feeling that way." When my hair fell out and I bawled my head off, they said, "This is minor. You've just come through a double mastectomy. You've just come through this. You've just come through that. Why are you crying over your hair? It will grow back!" And, it's like, "But that was me."

Now I hear a lot about post-traumatic stress disorder, and I'm just curious: What is the incidence of it, and what's the best way to deal with it?

**DAVID SACHS, MD:**

I don't have statistics. No one really does have statistics about such matters, but I think the incidence is quite high. Certainly breast cancer is very often a traumatic experience, as I said in my talk. But the ideas about the way in which the paradoxical effects of the trauma are experienced are not as widely known as they should be, and



they certainly aren't as widely known among the medical profession as they should be, because a doctor is just plain wrong to think that you shouldn't have that feeling at that time. His position should be exactly the opposite.

"I should be having that experience at this time," is what you should be saying. "I didn't have that experience before because I couldn't. Now I'm having it, and I want you to validate it. I don't want you to criticize me and traumatize me for having an emotional reaction that I have a perfect right to have." How much or how little the medical profession can get educated – I'm not an expert on that, but I'm not entirely pessimistic, because some doctors don't really understand this and would be glad to understand it so they could deal with it a lot better and have fewer problems with their patients.

But the only way to educate doctors in things like this is for people to speak up, and I would encourage you to do so. The doctor should be able to accept the fact that he misunderstood something, and he certainly should understand the fact that later reactions like yours, the one you described, are perfectly understandable if you take into account why they're happening. Doctors should understand that. If they don't, it's an opportunity to educate your doctor.

#### **ELYSE S. CAPLAN, MA:**

That's exactly what I was going to say, Dr. Sachs. We are in great positions to educate our healthcare providers about the things that they may not hold as close to their hearts as we do. We need to keep in mind when we see our doctors, nurses, social workers, whomever we're seeing, that if something isn't going quite right and you have some feelings about it, it's important for your own well-being, but you're actually helping others if you speak up. It gets your personal needs met, hopefully, opens their eyes to things that are of great importance, and it is an opportunity for you to teach the healthcare system what we need in order to experience breast cancer a little bit easier.

#### **DAVID SACHS, MD:**

I agree with you, Elyse. In regard to statistics, I want to mention one thing. We have a lot of statistical information about people returning from Iraq who have been in combat and witnessed many very, very traumatic situations. A best-guess estimate is that 50 percent of the veterans who have come back who have been in those situations have post-traumatic stress reactions, and the fact

that they weren't getting adequate treatment for it caused a great controversy. That's supposed to be addressed by improving the mental-health care for veterans who have been victimized in that way.

#### **ELYSE S. CAPLAN, MA:**

Thank you very much.

#### **OPERATOR:**

Your next question comes from Savannah, Ga.

#### **CALLER:**

I don't have a large support system. It's just my husband and I, and I worry about the damage that I may be doing to our relationship. I'm having a hard time. I was diagnosed a year ago, and I'm having a hard time feeling safe again. My husband is very supportive, but when I only have one person to vent to, how do you move on? How do you find a place where you can feel safe again? This has changed my personality, I know. I was always a very spontaneous, very happy, very "the glass is half full" kind of person, and I'm having a very difficult time getting back to that.

#### **DAVID SACHS, MD:**

There are several answers, one of which Elyse can provide you more information on than I can. My answer is that you should allow yourself some opportunity to feel sad because of what you've been through. You have experienced a very difficult process, because your body has been damaged, and your expectations that something unexpected could happen again that would be terrifying seem to be a possibility. You are worried about the future.

One of the things that I think is helpful is to recognize that what you went through is in the past. Of course, that doesn't completely protect you from imaginations about the future. But put it to yourself this way – that what you had may well be the only experience that you have, you may not have a recurrence, and if you do, you'll be able to have many things done that will help you to get through it.

The future is not entirely bleak, but you do have some need to recover from the sense of loss that you've experienced, and that's probably one of the things that you're going through. Nothing can make the future entirely safe for any of us, so the optimism or the courage that you had in living life the way you lived it before should return, because you didn't believe then that nothing bad would ever happen. You could return to a point of view that says, "I don't believe that I'm ever going to be totally safe." We live life with a certain

amount of courage about the future anyway, so why not resume that at this point when you're finished grieving for the damage done to you in the past?

The issue of loneliness is the thing I would like to defer to Elyse, because you don't have to be alone. She can explain to you that there are avenues that LBBC provides and other agencies supply that could help you.

#### **ELYSE S. CAPLAN, MA:**

Thanks so much, Dr. Sachs. That is a great segue, and I appreciate you tying it back to the organization's work. For the caller and everyone else out there, the LBBC Survivor's Helpline is a wonderful resource where you can talk to another woman who has experienced breast cancer and get emotional support from another peer who gets it, who has walked the walk, who has been there and done that. We have a wonderful corps of volunteers with a range of breast cancer experiences who can absolutely dispel those feelings of isolation and aloneness. I would like to give that number, and I'll repeat it at the end of the call. It's toll-free, and the number is 888-753-5222.

Please take advantage of our Helpline. We have wonderful women who have had breast cancer and have been trained to give peer emotional support and to help you to formulate questions to take back to your doctors and nurses so you can navigate your experience a little better. And, of course, our physical programs, our other teleconferences – we have a variety of ways in which you can connect with other women.

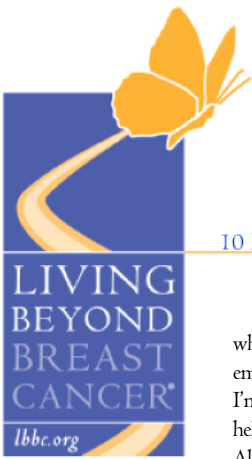
For those of you who use the Internet, Living Beyond Breast Cancer's message boards can be found online [<http://lbbc.org/>], and we have a handful of different forums that speak to young women, one for women with advanced or metastatic breast cancer, a general message board that anyone can post on – there's a host of different message-board forums where you can connect with other women, so please, I encourage everyone to take advantage of some of the resources we have. Thank you again, Dr. Sachs, for that opportunity.

#### **OPERATOR:**

Your next question comes from Brooklyn, N.Y.

#### **CALLER:**

I'm also getting a lot from this teleconference, and I just want to underscore a point that Dr. Sachs just made. He just used a word that has really helped me: "recovery." It didn't really dawn on me



when I was going through some very difficult emotions – I'm just a year past treatment – that I'm actually going through a recovery, and it has helped me to understand what I'm going through. Also, it has helped me find a way to simply say to others that this is what my experience is – that it's a recovery time. It's making me feel easier on myself, as well. That's one thing I wanted to say.

Also, I have two children, and they're dealing with this very differently. I didn't know if, Dr. Sachs, you might be able to speak at all about when a child – I have one child who is 8 years old, and it seems like she's going through some sort of almost parallel experience. Last year, she was coping, and this year she seems much more stressed, much angrier and is having problems with separation. She is seeing a therapist, but it has been very difficult, and I'm concerned about her.

#### **DAVID SACHS, MD:**

Thank you for that question. You're raising another huge topic, but let me deal with the first part first, and then I'll get to the second part of your question. The first part of your question is a recovery period. That's precisely what I'm talking about: recovery. There is this idea that when the treatment finishes, you're recovered. You may be finished and recovered in a biological sense. Your body may fairly quickly return to its normal functioning. That's a medical recovery. A medical recovery from the physical trauma of the surgery or the chemotherapy is not a psychological recovery.

A psychological recovery requires the person to integrate what happened into their personality again, once they are free to do so and they're not needing to suppress all of their feelings in order to go through the treatment and to take care of their lives. You've got children. You've got to take care of those children. You've got to be on the mark. Now that the treatment is over, you're not instantaneously emotionally recovered. There's not much respect given for that, because people are confusing the physical recovery with the psychological recovery.

I want to give an example from a person I know very well who had some major surgery, recovered very well from the surgery, was discharged from the hospital and really did fine. But a lot of damage was done to that person's life because of the surgery and a relatively trivial postoperative complication that developed that is very common: constipation. No one except the nurses who were

involved in the hospitalization was interested in that, and yet that was causing him more discomfort than the surgery.

As far as the surgeon was concerned, this person was finished because the wound had healed. All kinds of postoperative complications are ignored on that basis, and certainly among the ones that are most ignored is the need for an emotional recovery. That takes time, because you have had intimation of mortality, and whenever a person has intimations of their death, they have to reintegrate their life and regain a perspective of where they've been and where they're going. You're doing that.

As far as the child is concerned, I'd be very reluctant to make any kind of specific remark. Your 8-year-old has probably also modeled herself on you during the crisis last year and is probably having some post-traumatic reactions of her own in which some of the feelings that she wasn't able to express at the time, because mommy was sick, she is now expressing. I would think of that in terms of a post-traumatic reaction for her, although I certainly can't be sure of it, and I hope the therapist takes it into account. That's about all that I feel I have a right to say about that.

#### **OPERATOR:**

Your next question comes from Los Angeles.

#### **CALLER:**

Is there a general timeline for when you're taking too long to recover? I just finished my treatments in August, and just three days ago was I able to actually get up and start getting some exercise. I know what I need to do mentally, but physically, I can't seem to break through that wall that, I guess, is me just coping. When is it appropriate to seek help?

#### **DAVID SACHS, MD:**

That's a very good question. I'm sure it has a huge individual variation, because it has a lot to do with the person's activity levels prior to the incident and also the age at which it occurs. There are a lot of complicating factors, but I would say for you, in regards to the timing of it, whenever somebody has been very active and wants to get back to it, the step to get back to it is really difficult.

I suspect that you're not fully appreciating that when you try to go back to exercising, for example, you are going to be reminded of what you used to be able to do. You're not going to be able to get close to that, so it's going to feel like it's an insurmountable obstacle to get back to exercising,

and you're going to withdraw from it, because you're going to be aware of the difference between the past and the present.

Do you think that's an unusual reaction? Not really. It's a very common kind of reaction. People who pride themselves on being fit who stop exercising, that first time they go back to the gym or go back to work out is a big step, because that moment they feel like, "Oh, my God. I'm never going to do this." It's a huge step, but once you've taken that first step and you do it with a certain amount of tolerance – that is to say, you don't expect very much of yourself, so you can't be disappointed; you just expect a little bit, walk a little bit, don't run, just do a small amount – once you've crossed that threshold and just to get back to doing it, the rest will be much, much easier.

By the way, I've worked with many creative people who have just, for example, written a book – they write their first novel, and they want to get to writing a second novel, and they can't get back to doing it because the prospect of getting involved in such a major undertaking again just is so overwhelming that they can't get the first page written. What you have to encourage the person to do is, "Why don't you just write a paragraph? If you can write a paragraph, the rest may follow." That would be my recommendation to you.

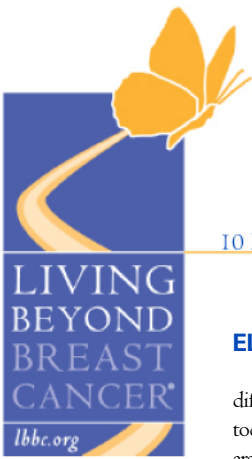
#### **CALLER:**

That's what I've tried to do – just a little bit at a time. I do have one comment from an earlier question about other people's responses to you. I'm lucky: My husband is a doctor, and his automatic response is, "I'm so sorry. What do you need?" Sometimes, I think, especially for children, you should just tell them, "I'm not feeling good today," and teach them what to say. Say, "I'm sorry that you're having this. What can I do to help?"

My friend had cancer before I did, and I was clueless then about what to do, so I think teaching people what to say and how to help you is a good way of having your children learn to cope, also, because they don't know what to do, so they're trying to help you by saying stupid things. It's a nice thing to say, "This would be a good way to help me. Say this and ask if I need help, and that way I know you care. That's all I need."

#### **DAVID SACHS, MD:**

I couldn't agree with you more.



**ELYSE S. CAPLAN, MA:**

Yes, having the right words to say makes a difference. Dr. Sachs has helped us with that a lot today. I also think, to your point, a lot of people are just comfortable being silent and maybe putting a hand on your shoulder and letting you know that they're there for you, and that's when sometimes those things come out of their mouths that most make us want to turn the other way, that are very disconcerting and distressing.

Generally in our culture and society, people want to fix things, and they often use words, because they think saying something might be helpful. And oftentimes, they put their foot in their mouths, and it feels very unhelpful. In today's program, we're getting a lot of information and a few tools and a few scripts, for lack of a better word, to help us to educate people – our healthcare team as well as our loved ones, family, friends, partners, you name it. We appreciate your question.

**OPERATOR:**

Your next question comes from St. Louis, Mo.

**CALLER:**

I have undergone a lumpectomy and just finished my radiation today, and you've kind of circled around my question of how do you go from here, from today? Everybody says, "Great, you're finished." I've maintained a very normal lifestyle, but back in your gut is the feeling, "What if the shoe drops again? How do I go on without looking over my shoulder?"

**DAVID SACHS, MD:**

I would say exactly what other people have said today. You're finished with the physical treatment. Congratulations. That is over, but the emotional work has yet to be done. There's a lot of emotional work to be done, and you should be tolerant of that for yourself.

I don't think you shouldn't look over your shoulder. The reason is that you're going to be reminded of what you went through, and you might as well accept that, because you're going to be reminded of things that you're not going to like to be reminded of. If you try not to be reminded of it, it's going to bite you in the neck some other time when you're not expecting to be reminded of it, and you'll have a much more massive reaction.

You have to work through what you went through emotionally, and that's done by being reminded of what you went through. That means you are, from time to time, unexpectedly, expectedly looking over your shoulder. You may

find that it's helpful not to try to eliminate that possibility, because during that time, there's not much opportunity to stay in complete tune. Just give yourself a break, and give yourself some time. It will take weeks or months to really work it out so that you have reintegrated what you've went through, what it means to you and the future.

That's about all I can say, but one part is ending today and another part is beginning.

**CALLER:**

I really appreciate the analogy to a soldier who's been to war. I think that's a really interesting way to look at it.

**DAVID SACHS, MD:**

It is. It's a very, very tight analogy. It really is.

**OPERATOR:**

Your next question comes from Washington, D.C.

**CALLER:**

I'm wondering whether you might recommend for women, either during treatment or after treatment, getting involved in a yoga program or learning meditation techniques to help relax and calm their emotional distress.

**DAVID SACHS, MD:**

Oh, sure. Elyse will also comment on this; I think it was an idea that came across LBCC's desk. It may have been my daughter's idea. I don't really know who originated it, but they have a yearly program called Yoga Unite, which is done on the steps of the art museum. Hundreds and hundreds of women come to that once a year to be introduced to and practice yoga techniques, which many women find helpful.

Yes, I think meditation and yoga techniques help for some people. Some people don't find it useful, but other people do, and those who do ought to make use of it. I'll let Elyse comment to that further. There are so many things to say about the various methods to help one recover that I don't want to emphasize any one against another, but yoga certainly helps many women.

Elyse, do you want to say anything to that?

**ELYSE S. CAPLAN, MA:**

The annual Yoga Unites for Living Beyond Breast Cancer is held in May on a Sunday morning in Philadelphia on the art museum steps. It's Living Beyond Breast Cancer's response to doing a fundraising event that's not a race or a run or a walk, many of which are available to participate in throughout the year. This ties in to our mission to help women live with the best quality of life for as long as possible. Yoga is one method to help restore fitness and well-being after a breast cancer diagnosis.

While I'm not a doctor, I can say there have been some studies, and more studies are in process, about the benefits of yoga after breast cancer. It's been found to help alleviate some common side effects of some of the treatments that are commonly prescribed. The most important thing is, if you're interested in yoga or any physical activity, that you always check with your oncologist first and any of your other doctors to make sure it is safe and secure for you to do. But, we're learning through research that yoga has great benefits for women affected by breast cancer.

With that, our 90-minute program is coming to a close. I would like to remind everyone that an audio replay is available on our website [<http://lbbc.org/>], and a transcript will be posted at a later date. As I said in my opening remarks, Dr. Sachs, your way of talking about emotions, the psychological well-being, and the experience of breast cancer as traumatic is unique, and your sharing it with so many people has been so helpful. From the bottom of all of our hearts, we thank you for your time and expertise.

For peer support, please feel free to connect with another survivor through Living Beyond Breast Cancer's toll-free Survivors' Helpline at 888.753.5222.

Dr. Sachs, do you have any comments before we close today?

**DAVID SACHS, MD:**

I am extremely grateful for the questions. They've stimulated a lot of new thoughts in my mind about how to improve the opening talk that I gave, and the people who participated were extremely helpful to me. It was a great privilege and pleasure for me to participate in this program, so I owe LBCC a debt of gratitude for that. Thank you.

[END OF TRANSCRIPT]