

FIND YOUR MBC VOICE

ABCs of MBC

Episode Title: A New Reality

Guest: Teri Pollastro, Patient & Research Advocate

MEREDITH: Why me? What do I say to my family? What'll happen to me? These are a few of the many questions that can overwhelm someone faced with a metastatic breast cancer diagnosis. It's a traumatic time for a person and their family. I'm Meredith Vieira, and I know firsthand how fear of the unknown can dictate the decisions we make. My maternal grandmother was diagnosed with metastatic breast cancer back in the 1970s. I was in college back then, and I really didn't understand much about it because she didn't talk about it with us. And I don't think that she shared many of her concerns with her doctors, didn't ask a lot of questions. But I did know that she was very scared and overwhelmed. However, if you're too afraid to ask questions, then you'll never get the answers you need to make informed decisions about your treatment plan. So I'm here to help you find your voice, your MBC voice. Throughout this series, we will provide you with information to help you speak up and have a more informed conversation with your doctor. Join me as we talk to Teri Pollastro, a mother and wife who's been living with metastatic breast cancer for 16 years. Teri will tell us how she went from being her own advocate to advocating for others. This is the ABC's of MBC. Teri, welcome. It's an honor to have you here.

TERI: Thank you.

MEREDITH: Teri, let's start with your story beginning when you were pregnant with your second daughter Joelle, and you discovered a lump in your breast.

TERI: So when I was pregnant, I mentioned it to my GYN that I felt a lump in my breast and she pretty much dismissed it as a blocked milk duct, which, you know, they didn't think anything, I was in my 30s, healthy, no breast cancer in my family. And then as I was laying on the delivery table and touching my breasts a lot because I was nursing, I could really feel that lump. And when the doctor walked into the room, I took her hand and I put it right there and the ball started rolling and I was in surgery six weeks later.

MEREDITH: Six weeks later. And you had a mastectomy?

TERI: I had a mastectomy and I had immediate reconstruction. I couldn't lift Joelle for six weeks. And that was difficult because I had this –

MEREDITH: Baby!

TERI: Newborn. And I think what was hard for me too was, I could...I saw death and I saw life all in the same...at the same time. I you know, I had early stage disease, they told me I was cured. But, when you're told you have cancer and you're a young mom, I mean, at any age. But I just saw life and death in the same sentence almost.

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MEREDITH: But you felt after the mastectomy and whatever treatment you underwent, that that was it. You were told, the doctor said you're good.

TERI: I was told I was cured. He told me, go live your life. And I did. I totally did everything that he told me to do, except that after about four years and I kept asking him questions, he would roll his eyes at me.

MEREDITH: What do you mean?

TERI: I would ask questions about, could I take hormone replacement? Could I have another baby? And it was just a lot of eye rolling and I said to my husband, he's rolled his eyes at me for the last time. I'm gonna go back to the woman who did my second opinion. And I'm not shaming - doctor shaming - or anything like that.

MEREDITH: Sure.

TERI: It's just, that's the way it was. And I don't think even, you know, 20 years ago, I'm not so sure it was as comfortable for people to advocate for themselves. And I was already starting to take that on. I was like, this is my life. I need to take control of it. So that's when I went back.

MEREDITH: And you clearly saw him being dismissive of your feelings.

TERI: Yes.

MEREDITH: So you went back to the doctor, who gave you your second opinion?

TERI: Yes. And she found my metastatic disease. And, I remember the doctor walking in the room with a piece of paper in her hand. And I thought, oh, that's interesting. And she looked very serious. And then she told me that I had metastatic or Stage 4, breast cancer, which I didn't even know what that meant. I thought that once you had breast cancer, it would go to the other breast first. I didn't think it would go to an organ. So I was like, wait a minute, how did that skip?

MEREDITH: What's going on?

TERI: Yeah. And then I felt shocked and I felt fear. And I had this out of body experience where I felt like I was up above just watching her talk and all I could hear was wah, wah, wah. And she was talking to my husband and this woman, who was me, sitting there nodding her head. But I was not there. And that's how I felt when I got my diagnosis.

MEREDITH: So nothing was really computing at all.

TERI: Nothing. Once I heard that word, I don't think that's a really good time for doctors to share much information. And she didn't. And she had to repeat herself in lots of upcoming

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appointments because you're so overwhelmed with that news at first and so shocked. And you just think about death.

MEREDITH: Is that immediately where you went in your head?

TERI: Yes, because my father had died from cancer and it had metastasized to his liver. And I just knew I didn't want to have happen to me, what I watched happen to him.

MEREDITH: It's interesting you say that isn't a time to impart a lot of information to a patient.

TERI: Right.

MEREDITH: Because it's too much to take in? Is that - What should the doctor be saying? What was she saying?

TERI: I don't...

MEREDITH: Okay, it was wah, wah, wah, right?

TERI: Right. It took some time after that. She actually left on a trip. And then she called me from Europe one night because she knew I needed to talk, and she answered a lot of my questions over the phone. And by then I had a chance to go home and my husband and I kind of hit the ground running. We decided that we were going to take my care into our own hands with my care team. And my doctor was one piece of that.

MEREDITH: What convinced you to hit the ground running because you were at a total standstill?

TERI: Right.

MEREDITH: So how were you able to move forward? Was it because of your husband? Was it...

TERI: Well, my driving force was I wanted to raise my girls. I just kept thinking, I can't leave them here with him! I mean I love him to death but you know he's not a mom. And I just-

MEREDITH: How old were your girls at the time?

TERI: Three and seven.

MEREDITH: Three and seven, yeah.

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TERI: And my seven-year-old definitely had an inkling that something was going on. My three-year-old was oblivious, thank goodness. And I prepared a care team. So I saw a counselor and she helped me role play in how to tell my daughter. And so, we took a tub together and I told my daughter my spiel, which was, you know, I have this cancer. And, I don't know right now how I'm going to respond to the medicine, but I might get sick, I might lose my hair and those types of things. And she said to me, are you going to die? And that was my fear. And I told the counselor my goal was to answer her without crying. And I said, right now I'm not. And she said, okay. And she plugged her nose and went in the tub. And that was that. And I felt so relieved and so grateful to have access to such, you know, supportive care that could help me with that.

MEREDITH: How were you able to find that support? Because so many patients say they don't know where to look.

TERI: I was really lucky at my cancer center. They had me just hooked up and dialed in. And not everyone's going to be the right one, so it's okay to say that's probably not a match for me. I'd like to see someone else. And I've had those experiences as well where, you know, like I said with that doctor, that first oncologist, he just wasn't the right match for me. You just have to find, and make, your own team.

MEREDITH: And also, I guess, understand that moving forward, no one day is going to be like any other day.

TERI: Right. It's, again, it's overwhelming. It's scary. It's isolating. I didn't know anybody you know, my age who was going through that. I was in my early 40s now with little children, especially then, I think. And when they knew my diagnosis, they thought I was going to die. Some people run for me. Some people would run away from me. They didn't know what to say, you know. So there was, there was a lot of those kinds of things.

MEREDITH: Yeah. So what did motivate you day-to-day? I know wanting to be there for your girls, but beyond that.

TERI: Well, I tried to do things that brought me joy.

MEREDITH: Like what?

TERI: Every day I did something; I would go for a walk in the woods, I would read a book, I would have an authentic conversation with a friend. Every single day, and I continue to do that to this day. I try to do something that brings me joy.

MEREDITH: What does that do for you?

TERI: It helps me stay centered and no matter what's going to happen tomorrow. I know today if some bad things happened and maybe if I got some bad news on a scan, what we would do in those instances is we would, my husband and I would call it circling the

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wagons, and we'd take the kids and we'd just be quiet in our house and play games. And it would help us feel re-centered and kind of re-focused again.

MEREDITH: What has it been like for the people that love you?

TERI: I think it's been difficult. We've all been in therapy.

MEREDITH: Yeah. We all need that, right?

TERI: Yeah, it's been difficult. I think in some ways it was hardest for my mom because no one wants to think that they're going to lose their child. So I think that was hard for her. But here I am six-

MEREDITH: Sixteen years later.

TERI: And I mean, I don't have my mom with me anymore. But it was really nice to have her, and I think it was hardest for her. I think my husband was second. You know, I think it was really hard for him too. He always was the strong one. And when we would go to the doctors, if there was something that we wanted to talk about, that was difficult. He was the bad cop. So he would always bring up the, well, this happened. And, you know, people second guess you. They tell you you're not going to the right place. You're not getting the right care. Did you try that carrot juice diet? You know, are you supposed to be eating that? You know, should you be doing that? There was a lot of that. There continues to be a lot of that for people.

MEREDITH: Is that coming from a good place? Because people are concerned or a place of...?

TERI: I'd say it's a place of ignorance.

MEREDITH: Ignorance yeah okay.

TERI: But I do think people mean well

MEREDITH: Yeah

TERI: I really do. And I try to remember that when you're going, when you're in the throes of it, though, it can be hard sometimes to hear those things because you grasp at anything, you want to just get better. And that's one of the reasons why I became an advocate. And so I always say, you know, I advocate for myself selfishly. I advocate for those who can't advocate for themselves because I can come to conferences and do a lot of things to explain the patient viewpoint. And then I advocate for all the friends that I've lost. And when I said to you earlier about being isolating, the women I met who had my disease, you know, sixteen years ago, fifteen years ago, they're all dead. Not one of them lived.

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MEREDITH: I mean, it's so interesting that you do advocate for others because this whole campaign is about finding your voice. And then once you find it, I've discovered so many people when they have it, want to scream it to others.

TERI: Yes.

MEREDITH: To give back, to help guide others.

TERI: Yes, it's really important. I meet with newly diagnosed patients and, when I go into the room, I always kind of, I always am ready to meet them where they are, because different people require different things. And so I try to get a gauge on where they are and then I provide them with what I think that they need, you know. But I'm always saying bring someone with you to appointments. Have a notebook. Have your questions ready. If you need a follow up appointment with something, don't be afraid to ask. If you need outside help, financial, hotels, you know, psychological, it's okay to ask for those things. And I think I use the social worker more than the doctors did. I was always like, oh, let's get a social worker to talk to you about that, because they have a lot of resources that they can share.

MEREDITH: Is there one question in particular that you tend to get the first time you meet someone who's just been diagnosed when they know that you've been going through this?

TERI: They asked me how long I've been living with my disease.

MEREDITH: That's the first?

TERI: Because I provide them with hope. And that's a double-edged sword because, you know, like I said, I think it is just where the marbles fall and not everyone is this lucky. And so that's why I do feel like because this happened to me and I was so lucky I needed to do something with this. Why me? You know, so that's what made me go, all right, what can I do to help? And then my oncologist, she is the one who's kind of pushed me into advocacy. She's nudged me in, first meeting with patients and she had to get me approved for that because they didn't want metastatic patients in with newly diagnosed patients.

MEREDITH: Why?

TERI: I think they were afraid of what that would do. So if it's an early stage patient, not someone whose Stage 4 and I'm a Stage 4 patient, they were afraid I would scare them. But that isn't what happened at all. And most of the time I didn't share with them what stage I was. They didn't need to know that unless they were Stage 4 and they were really down and I would sometimes say this might be you. You know, it doesn't necessarily mean it's a death sentence.

MEREDITH: Well, I want to talk about your girls a little bit, Maddie and Joelle. Maddie has actually moved into breast cancer research.

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TERI: Yes. She's in clinical research now.

MEREDITH: You're smiling. Others can't see it, I can see your pride.

TERI: I am so proud of her and it's her passion as well. You know.

MEREDITH: Because of you.

TERI: Yes. My younger daughter went and spoke to some researchers about what it was like growing up with a mom who had metastatic disease.

MEREDITH: What did they say?

TERI: Oh, my God. Some of the things she said. I was like oh, please. I walked into her school one time. I was in my slippers because she got in trouble for not having an assignment in. I had been in the hospital the night before. So I went marching in there. I gave them a piece of my mind. I said, sometimes life gets in the way of homework. So get over yourselves. She wasn't one of those kids that would just blow off her homework.

MEREDITH: Yeah.

TERI: So when she didn't do it and then she got in trouble, I was like, okay. And they weren't really interested. Plus, I didn't share with the school what was going on with me at that point.

MEREDITH: Because?

TERI: I didn't want to call attention to Joelle. She didn't like that, and both of my kids were different that way. You know, they require different things from me as a mom.

MEREDITH: So your older daughter Maddie, I just have this image of her in the bathtub going, you know when she knows you are not gonna die today and go, okay, mom, I'm good for now. I'll be the first to know when things are. And then the woman that she evolved into.

TERI: Right.

MEREDITH: Still, okay we'll keep going. And she gets information before, well, a lot of people that she can share with you when there are new treatments.

TERI: Right. She went to a conference with me a few weeks ago, a breast cancer conference, and she said, you want to share a room? So we shared a room together. It was, it was great. And it was great having her there.

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MEREDITH: You've obviously raised wonderful girls. I'm sure that's your number one accomplishment, that and surviving and living your life.

TERI: Yes.

MEREDITH: Yeah. And finally, for somebody who's just been diagnosed, two things. What do you want them to know in that moment? And what should the person that they're telling, what would be the most helpful thing they could hear back?

TERI: I think you need to really understand your disease and know your subtype. There are a lot of patients out there that still don't know what subtype they are. I think that's important. And I think it's important to educate yourself about your disease. Don't be afraid to ask questions. I know sometimes doctors get mad that we use Dr. Google but we have to, that's how we learn. And we can go on the Internet and look up things when we have the time to do it in the safety of our own home and put it away when we want to. I always say, if I don't see it three times in a reputable journal or some kind of article like that, I don't believe it. You know-

MEREDITH: I just going to ask you how to weed out misinformation?

TERI: That's how I weed it out. If it isn't from a reputable journal or like you said, I don't see it a few times. I don't believe it. And then I always had a list going for my doctor, of questions that they, you know, so if you did see a study, would I qualify for that study? How does that work? You know, those kinds of things. It's good to go prepared into your appointments. I also say ask for copies of all your scans, your blood work, because when you get home, you can have the time to look through them. I'm not going to look when the doctors in the room and pick up that one word.

MEREDITH: Right.

TERI: That I don't know what that means. And that word looks scary to me. So I always say make sure you get copies of your reports and your scans. And then the other thing is make your appointments around your schedule. You know, you're important. It's what works for you. If you're working, make your appointments, you know, after work, before work or during the day, if that's what works. Don't let others push you into what doesn't work for you.

MEREDITH: Speaking of others, people who do not have the disease. When someone tells them they do, they don't know what to say.

TERI: Right.

MEREDITH: You know, and it's an awkward moment. What should they say?

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TERI: You know, it depends on the person and who you're talking to, right? Someone close, you might say, I'm really sorry this is happening to you and how are you doing? How are you really doing? I often said, and someone just asked me this last night, what's something I could do? I always say send a card. It takes a lot of effort for a person today to go out, buy a card, put it in the mail and the person that receives it, there's nothing required of them. They don't have to return a phone call. They don't have to write a thank you note. They don't have to return an email. It's just pleasure. Who doesn't like to get something nice in the mail, today all we get the mail are a few bills, right? Nobody sends anything in the mail. So I think those kinds of things are really important. They have all kinds of meal sign ups. There's so much more today for people that are going through treatment, you know, meals and rides for your children, all those things. If you need it, don't be afraid to ask for it. Friends can help and ask for specific things. So if you are going to ask me, what do you need? Say, how about I bring dinner on Tuesday night and would a lasagna sound good. I got so many lasagnas. I didn't need another one.

MEREDITH: Your last name alone, you're Italian. I'll just fill in the blank here and I'll let you go for me, Teri. Living with metastatic breast cancer means...

TERI: I try to live an authentic life every day of my life. You never know what's going to happen tomorrow. And I try not to think about that when I have bad scan results. I might think about it a little more, but I just try to live an authentic life.

MEREDITH: It's such a pleasure to sit down and talk with you. I'd love to have a slice of lasagna with you, I know you're sick of it! Thank you so much for your time.

TERI: Thank you.

MEREDITH: And thanks to Pfizer for sponsoring this conversation. It is important to remember that it's okay to not feel okay, and there's something that you can do about it. Oftentimes fear can cripple us from speaking up, but it's important to always ask the questions you want answers to. Just ask Teri. Even when you think it's an obvious question, make sure your voice is heard. Working together, you and your doctor can come up with the right treatment plan for you. Looking for more information on how to do this? Visit [find your MBC voice dot com](http://findyourMBCvoice.com) for an interactive discussion guide to help you have an informed conversation with your doctor. I'm Meredith Vieira, thank you.

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