

# FIND YOUR MBC VOICE

## ABCs of MBC

### Episode Title: "The" Conversation

Guest: Christine Verini, Chief Operating Officer, CancerCare

**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 Christine Verini, chief operating officer of Cancer Care, a leading organization that provides people living with cancer and their loved ones with support services as they navigate the complexities of this disease. We know that a metastatic breast cancer diagnosis impacts more than just the patient. It impacts their friends and family, too. Christine is here to share tips and resources on how to have a conversation about a metastatic breast cancer diagnosis with the people you love. This is the ABC's of MBC. Christine, welcome. It's an honor to have you here.

**CHRISTINE:** Thank you. It's a pleasure to be here.

**MEREDITH:** Thank you. How did you get into this field of oncology in the first place?

**CHRISTINE:** I'm a pharmacist by training. And at the same time, when I graduated school, my sister was 28 years old. She had a three-year-old and one-year-old, and she was diagnosed with inflammatory breast cancer. And I decided then and there that I would dedicate my career to making a difference to people living with cancer as well as their families.

**MEREDITH:** I imagine that meant a great deal to your sister as well.

**CHRISTINE:** She's still my best friend.

**MEREDITH:** And CancerCare. What exactly does that organization do to help patients navigate their way once they get this diagnosis?

**CHRISTINE:** So we are a 75 year old organization, we're not for profit. We have three foundational pillars that help the patients. We help with financial assistance. We help with education because it's important to know what you're going through and understand all of

# FIND YOUR MBC VOICE

the treatments and understand some of the side effects and just managing through the disease. And the third and most important thing is we help with emotional assistance. We have over 35 masters trained social workers on staff that answer our help line.

**MEREDITH:** Why is that so important?

**CHRISTINE:** Because the social worker has the ability to help people deal with their feelings. They help them cope with the challenges of the situation in general. We also help them with resources that may be available. If we don't have those resources, we try to help them get resources within their community. We also have the ability to help them from a standpoint of ensuring that they have the discussion with the health care team because it's often the health care team is speaking to them about what should be done. But they also should be able to go back and ask the health care team questions.

**MEREDITH:** What is the range of emotions that someone experiences when they receive this kind of diagnosis?

**CHRISTINE:** It's a broad range. It could be sadness, anxiety, primarily because they could have had early stage breast and lived for many years without having to be treated with anything, and then the metastatic breast cancer is back and it's somewhere else in their body. So it really is foundationally scary for them.

**MEREDITH:** And probably anger too, in those situations.

**CHRISTINE:** There's definitely anger. You know, there's a great opportunity for people to reach out to kind of their trusting group of people, their friends or their family, to really kind of talk through and communicate with them what they're experiencing and not hold that in. That's an important component of when they're diagnosed to not hold in those feelings of anger, frustration, sadness and anxiety to get that out. But more importantly, also to speak to a social worker that can help them with the psychosocial aspect of the situation as well.

**MEREDITH:** But you're totally in shock. How do you even start the conversation?

**CHRISTINE:** I think you start small. You start small with people that you trust. That could be a friend, a family member, and really let that information or let your voice come out. Have the conversation where you can actually talk to them about how you're feeling. But it's more importantly the person that you're talking to, for them to listen. That's a key component.

**MEREDITH:** And when you say listen, what do you mean? Because obviously you've seen that not be the case.

# FIND YOUR MBC VOICE

**CHRISTINE:** It's a simple thing that people often... 'it'll be okay.' Well, do you know that? Is the person that has the metastatic breast cancer saying to themselves. So listen and don't judge and listen and don't cheerlead, is a key component.

**MEREDITH:** Don't cheerlead as in saying what you just said, it'll be okay. Just be in the moment with that person, whatever their truth is in the moment.

**CHRISTINE:** Give advice when asked. It's a key component, right? Often people want to look up everything and tell them all the different things that are going on. That's not necessarily what that person needs. The person needs you to be there and to love them and be kind to be patient with them. For them to take the burden of the feelings that they have and just talk them through with you.

**MEREDITH:** And then where you go from that? Now, you have spoken out, which is not easy, with this small circle of family and friends. What's the next step forward?

**CHRISTINE:** I think part of it is actually keeping them in a communication, from a communications standpoint, keeping them engaged or involved as best you can because there are gonna be ups and downs, it's a rollercoaster, right, it's anything else in life, but it's a roller coaster. And I think it's important for people to help the people that you're friends with or your family to be educated as much as you are because you're making decisions. And maybe they may not understand those decisions, but they should be there to support your decisions. And education is half of the battle and really letting them know what's going on, what you're feeling, what's transpiring in your mind, where you're going with your next step with your physician, what's the next treatment? What's the next step? It's all about communicating to them and keeping an open line of communication, not holding it in and burdening yourself with all those feelings.

**MEREDITH:** Why do people have that tendency, you think, to hold it in?

**CHRISTINE:** They want to feel strong. They want to gain control, or maintain control, because it's a challenge. I think anyone in whatever disease that you have, it's a challenge to maintain control. But in metastatic breast cancer, it's definitely there for sure.

**MEREDITH:** But sometimes, if I've learned anything, it's when you, find your voice and share, that's when you're really in control as opposed to holding back. You think that's being control, but it's really not.

**CHRISTINE:** I think part of the reason is it's not always great news that they have to share. So they hold it in. And I think that's a challenge for them and it's a choice as well, right? They have the choice. But I think it's a challenge for them to hold all that and burden themselves with all those feelings and keeping them inside. And that's, again, the importance of at CancerCare, why we have so many social workers there available to listen to them and help them cope with the feelings that they're experiencing. Helping them better communicate, whether it be with their family or their health care provider. And we

# FIND YOUR MBC VOICE

often talk about shared decision making in general when we're talking about making a decision in life, when you're making a shared decision within this area, you have choices that you have to make that sometimes are hard choices and sometimes just talking to somebody and them just again, listening to what you have to say is just as important as the decision in and of itself.

**MEREDITH:** How important do you think it is, Christine, if you know someone with metastatic breast cancer, love somebody with metastatic breast cancer, to engage in their appointments with the physician? Is it important to you that somebody be there with a patient to advocate for them as a second voice?

**CHRISTINE:** Yes. So, when you hear the words, I have cancer, or you have cancer, it's polarizing. And I think it's important for someone, a caregiver, a person who's caring for you to be by your side when you're having those appointments with the physician, because you often don't hear a lot of what they're saying. Right. So when you, before you go into that appointment, you should be discussing who's going to take the lead. Are you as the patient going to take the lead or is the caregiver going to take the lead? What are the questions we want to ask? Be thoughtful about what you want to ask that physician in front of you. Be thoughtful about what are the key things that you want to focus on in general overall. What are your future expectations, whether it be about treatment, whether it be about side effects, whether it be about, you know, able to go to San Diego for a visit to see a grandson, be thoughtful about all of the types of questions that you want to ask and come together as a unit or family or a caregiver or a family type unit to be able to make the decision.

**MEREDITH:** You've dealt, obviously, with many people in this situation. What have you learned from them?

**CHRISTINE:** That's an interesting question. I actually have learned to appreciate every day. Every moment of every day. I always say life is a moment in time and you have a choice, you can enjoy it, or you cannot. And I choose to enjoy every moment. And it's rewarding. I would say, you know, with my experience with my sister being diagnosed with cancer early on in her life, it changes your perspective on what you want out of life. And I've been very blessed in many ways. I live a humble, simple life. But it's mine and I love it. And that's how people should look at life, not be caught up in what you don't have, but love what you do have and appreciate every moment of it.

**MEREDITH:** We talked about sharing your information with family and friends. A lot of women who were diagnosed have kids, from little to big. That's another difficult conversation to start.

**CHRISTINE:** It is definitely a difficult conversation. Depending on the age group sometimes we actually have people work with us and the social workers to really kind of go through the messaging of what they want to say and how they want to say it. That's an important component. I think that people don't recognize. People stop talking to people who have

# FIND YOUR MBC VOICE

cancer often because they don't know what to say. But it's so much better to say, I don't know what to say, but I'm here for you. It's such a small point, but it's a significant point.

**MEREDITH:** Your organization, CancerCare, the number one goal is to guide people through this new normal in their life?

**CHRISTINE:** Yes. We actually help with everyday practical daily needs. Right. So if it's education and they need to understand something from what their physicians or nurses have said to them, we can get them education opportunities. We do a lot of workshops with thought leaders across the nation on different topics. We help from a financial perspective, if people need home care, childcare, transportation, we help those have great grants across the nation for that. And then we also help from the emotional perspective, which is the psychosocial perspective with the social worker. So they really have the ability to listen to what their needs are. So it's just a conversation, but they're listening to what the needs are.

**MEREDITH:** You know, thinking back to my grandmother who was diagnosed in the 70s. I don't think people back then ever challenged a doctor, ever asked questions. I mean, I'm sure there were some. But the doctors' word was, it.

**CHRISTINE:** Yeah, I think this program is a great program, primarily because people are becoming more consumerized in their health care. And I think some physicians do have to adapt to people asking lots of questions. We recently had a meeting with about eight metastatic breast cancer patients and three caregivers. And it was amazing. There was such a variability in wide range of the discussions that the physicians had with each of those individuals. We found it fascinating from our perspective, because when you meet one cancer patient, you really, truly meet one cancer patient. When you are talking to them about their situation, it's only their situation. It's uniquely different for each individual.

**MEREDITH:** Which is not the way most people think of it. Is there anything you want to add, anything that you've learned along the way that might help folks who are now being diagnosed with metastatic breast cancer as to how to communicate their needs, in a way that helps them become better informed and more able to take control of their lives?

**CHRISTINE:** I think it's important from a standpoint of, people need to understand that there is not one facet to this disease. There's an emotional component to it. There's a physical component to it. And I think people need to recognize that when a person makes a decision about whatever treatment choice they decide or whatever they decide, that it's their choice and it's their body and it's their spirit. So they have to respect whatever that is. That's the one thing that I would say as a caregiver of my life and other caregivers in general, that people have to respect the decision that the person who has the cancer makes.

**MEREDITH:** Is it important for that person, also, the person who has the cancer to when they're selecting this, sort of support group around them, to make sure that those people are folks that they totally trust.

# FIND YOUR MBC VOICE

**CHRISTINE:** Yes. That's of the utmost importance. Trust in the people that you are communicating with in your, it could be a small group. It could be one person. It could be two people. It could be five. Whatever it is, you have to trust them and they have to be there for you, whether they agree with your decision or they don't agree with their decisions. Whatever those are, they should be there. A caregiver, I often say people like, well, what is a caregiver? I'm like, if you're helping somebody with something, then you're a caregiver. It could be driving them to their appointments. It could be helping them organize their insurance papers. It could be driving the kids to work. It could be walking their dog. So there's so many different avenues that you could effect on a practical daily living component that CancerCare helps with and others with different resources that are out there that help with that are so key. So helping practically, helping emotionally, and helping educate them to understand the decisions that you've made and the reasons why is so important to make a difference to what they're going through.

**MEREDITH:** Thank you so much.

**CHRISTINE:** Thank you.

**MEREDITH:** For joining us, it's such a pleasure to have you here. Our thanks to Christine and thanks to Pfizer for sponsoring this conversation. It is hard to receive a metastatic breast cancer diagnosis, but it can be even harder to talk about it with your friends and family. We hope that this discussion has empowered you to talk to your loved ones about how they can support you as you cope with a metastatic breast cancer diagnosis. In addition to talking to your loved ones, it can also be difficult having an open and honest conversation with your doctor. So if you're looking for more information and want to be heard, there is a resource for you. 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**