

About Health TV with Jeanne Blake
Breast Cancer: Liz's story
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JEANNE BLAKE: Welcome to *About Health* TV. I'm Jeanne Blake. We all know someone living with breast cancer. Imagine being told that your breast cancer has come back. When Liz Nichols heard that news, that her cancer had come back and spread to her bones, she desperately searched for material – a video, a book – something that would help her cope with the emotions she was feeling. But she couldn't find much, so she produced her own. Liz has been on this program before to talk about her project, "When Breast Cancer Comes Back: Skills for Living," a video for women living with the disease she's living with. And now that the project has met its completion, she's here once again to talk with us about what she hopes to accomplish with this videotape and accompanying viewers' guide. Liz, I must say as a disclaimer, is one of my dearest friends, and I worked with her on the project, "When Breast Cancer Comes Back." Liz, thanks for coming back in.

LIZ: My pleasure.

JEANNE BLAKE: What do you hope to accomplish, now that this video is done and starting to get out there to folks, what are you hoping that it will do?

LIZ: I'm hoping that it will do what I didn't have. It would be something that a woman could plug in to her television at 3:00 in the morning and be able to see something that would be very close to her, and only to her, that no one else would understand, and that she can just listen to it in the privacy of her own home and just feel comfortable that she's not alone, that other women have the same problems and the same thoughts, and that she can, hopefully, find some comfort in this video.

JEANNE BLAKE: The video profiles five women, including you, who share sort of the ways that they've met the many challenges that you meet when you face a disease like breast cancer that's spread to your bones. In other words, for which there is no cure. What did you want them to share on a personal level? We went into the interviews, really, very open-ended. What were the nuggets that you hoped to pull out that would be able to inspire other women living with that disease?

LIZ: Every day, people ask me how do I do it, how do I manage to stay happy and do all the things I normally would do. And I was hoping that the other women could express the ways that they

find a comfort zone to get out of the depression of being told that you have an incurable disease that could possibly kill you, and more than likely it will kill you. But this is something that I feel very good about, that the other women also talk about when they go into that deep, dark place. It's how they get out of there.

JEANNE BLAKE: What surprised you the most about what the other women said?

LIZ: I think the similarity in all of us is amazing, that we all have gone through the same emotions. It's comforting just to know that you're not the only one who's thinking scary thoughts like this. We're all mothers. That's the first thing, I think, on all of our minds, is our children, our family, our husband. And I think that it's just a wonderful piece of material to have, to be able to share, all by yourself or with others, just to let them in to your very scary world, and to hopefully have them understand a little more of what you're going through also.

JEANNE BLAKE: In fact, the first segment is called "Facing Your Fear," the second is called "You're Not Alone." I think that when you talked about wanting something for the middle of the night, it was to sort of help you – you said it here again today – to help you remember that there are other people who share this common experience. I can't know what that feels like, but somehow, in the middle of the night, you found comfort in just knowing there are other women out there somewhere.

LIZ: And it's amazing that every single one of those women say, "If you are awake at 2:00 in the morning, give me a call." And I think we all feel the same way. It's a wonderful bonding that happened, and it happens every time I meet someone with breast cancer. We just feel instantly, "OK, I'll help you. You can help me, and I'll help you." And to listen to these other women say, "Please call me at 2:00 in the morning" – I've never called anyone at 2, but I can. If I need to, I know they're there, and I can do it.

JEANNE BLAKE: You can call me at 2 in the morning.

LIZ: I know I could.

JEANNE BLAKE: I'd pick up the phone.

LIZ: I know I could, and I would.

JEANNE BLAKE: But you know, with friends – I mean, you're an unusual person. I can say that even objectively, and subjectively. But you are unusual in that you bring a tremendous energy to life, and no one could not love you. So when you meet breast cancer, and the challenge of that, you brought the same zest you brought to coaching your kid's ski team. You face everything the same way, Liz. But it is true for women, and I think for you, that a diagnosis of breast cancer, particularly breast cancer that's spread, changes and alters relationships in your life.

LIZ: Absolutely. I have found some of my friends didn't want to be with me anymore. I think the fear of losing me was more than they could handle, and so they just sort of gently kind of eased me out of the program that I would have had with them, or the friendship – not program, the friendship that I would have had with them. It was just too difficult for some of them. And for other relationships, I've become more close.

JEANNE BLAKE: You've been living with breast cancer for seven years. Did any of your friends – and I really don't know the answer to this, I'm not faking it for the camera, I don't know the answer – did some women, or me, pull away and then come back in and tell you that they went away because it was scary?

LIZ: Yes.

JEANNE BLAKE: I don't think that I've heard this. Can you share that with me?

LIZ: Yes. I have one friend that went through a woman who had breast cancer, and she was very close to this person, and the lady died. And it was devastating for her. She was just a wreck for a long time. When she heard that my breast cancer had come back and spread to the bones, she definitely pulled away for a while, because it was just, she thought, I can't go through this again. I can't lose another friend. It's just too hard for me to do. So therefore, I'm just going to pull away for a while. And then I didn't really realize that until we talked about it. Kept calling her, because I really liked her, she was one of my dearest friends. This is Mary.

JEANNE BLAKE: No kidding.

LIZ: Yes. And she had a real hard time with it. And so now we've discussed it, and she comes with me to many of my doctor's appointments, and she's a real part of my life right now, a major part of my life. As you are. You would come with me to all my doctor's appointments and things, and

that's very helpful. It is. To have you be part of this thing with me, I'm not alone. I have Scott, but I'm not alone in my friends, and I need that.

JEANNE BLAKE: Liz, you could extrapolate this to anyone living with any life-threatening disease, that the diagnosis alters relationships. What advice do you have for those people who maybe are just starting to deal with this, and they haven't gotten the insight that you have?

LIZ: I understand their fears, but please, if they could only just hear my fears inside, which are ten times more than their fears of losing me, it would be, Please don't pull away, please don't. I need you more than ever now. And that's the message I guess I would like to say to any of those who are dealing with friends who are going through this, is just to stay by their side as much as you possibly can. Because we really them.

JEANNE BLAKE: What if someone has been newly diagnosed and they detect a shift in the way people – I mean, let's face it, you and I have had some laughs about the things that people say.

LIZ: "Did they get it all?"

JEANNE BLAKE: "What's your prognosis?" "How much time do you have?" It's like the one-liners. But I think in our society people don't know how to deal with the issue of death.

LIZ: No, and I understand that.

JEANNE BLAKE: I'm not saying that you need to – it still hurts. What I'd like you to be able to share with people who've been diagnosed, let's say with cancer, for the first time, that if they're detecting a shift in their relationships, and some people are pulling away, what do you say to that person who has the diagnosis, who's living with cancer? How do you handle that? What's your advice, now with the insight that you have?

LIZ: I think it's a normal thing, that people do pull away, because they're afraid. I think it's very normal. It's a hard thing, in addition to living with cancer, of losing some of your friends as well. It's a double whammy there that's very difficult. And I think only with time is that going to improve. There's nothing that you can do, other than maybe confront that friend and just say, "You know, I know that you've pulled away, and I know that this is very hard for you, and I do understand that, but I really need

you, and if you could possibly stand by me, I would really appreciate it.” Because you do, you need your friends more than ever. And this is a very stressful time.

JEANNE BLAKE: The other topic that – and that is covered in the video program – the other topic that you and the other women take on is the issue around making sure that you pick the right doctor, making sure that you’ve got a team of healthcare providers around you that works for you.

LIZ: They’re just another person. They’re very well educated, you hope, but they’re just another person, and you should be able to talk to them just like another person, not put them on a pedestal as if they’re some god-like figure who’s going to find the cure for you and only you. I mean, you just have to really be an advocate for yourself as well.

JEANNE BLAKE: You quit seeing a doctor that you didn’t –

LIZ: Definitely. She told me to go home and have a nice day, and this was the second time I found a lump in my other breast. So I had already had breast cancer once, I came to her with a second lump in the other breast, and she didn’t do anything. She didn’t do a mammogram, a biopsy, or anything. She just said, “Oh, it’s glandular tissue. Go home and have a nice day.” Which, of course, that’s what I did. What else did I want to hear? I was happy to hear that diagnosis. But I didn’t stop, because the lump did not go away. And I just knew that I had to face the music, and I had to go back to a doctor – a different doctor – to get a second opinion. Which I did, and there was the cancer again.

JEANNE BLAKE: I think it’s so hard, when you say, to be an advocate for your own healthcare, and yet you’re so dependent on healthcare providers that are around you. You have to walk, I would think, a fine line of being able to say, “This is what I need. This is my body and my disease,” but still, I think that so many, probably women, but maybe men too, are afraid they’re going to offend someone, and then, “They won’t want to take care of me and I need them.”

LIZ: Right. I think that’s very true, but you’ve got to do it. You have to do it. I mean, you don’t know what you need. I don’t know what kind of new drugs are out there that are available to me. So I need a doctor that I can depend on that knows all the latest of every single drug that’s out there and that will explain it to me gently, slowly, so I don’t leave that office without a clear understanding of exactly what I’m going to be going through next.

JEANNE BLAKE: I wanted to show just a short clip of that segment, the doctor-patient, choosing the right doctor. ... This is "When Breast Cancer Comes Back: Skills for Living," and let's take a quick look.

[VIDEO CLIP]

NARRATOR: Breast cancer takes a huge toll on us. The treatment can be really tough. Last summer, as I lay in the hospital weak could be, waiting for a stem cell transplant, I thought about how much faith I had in my doctors and nurses. Thank God I trusted them. But that's not the case for everyone. If you don't trust your doctor, it's really important that you follow your instincts.

WOMAN 1: If you have any doubts about whether that's the right person to hear you and to be proactive on your behalf, then you need to look around and see who else might be a better fit.

WOMAN 2: My first oncologist was horrendous. He was from the old school. I mean, I went there and I was dictated what I was going to do. I was told what treatment I was going to take.

WOMAN 3: My first breast surgeon talked to me as if I were a bad child. I had a radiation oncologist who didn't listen to me when I said that I had pain in my shoulder.

NARRATOR: It's your life that you're dealing with. Who cares if you hurt someone's feelings along the way? You're going to hurt someone's feelings. Get over it, you know? It's your life that you're taking charge of right now. Take charge of it, be responsible for it, and get what you need. The squeaky wheel gets the oil.

WOMAN 4: I think there's a defining moment when you know whether you chose the right doctor. And I had that moment with mine on the day that he had to tell me that the cancer had spread. And those words, they sort of go right over your head. You feel numb, because they're too much to take in. But what counteracted that numbness, and was so wonderful, is he put his arms around me and he hugged me, and then he just kept his arm around me and looked right at me and said, "I will be with you every step of the way." And even talking about it, I feel it now. My biggest fear is living alone. Who will be there? Will I be abandoned? And I love this man. He's been my partner, my ally, he respects my values, he listens to me, he cares, and I know he will not stop caring and he will not stop being there till the very last minute.

[END CLIP]

JEANNE BLAKE: So, Liz, you encourage other people who are living with a disease that requires medical care to find, I guess, a partnership with a physician and healthcare providers.

LIZ: Absolutely. It just makes your life so much easier when you know that you can call your doctor any time during the day and he will interrupt whatever he's doing to speak to me, which he has done many, many times. It's a wonderful, comforting feeling to know that he cares about me. He really does. And I care about him, too. I wouldn't call him at crazy hours in the morning if it wasn't really, really important, and he knows that. He knows that I wouldn't ever come to him unless it was really important. So we have a very nice relationship, and I'm most appreciative of that. And I feel it's so important, also.

JEANNE BLAKE: Let's talk a bit now about the videotape, "When Breast Cancer Comes Back: Skills for Living," and how it's being used, and the kinds of feedback that you're getting.

LIZ: It's been wonderful. Everyone who has seen it has just told me how they want to buy it for their sister, they want to buy it for their sister's friend. As a matter of fact, this morning, a friend of mine called, and her husband wants to buy it for his office. He's doing a job where he's away during the week and he comes home on the weekends, so my friend doesn't know the people that he works with. I guess there's apparently quite a few women – this is out in the Midwest somewhere – who have this, and he wants to buy it for the office as a present, to give to them, which I think is really nice. But it's happened to me time and time again, where people are asking me, "Where can I get it? Where can I get it?" "I need one to send to someone" or "I need it for my office."

JEANNE BLAKE: I guess we can mention, Roche is one of the major production and distribution sponsors, the pharmaceutical company, and they made copies available initially, nationally, to doctors' offices, and they've been used in support groups. How would you see it used in a support group? You've got to feel great, knowing that. You're touching lives, you're bringing your message and the words of wisdom of the other four women in the video to women that you could never meet no matter how many times you went out and tried to talk with other people.

LIZ: Exactly. I feel wonderful about it, because I think the messages that we give in there, the different categories of the messages that we hope to bring out, they're very clear, they're very honest and clear and easy to understand. I think it's – I'm so proud of it. I really am. I'm very, very happy to be a part of it. You did a great job.

JEANNE BLAKE: You did a great job. You worked hard. We could get into the mutual admiration society here, and I don't think we should take time for that, but you worked really hard on it, and you put a lot of your heart and soul in it, and it's obvious in the words that you said on the video. Let's talk a little bit about your new mission. You said three years ago, "I really want to make a difference. I want to provide some resource for women, some help. I want them to be able to see things that I want to see things." So you set out to produce this video, you did it, and it's out there nationally. It's being used in hospitals and support groups, as we said. And now you've decided that you're going to go straight after the disease that's threatening to shorten your life.

LIZ: I just feel as though it's a clear message, this came from God, this didn't come from me, really, it was just, I have a mission that I need to help as much as I can. I tend to deal with breast cancer a little differently than I think some other people may deal with it, and I feel as though how I do deal with it might be helpful to others. So therefore, I just want to raise awareness as much as possible, and I want to raise money, so that we can get some kind of research going here – I know we're close. I really feel it in my heart that we're very close. And I just want to keep it getting closer and closer and closer, and by doing that we need money.

JEANNE BLAKE: So you started the Liz Nichols Foundation. ... And the mission of the Liz Nichols Foundation is to raise funds for research. And it's just getting off the ground. What are some of the ways that you'll raise funds?

LIZ: I designed this beautiful bracelet, as a matter of fact. I don't know if you can get a shot of this. But I designed this bracelet, and we're trying to get – the man who did this did a beautiful job, and we're trying to do another one now where we can keep the costs down a little bit lower so that more money goes to research. So we're doing a little research on that, to find that.

JEANNE BLAKE: Liz, by profession, is a jewelry designer, so she's designed this, and it's going – with the help of a major jeweler in Boston – I, of course, have one.

LIZ: Which I gave to Jeanne. That was a special one, right.

JEANNE BLAKE: And it's being tweaked just a bit, and then they'll be available. And I guess they will be available in the Boston area in ways that we don't know yet, but the woman with whom we're working is dedicated –

LIZ: We're going to have a website that will tell you more information on how to find it.

JEANNE BLAKE: www.liznicholsfoundation.com. But in the interim, because I don't think it's up yet, it was donated by Harbor Light Productions in Portsmouth, New Hampshire, and they're spectacular, it's going to be beautiful. They're a really talented group of young people that have donated this website. But in the interim, let's give let's give www.aboutthehealth.com, where you can learn a lot more about "When Breast Cancer Comes Back," but also, I think that by the time this program is on the air, we will have information about the Liz Nichols Foundation on that too. So if you want more information about the Liz Nichols Foundation, how to donate, or about your video program, that's the place to find it, www.aboutthehealth.com

LIZ: I don't want this money that's being so generously given to me for the bracelets just to be thrown out into the air and going to cancer organizations somewhere. I mean, I really want to delegate where it's going to go. That's why I wanted to do the Liz Nichols Foundation, so that I can do this. I have a major medical company, the institution that would like to take – certainly if anyone would like to take it – but I have someone in mind that I think will do a really good job, so I'm excited about this.

JEANNE BLAKE: A researcher.

LIZ: A researcher, right.

JEANNE BLAKE: As your foundation grows and you get more funds in it, and you have more bracelets that are out there, then people can apply for funds as the foundation grows, correct?

LIZ: Sure. Absolutely. Any way that anyone wants to help, they certainly can.

JEANNE BLAKE: And you'll be raising funds not just through the bracelet but through events. I know that the Women's Business Network out in Harvard, where you're from, is planning an event.

LIZ: Yes. Hopefully we'll get that up on the Web in time also.

JEANNE BLAKE: And also, folks can just, anyone who wants to contribute can send a check to the Liz Nichols Foundation.

LIZ: Yes. It's a good one, too. Please do it.

JEANNE BLAKE: Liz, let's talk a bit about your family. You have young children, they're in high school. I think people always wonder how they would handle something like this with their children.

LIZ: My way of doing it is maybe different than anybody else's. I think you just have to do what you feel is right. But I just tell them the truth. I mean, I give them 100 percent, when I come home from the doctor, of what the doctor said. The doctor has never given me a time, saying, "You have six months to live," or anything like that. I don't think even if I did get that information I would share that with my children, because how often are they wrong on something like that? They are. But I tell my kids, straight out, just, "Oh, this chemo didn't work, so we're going to try another one, and hopefully this one's going to work, and we'll just keep going on until we find something else that's going to work a little better." This is a chronic disease and they need to just keep treating it, and I think once you understand that, it makes life a lot easier for you.

JEANNE BLAKE: And I think that you needed, when you were diagnosed seven years ago, it probably did feel like a death sentence to you.

LIZ: Oh, it did. Definitely. Immediately. I'm not there anymore.

JEANNE BLAKE: I don't think that you are, and you've heard about enough other women who are 10, 12, and more years out with metastatic disease, disease that's in their bones, and as you say, it's chronic. I remember one time, your doctor – when I was at one of your appointments with you, I remember the doctor saying, and telling me specifically that he had patients that had metastatic cancer that spread for over 10 years, and that they just treat the area. For example, you're getting radiation right now.

LIZ: On my shoulder, yes. Yes, so we just keep patching me up in different places. I've been radiated seven times, and seven different kinds of chemotherapy, and we just keep trying new things all the time. And I just have to hold on. I trust my doctor, that he's going to progressively give me the right medication when I should have it, saving the best for last. The one that's going to get it.

JEANNE BLAKE: And in the meantime, working to raise funds for the Liz Nichols Foundation so that you can be part of that cure.

LIZ: I want to help. I just want to help. I don't want to be doing this – I have cancer, and it's a terrible thing, and I don't want it, but I don't want to just sit here and do nothing about it. I want to help. And that's what I really feel my mission is that came from a god somehow, that he just said, "Liz, you've got to help. You can do it."

JEANNE BLAKE: And I think this is probably the really appropriate time to show the close of the video that you made, because you say, "I have cancer, but cancer doesn't have me." And you wanted women to be left on an upbeat note. So let's take a look at how you did that.

[VIDEO CLIP]

LIZ: Dear Lord, thank you very much for this beautiful dinner before us, and it's so nice that I can be able to cook again. ... Throughout our journey with cancer, we've all learned we're much braver and stronger than we'd ever dreamed possible. We've worked hard to stay alive and to find a sense of peace. For us, life will never be as it was before we had cancer. But we all agree that in some ways, it's even richer. What's most important is that we're here, we're alive.

[END CLIP]

JEANNE BLAKE: It's so interesting that people can look at this videotape called "When Breast Cancer Comes Back: Skills for Living," and they expect it to be kind of grim, and at the end they say, "I couldn't believe it. It was so uplifting." I think that part of what we just saw helps explain why.

LIZ: That's what I wanted the whole thing to be about. I didn't want for people to go back to bed in tears. I wanted them to be able to be comfortable, to go back to their bed and hug their husband or whomever happens to be on the pillow beside them, just be able to say, "I'm going to be OK. Hold on as long as I can."

JEANNE BLAKE: Well, good job, Liz.

LIZ: Thanks.

JEANNE BLAKE: And good luck with the Liz Nichols Foundation.

LIZ: Thank you very much, Jeanne.

JEANNE BLAKE: We've given you a website, we'll repeat it right now, and this will also give you information about the Liz Nichols Foundation until the Liz Nichols Foundation gets its own website, which will be soon. It's in the works, as we said. But if you'd like more information about the program that Liz was part of, called "When Breast Cancer Comes Back: Skills for Living," you can find it at www.abouthealth.com. Liz, we wish you good health and lots of success with your many ventures now.

LIZ: What am I going to do after the bracelet?

JEANNE BLAKE: You'll come up with something, trust me.

LIZ: Right. I'll be back.

JEANNE BLAKE: You'll be back. We hope so. Thanks a lot for joining us, Liz, and thank you for joining us for this special program with Liz Nichols. I'm Jeanne Blake. We'll see you next time.

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