

# FIND YOUR MBC VOICE

## ABCs of MBC

### Episode Topic: What Did You Say

Guest: Beth Fairchild, President, METAvivor & Director, #Cancerland

**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 Beth Fairchild, who was diagnosed with metastatic breast cancer when she was 34 years old. Beth is the president of METAvivor, an organization dedicated to this specific fight of women and men living with metastatic breast cancer. When you receive a metastatic breast cancer diagnosis, you're not expected to know the ins and outs of your disease immediately. But often doctors can use words and abbreviations that you have never heard before. Beth has first-hand experience with this and is here to tell us how she navigated this when she was first diagnosed with metastatic breast cancer. This is the ABC's of MBC.

**MEREDITH:** Beth, welcome. Honored to have you here.

**BETH:** Hi Meredith, thank you for having me.

**MEREDITH:** Of course. I saw you nodding your head when I talked about all those words that are thrown at you by doctors that you can't possibly know the meaning of. You've been there, you know that.

**BETH:** Right.

**MEREDITH:** So take us back to when you were first diagnosed with metastatic breast cancer, and those first conversations you had with your doctor.

**BETH:** Well, it's like it is on the movies. All the air leaves the room. You don't hear anything else after the word cancer. And, even as a layperson, you understand what Stage 4 means. And, while you may not know the statistics, you know that it's not good when it comes to cancer. And so, you really get a crash course in oncology. You know, you learn about metastatic disease. You learn how cancer cells travel through the body. All of these things that you never really want to know about. But in order to advocate for yourself as a patient,

# FIND YOUR MBC VOICE

these are things that you need to know. And it can be like another language, and difficult for a lot of people to learn, especially people who don't have access to educational tools. And so I think it's important that there are programs that teach people what a lot of these terms mean.

**MEREDITH:** Well, how did you learn?

**BETH:** I turned largely to the patient community, online support groups, women who share my diagnosis and had been living with it for some time. I remember wanting to know what N-E-D meant. A lot of women were posting that they were NED and I had no idea what it meant, and it means no evidence of disease. And I wanted so desperately to be N-E-D. And, a couple of years into my diagnosis, I was telling newly diagnosed people what N-E-D meant. And so it came full circle. But my peers were really the greatest source of information for me in the beginning.

**MEREDITH:** Much more so than the doctors.

**BETH:** Exactly. Most doctors speak in medical terms because it's what they know. And a lot of people in the medical community, health care community, scientific community have a hard time translating what they know into lay terms for patients to understand. And that can be really frightening in the beginning. So I think that, patients, especially newly diagnosed patients, should turn to their community, their peer-to-peer support. And that's where they're going to find a lot of information.

**MEREDITH:** But, you know, when you're – and I don't know - but when you're hit with that kind of diagnosis, I would think the instinct would be to curl up in a ball, rather than...

**BETH:** Yeah. You know, people see me sharing my story and look to me for hope and support. And in the beginning, I was a mess. I would say probably eight to 10 weeks. I didn't want to leave the house. I was in the bed. I was crying in the shower. And I feel like everyone who's diagnosed goes through those why me moments. Why is this happening to me? And I think it's important for people to understand that that's normal and to honor those feelings. And, you know, I want people to know that, newly diagnosed people that, where I am now is not where I was when I got that diagnosis. Just like where they are when they're just receiving the news, that's not where they're gonna be in a year, in two years. And, if they just keep turning to their peers for support and their medical staff as they become more comfortable and more well versed and more understanding of what's happening with their bodies and their treatment, then I think they'll be more comfortable and understanding that there is life after a cancer diagnosis, that there can be hope. And after they get their footing, then they can, go out and be advocates for themselves and other people.

**MEREDITH:** Your oldest daughter, what's her name?

**BETH:** Leigh Ann.

# FIND YOUR MBC VOICE

**MEREDITH:** Leigh Ann was 14 when you were diagnosed. And your younger daughter?

**BETH:** She was 14 as well.

**MEREDITH:** So what is her name? Cylest.

**MEREDITH:** Cylest.

**BETH:** My oldest daughter is mine biologically. And my younger daughter, Cylest, I adopted. And, they were both 14 when I was diagnosed.

**MEREDITH:** So how did you tell them?

**BETH:** I waited a week. I was diagnosed with breast cancer, metastatic from the beginning, which is de novo metastatic disease.

**MEREDITH:** You've never had anything prior? No.

**BETH:** Never had an early stage, actually never had a lump in my breast. I had a clean mammogram the week before my diagnosis and, my children were in school, it was end of year testing. And I didn't want to tell them that I had this terminal illness. So I waited a week, which was probably one of the hardest weeks of my life to, to, you know, smile when they came home from school and ask them about their day and really internalize everything that I felt to protect my children. And, the last day of school, their exams, they came home and, you know, they were jolly and happy that summer was here. And I had to go to them one by one, you know, telling Leigh Ann who she was from my first marriage and she doesn't have a relationship with her father. And so to lose me would be devastating to her. And I didn't tell them that, you know, that I had two years to live, which was the statistic I was told. I just told them that I had a terminal illness and that I would fight as long and as hard as I could. And I intended to be there for, you know, their graduations and their marriages. And really at the time not believing that but saying what I needed to say.

**MEREDITH:** You didn't believe it.

**BETH:** I didn't believe it for a second. I thought my life was over. And then to, to have that conversation with Cylest. Her first thought, she'd been in and out of foster care since she was six months old. And her first thought was, this family is going to abandon me in this dark time. And I said, you know, we signed on for this and good or bad, you're stuck with us. And you know, she's hung in there through it all. And it's been a rocky ride. And actually, I don't know if I can even say this, but today, she had a mammogram because she has a lump in her breast. And, you know, it's really scary. And my biological daughter's health has always been at the forefront because so fearful that I pass something genetic onto her. And then my adopted daughter is experiencing this. And it's frightening.

# FIND YOUR MBC VOICE

**MEREDITH:** You said when you talked to your daughters, you told them you were going to fight this, but in your heart, you didn't think you were gonna win. That's sort of what you were saying to them. You were. How long ago was that?

**BETH:** I was diagnosed in May of 2014.

**MEREDITH:** Okay.

**BETH:** And the oncologist at the time told me I had two years to live.

**MEREDITH:** And now it's five years later.

**BETH:** Yeah. The oncologist at the time told me I had two years to live and maybe more, maybe less, depending on how I responded to treatment. But she didn't leave me with a lot of hope. And I was in a wheelchair. I just had this horrible surgery, blood transfusion. I couldn't walk. It was emaciated. And I thought I would die like that in that wheelchair. And it was hard to see past that point.

**MEREDITH:** So how did you get to the point where you could see beyond that and see a life for yourself that included hope?

**BETH:** Just time. You know, I got stronger every day. My oncologist, I changed oncologists to one who was a little more empathetic and compassionate. And he said, you know, Beth, you're not going to die in this wheelchair. You're going to get better and you're going to have a normal life until you don't. And the one piece of advice that he gave me on that day and I think about it all the time, is he said, Beth, let me worry about your cancer, and I will let you know when it's time to worry. That was for me, great peace of mind, because I was able to leave all of the worry and fret and the "what ifs" with my doctor, and really trust that he was going to walk this road with me and make the proper decisions in my care.

**MEREDITH:** But it's interesting that was not your first doctor.

**BETH:** No.

**MEREDITH:** So clearly you had to do some shopping around as a patient to find a doctor who really heard your voice.

**BETH:** Yes, so, most people spend more time researching a house or a car or a washer and dryer than they do vetting their health care provider. And so I just, you know, got the person on call because of my surgery and the way I was diagnosed. And that was my doctor. And I didn't fit with her. So I had to shop around and find that. I mean, this is a marathon. This isn't a sprint. We're not fighting the flu. I'm gonna be in this until I die. And I needed someone who was gonna be there and be steadfast. And so I took the time and found another doctor. And I often recommend to newly diagnosed patients that they get a second or third opinion. And if they don't like their doctor, it's not personal. But you need

# FIND YOUR MBC VOICE

to find someone that you fit with and someone who's gonna take time and explain things to you, because that's often not the case.

**MEREDITH:** What is, I'm sure there's not a typical day, but when you look at your new normal, your life. How do you describe it?

**BETH:** My life is pretty great. Despite cancer, you know, I have a pretty normal day. Probably what's different from me than to someone who doesn't have a terminal illness is that I find joy in the mundane things, you know.

**MEREDITH:** Like what?

**BETH:** Like cooking dinner with my husband. You know, we cook and we laugh and we sing. If we're in traffic, we just turn on the radio and sing songs and act silly. And that's fun for me. You know, when I was taking my kids to school every day and packing their lunches, that can be a chore for some patients. And, you know, a lot of yelling and rushing in the mornings. And I just don't get in a hurry anymore because, you know, life is too fast as it is. There's no need to rush it along. So just, you know, finding joy in the little things and finding value in the mundane tasks that most people, you know, consider a chore. It's a gift for me to be able to do those things.

**MEREDITH:** Most people are just sort of living their life without looking in either direction. And you're absorbing every moment, clearly.

**BETH:** Yeah, I think, you know, as a young person, right, you start out life, you want to get into a good school and then you want to get a good job and you want a nice car and the nice house and then a promotion. And those things are all great. But if you're not happy in your life and you're not surrounded by people who love you, then they're all really worthless.

**MEREDITH:** What about the hard days?

**BETH:** I certainly have those days. They're not as frequent as they were in the beginning. But I have days where physically I hurt, you know. Fatigue is overwhelming. I may be able to do one thing a day. And I think it's important for people to know that that's okay. You know, we don't have to be everything to everybody. We can only do what we can do. And then I certainly have days that are just, you know, mental and emotionally challenging where I can't get away from it. I can't escape the thought that I'm facing my own mortality every time I look in the mirror. And that is a really heavy thing to carry and to do it day after day after day. And to be an advocacy, work in this the way that I do and I mean, literally hundreds of people that I have connected with have died over the last five and a half years. And it can be mentally and emotionally exhausting.

**MEREDITH:** So why do you keep doing it?

# FIND YOUR MBC VOICE

**BETH:** Because who else is going to do it? There are people that are listening at home and can't find the voice to do this. And I, for whatever reason, found my spot and my platform and people listen to me and people reach out to me. And I've been able to see tangible changes from the work that I've done in advocacy. And that's life to me. That equates life, change, more funding for research. More drugs coming to market. That's a bridge to a bridge to a bridge to me. Which means more time with my kids, more time with my mom or time with my husband, more time with my friends and family. And more time to advocate for other people, people who can't advocate for themselves.

**MEREDITH:** And people can't see you, but you have so many beautiful tattoos. And I know you use your artistry on many women...

**BETH:** Right.

**MEREDITH:** ...Who have suffered from breast cancer or metastatic breast cancer. Can you talk about that?

**BETH:** Sure. So I am an artist by trade. I've been tattooing my entire adult life and, my mom had breast cancer, stage 2B, about 20 years ago. And I saw that her lumpectomy left her without an areola on her breast. And I knew that I could use art to fix that. You know, the way that I create images on skin and I thought, well, I can fix that. So, I started doing it and I was doing areola complex tattooing on breast cancer patients for probably 10 years before I was diagnosed with cancer. And actually, after my diagnosis, I would still go to work and I would go to the studio and I would tattoo my patients. And I'd never even told them that I had cancer because they're there and they're sharing their story with me. And that's therapeutic for them. And then they get up from the chair and they look in the mirror and they see, something that's very similar to what they had before. And they feel like it's the end of their journey. Their completion. And to be able to give that gift to women and men is just so, I can't even put into words how meaningful and touching that is. But it was kind of nice to just be able to give back and not be the patient in that moment. And I still do it to this day. If people come to me, I tattoo their areolas for free. Of course, if I traveled to them, there's expenses that are incurred, but I love it. There's no other work as rewarding as being able to do that for someone.

**MEREDITH:** And, meeting all of these people, what have you learned from them? What? I mean, obviously, you've probably helped them develop their voice and their confidence just in what you do as a tattoo artist.

**BETH:** Yeah. I mean, I think what I learn from other patients is perseverance. Because, you know, I, relatively speaking am doing okay. I didn't achieve the N-E-D status that we talked about, but I have no evidence of active disease. So my cancer's been totally stable for five years. It's still in all my bones. Every bone in my body and two lesions on my liver. And there was tons of tissue in my pelvis that they left behind. So I know that I have cancer, but it's just not doing anything. And so, I've kind of made an agreement that it can lease space in my body as long as it behaves. But what I've learned from other patients who have not

# FIND YOUR MBC VOICE

been as fortunate as I have been, who don't respond well to therapies is just perseverance and never giving up.

**BETH:** And, you know, keeping that attitude of living and thriving until you can't. And I think that if you can do that, then you have won, even if you lose your life to cancer. Right. You have won, because you didn't let it stop you from living your life.

**MEREDITH:** And to those people who have said, we were talking about this before, to those people who have said we can't really hear your story because it's a downer, we don't want to really listen to this particular group of cancer patients because their story is too sad. What do you say in response to that?

**BETH:** I say the opposite. I mean, you have all of these people who are living with this terminal illness day after day and still get up and smile and laugh with their friends and go on vacation. And honestly, I can't think of anything more inspirational than that, than living in spite of adversity. And I think knowledge is power. You know, I think you should know that early stage cancer has, you know, almost a 30 percent chance of recurring metastatic. And I think people should know about that so that they can stay on top of their health so that they can be mindful if they have a pain in their hip or their back. It could be metastatic disease and they should talk to their health care provider. But if they don't know that metastatic disease exists or how early stage cancer can become metastatic, then they're not looking for it. And they're not going to be as proactive. And so to me, knowledge is power. And sharing these stories, even though they may not have a happy ending, is really important.

**MEREDITH:** Have you adopted a different vocabulary of your own in terms of talking?

**BETH:** Oh of course. Yeah. I mean, probably things I can't say on this podcast.

**MEREDITH:** Tell me later.

**BETH:** There are a lot of things that cancer patients, you know, different names for drugs or therapies or the horrible side effects that come with the drugs that are quite comical in themselves. But there's definitely a different language in the cancer community.

**MEREDITH:** Do you have any final thoughts you want to share with us? I mean, a lot of people who will be listening to this podcast have literally just been diagnosed, or someone they love has just been diagnosed with metastatic breast cancer.

**BETH:** I mean, I think the biggest thing, is look for resources. Educate yourself about your disease, because if you don't know what your tumor receptor status is, if you don't know, what your treatment options are, then you can't make an informed decision and you don't always get that information at that point of care. Unfortunately, you know, doctors can only do so much in the time frame that they're allotted to see you. And if you don't know to ask, then you're not getting the answers from your providers. So find a support group, whether

# FIND YOUR MBC VOICE

it's online, whether it's face to face, find your people in that group that you can ask questions of, and then you can take those lists of questions back to your doctor. Don't be afraid to ask your doctor questions. I know a lot of people don't want to ask, but make your list. Go to your doctor. Write it down. I remember sending my oncologist so many trials and he responded back, are you a woman or a mouse? And you know I was just sending him all these trials. Can I do this? Can I do this? But do that. You know, there is no right or wrong. But, find your people, find credible resources online for information and, don't lose hope, because even in the darkest of times, right, there is hope.

**MEREDITH:** Thank you so much for your time and thanks to Pfizer for sponsoring this conversation. There is an overwhelming amount of information that patients receive when they're diagnosed with metastatic breast cancer. We learned from Beth that you aren't alone in thinking that your health care team uses confusing words and acronyms without much explanation. So it is very important to stop them if they are using words that you don't understand. 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. Thanks for listening.

**END**