

FIND YOUR MBC VOICE

ABCs of MBC

Episode title: An Education

Guest: Cathy Ormerod, Vice President, Programs & Partnerships, Living Beyond Breast Cancer

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 Cathy Ormerod, Vice President of programs at Living Beyond Breast Cancer, more commonly known as LBBC, helping to connect people with trusted breast cancer information and a community of support. She's here to discuss some of the resources and support services available to patients and their families when they are faced with a metastatic breast cancer diagnosis. This is the ABC's of MBC. Cathy, thank you so much for joining us, honored to have you here.

CATHY: My pleasure to be here. Thank you.

MEREDITH: You're there to help people in that moment when they are diagnosed, first diagnosed with metastatic breast cancer. It has to be so frightening for them. Overwhelming and they don't know where to turn. So what do you tell them? What's the first place that somebody should go to?

CATHY: Well, we really, everyone's experience is different. And people approach information gathering and getting through the shock of the initial diagnosis, because you're right. It is a life changing diagnosis. There is no way to get around that.

MEREDITH: It brings you to your knees.

CATHY: It brings you to your knees. And I speak to people all the time and ask them, you know, what would have been helpful in your experience. And people were like, okay, I needed to cry. I needed to grieve. I needed to figure out what to tell my family, when to tell my family. If there are children, what are the ages of the children? How do you craft your message to be appropriate? There are a million questions to ask, but you need to first gather your supporters around you, and figure out who in your life can you count on to share this journey with you, this difficult journey. And you also need to find trusted information and a community of support. We know at Living Beyond Breast Cancer, that

FIND YOUR MBC VOICE

finding that community, especially for newly diagnosed metastatic women, is critically important because isolation is sort of the hallmark of this disease.

MEREDITH: Why is that?

CATHY: Because, you know, particularly in this world, we are coming out of this world of early stage breast cancer, you know, people are warriors that are going to beat this. They're all supportive. They wear pink boas. They're all happy. And they're going to succeed.

MEREDITH: Because good things are happening.

CATHY: Yes, good things are happening, and we are all grateful for those good things. Don't get me wrong. But when you have a metastatic diagnosis, what does that mean? Does that mean if it's a recurrence, did you fail? Did you do something wrong?

MEREDITH: Do patients feel that way?

CATHY: Patients do feel that way all the time. And they express that, and they wonder about that. You know, I did everything I could. I changed my diet. I did all the treatments that they asked of me. I wanted the most aggressive treatments. And still it came back. It is very shocking for early stage, people who have experienced early stage breast cancer -

MEREDITH: To then have this reoccurrence and it's metastatic.

CATHY: Yes. And it's...20 to 30 percent of people with early stage breast cancer will recur. And many are shocked by that.

MEREDITH: Well many have said, that their doctors never even inform them that that was a possibility.

CATHY: That's right. And so when it returns two years later, five years later, 25 years later, it is shocking. And there's kind of a societal guilt and there is a personal guilt. And, you know, it is wrong to feel that way, because, of course, we really don't understand why metastatic breast cancer, or why breast cancer, recurs and why does it come back. It can be dormant for twenty-five years and then something wakes it up. What is it? We don't know that yet. We need to know that.

MEREDITH: It's interesting, because you said patients have said to you in the past, well when you have asked them what do you need? The first thing they say is I need to be able to grieve. I need to be able to cry. Emotion is such a key component in terms of the impact that this disease has on somebody.

CATHY: Its very interesting to talk to a variety of people about their experiences. And when people are first diagnosed, they are really trusting their health care providers. They want the plan. They want to know what they're going to do, you know, and figure out again how

FIND YOUR MBC VOICE

they'll communicate, how they'll gather their support. But then they need to begin to process those emotions as they begin to realize that most of them will be in treatment for the rest of their lives. And hopefully that will be a long time. But you don't know. And not knowing and not being in control is so difficult and brings up a variety of emotions.

MEREDITH: So where do you go to find that control? To get your emotions in check? Or I mean, obviously, you're allowing them to be what they are, but to deal with them?

CATHY: Right. Well, at Living Beyond Breast Cancer, we really try to honor where people are so, overwhelmed, hysterical, or calmly saying, okay, I'm going to figure this out and approaching it. Every woman has a different approach and that's fine and appropriate. So we begin where they are. But we also feel that having medical information that is, evidence based and medically vetted, such as ours and other organizations I can talk about, is key, because breast cancer is nothing if not complicated. It is not simple. And that's a good thing because there are many treatments that are targeted for specific types and subtypes of breast cancer. And we're learning more all the time. But it's a crash course. So you need to understand the treatments so you can be a partner in your care.

MEREDITH: And that's a very personal treatment. Obviously, as you said, everybody's different.

CATHY: Everybody's different. Everyone's journey's different. People look at the statistics and get very frightened by them. But the best oncologists and oncology nurses and social workers will tell them your path is yours and you are not a statistic. So, let's deal with what you need to deal with. So gather your information. Understand your subtype. Are you triple negative? Are you Her-2 positive? Are you, estrogen sensitive? And find out what those treatments are and begin the long process of understanding your diagnosis.

MEREDITH: So patients could come to LBBC for that specific information?

CATHY: Yes, we have a variety of ways as individuals are different people like to get their information in different formats. And so we have, of course, online resources for the newly diagnosed metastatic. And then as they go through their experience with the disease additional information. I mentioned a little bit about how important it is to find support. We have a peer help line where people can call and speak to another woman or man with metastatic breast cancer and ask the questions they need to ask, whatever they are, and get that perspective. And then we have an annual conference just for metastatic...people with metastatic disease. And I have heard from so many people, I'm not really a conference goer, I don't like that, but I made myself come to the LBBC conference and people who live in New York City, to people who live in rural communities in Indiana say, I have never met another person with metastatic breast cancer and I came into a room and there were 400 plus people. They were incredibly wonderful women and men. And I found, for the first time, support I needed and a community. And that is really important because it is a tough disease and the treatments can be difficult.

FIND YOUR MBC VOICE

MEREDITH: You talk about community. So many of these people, like you said that they don't want to do that. They are already feeling isolated. It's a big jump for them to find that community. It's hard to know where to start.

CATHY: And some people, you know, don't want to accept that they have metastatic breast cancer and wouldn't want to go into a room full of people. But our conferences are the most joyous conferences. Many people find support online and connect online. But there is nothing like that individual face-to-face meeting and seeing a person you've been communicating with online for so many months and for years, and then you actually meet at a conference.

MEREDITH: It's so interesting, you use the word joyous because I would never associate that with metastatic breast cancer.

CATHY: Right. You look across the room and you will see people living. They are living their best lives. And that is what they're all dedicated to. Early on in the diagnosis, often, doctors or nurses will talk to people. What are your goals? You know, and sometimes it's a wedding or a graduation or the birth of a grandchild. There are goals and you can reset those goals as you go along. But often it's when you find a community, you can share the joy of, okay, we're living, it's not perfect. It's not what anyone wanted. But there are some of the greatest people here. And we'll help each other get through this.

MEREDITH: It's so interesting to talk about LBBC and your efforts because you're helping people to move forward at a time when their life is in such flux. It's almost they work opposite each other.

CATHY: Yes, there is so much to figure out, because breast cancer is complicated, your life will change. Many people have to step back from careers and work and concentrate on maintaining their health as best they can. And so. And then communicating. You talked a little bit about you didn't understand what your grandmother was going through.

MEREDITH: Exactly. Cause she didn't talk about it.

CATHY: And in the 1970s, that was very common. We do live in a different time where people are finally talking about metastatic breast cancer. But for a long time, we talked a little bit about the earliest stage. The voice of the metastatic patient was not really heard. I've heard terrible stories where people were told in support groups that they were too - their stage of cancer was too frightening and asked not to attend.

MEREDITH: What does that do to a person?

CATHY: It creates more isolation and anger and resentment, because they need and deserve the same kind of support and they can get it now. It's more available now and hopefully we're changing some of that.

FIND YOUR MBC VOICE

MEREDITH: You mentioned a while ago about patients who say to you once they work through some of the grief and the anger and now, I need to tell my family I don't even know how to start that conversation. Or friends. What do you say to them?

CATHY: Yeah. Well, they have to tell their truth. They have to be as clear as possible. That's why gathering some information, some basic information, particularly when there are children, you really do need to be sensitive to their needs. Not telling children is mostly not a good idea.

MEREDITH: Because they're so intuitive or...

CATHY: Because they're so intuitive. They know if something's wrong in their household, they understand they may not know exactly what it is. So talking to them in appropriate ways.

MEREDITH: What is the appropriate way to start that conversation?

CATHY: Depending on the age, you know, I have breast cancer. I'm going to need treatment. Sometimes it will be difficult. But I am here for you and I want you to be here for me. And we'll continue to talk about it, I think are some of the most successful tips that I've heard from parents and what some of the literature tells us.

MEREDITH: So let's tick through some of the tools and resources that are available for people, not just when they're newly diagnosed, but moving forward in their new life, their new normal.

CATHY: Well, I've mentioned we have a wonderful, printed brochure that's also digitally available on LBBC dot org, the guide for the newly diagnosed. And it really lays out in very simple, plain language, sometimes doctors, as we know, do not talk simply or plainly. And when you're new to, breast cancer, you need a simple, straightforward answer. And that's LBBC's voice. We have the voice of an informed friend and help you get your way through this experience. Find your grounding. What information do you need? Basic information is in that brochure to get you started. It is a wonderful resource also for caregivers to help them understand. And we partnered with, in that brochure with the Metastatic Breast Cancer Network, which is another wonderful organization that serves metastatic patients. So that is one thing I mentioned our peer support help line to answer questions, not medically related, but share experiences and find the support and tips. Our website is full of different stages. We do webinars. We do large-scale conferences where we have exhibit tables with a myriad of resources. That's another thing people say. I didn't realize there were so many resources and thankfully there are increased number of resources. There are organizations that have information in different languages. SHARE is one in New York City that has a great Latina program. You're talking about finding your voice. We're helping them take their voice and communicate it and educate the public about metastatic breast cancer, their communities, and really say, this is what it's like living with metastatic breast cancer. So it doesn't feel so isolating for the next person.

FIND YOUR MBC VOICE

MEREDITH: It's so interesting to me how very often people once they do find their voice, they want to scream from the rooftops.

CATHY: They do.

MEREDITH: It's like it's that sense of empowerment.

CATHY: It is.

MEREDITH: And I am here. And I have something to say.

CATHY: Yeah, it is healing, yeah. Exactly right.

MEREDITH: Tell me about your experience, meeting these women and men dealing with such devastating news and moving forward.

CATHY: So we have a variety we have online communities, closed Facebook communities. We have these gatherings. We have these leadership volunteer programs. So we get very close to a number of people as well as have large-scale conferences. The advocates are amazing and working in the metastatic field and becoming, creating a network of people who really care about each other and are in this journey together, they're also experiencing the loss of volunteers. We still lose 116 people every day to metastatic breast cancer, and many of them are the volunteers we know and love and that the community knows and loves. And so, we need to grieve together and understand why we're doing this work both as an advocate or as a professional that I am. I have been dedicated to women's empowerment and leadership my entire career. And I see, I see us getting through this together, supporting each other and knowing when to step back, to take a break when you need to, but then return because it's such important work and, again, I see it in the faces of people who have never met another person with metastatic breast cancer and what community really means.

MEREDITH: And what's in those faces?

CATHY: Joy and our conference is one of the most joyful places you can be in Philadelphia on a weekend in April.

MEREDITH: You just need a cheese steak and it's complete. How important do you think it is, Cathy, to have somebody by your side when you go in to see your doctor?

CATHY: Especially when you're finding your voice, it's very important because it is overwhelming. I was speaking to, about three women last night, and one said, you know, when I couldn't hear anything my doctor said after getting the diagnosis, I could not hear for the first three appointments. And then finally, if it wasn't for my spouse, I never would have gotten through it. So it is critically important to have someone with you taking notes,

FIND YOUR MBC VOICE

asking questions. You may not be able to, processing information that you might not be able to process in that moment. There is sometimes a real disconnect between the health care provider and the patient and what one is saying and the other is hearing. And it's always good to have another person or persons.

MEREDITH: Totally. Yeah. In my family we're dealing with MS. There's at least in my husband's case, really no treatments. Living day by day. And you're right. I mean, having somebody by your side is very important because often you don't hear the conversation. That's just the way it is. And facing the fact that, you know, this is your new normal, but it's sort of what your organization is: living beyond. The key word there is living.

CATHY: Exactly. It is living. There is no one way to have breast cancer. There's no one way to have metastatic breast cancer. It is your life. How can we help you live it? And that's what we do. Your life becomes perhaps dominated by breast cancer, but it is still your life. And you are still you know, a wife, a mother, an employee, perhaps a retired employee. But you still have great value. And there is much we can help you with.

MEREDITH: It's so nice to have you here. And you're so calming. I have say dealing with very difficult matter, but you just, I don't know where that comes from.

CATHY: I'm a middle child. I don't know.

MEREDITH: Any final thoughts for those who are listening to this podcast, who may have just been diagnosed?

CATHY: Sure. I would say reach out, find information. There is information out there. My organization, we have many sister organizations that do incredible work. So, we are here. Don't be isolated. Find us and we will find you.

MEREDITH: Thank you so much Cathy.

CATHY: Thank you it's been a pleasure.

MEREDITH: And thanks to Pfizer for sponsoring this conversation. As Cathy shared today, there are many resources and support services available to people living with metastatic breast cancer and their families. It's important that you take advantage of those resources and services. They'll help you play an active role in your care. And you can start also by visiting us at Find your MBC voice dot com for an interactive discussion guide to help you have an informed conversation with your doctor. I'm Meredith Vieira. Thanks so much for joining us.

END