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ABCs of MBC

Episode Title: Untold Tolls

Guest: Monica Fawzy Bryant, Esq., Cancer Rights Attorney & COO, Triage 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 Monica Bryant, the chief operating officer of Triage Cancer, a national nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers. She is also an accomplished attorney, speaker, author and adjunct law professor. Monica will help us dissect a topic that many of you probably think about, but only after it's already a problem. Finances. This is the ABC's of MBC. Monica, welcome.

MONICA: Thank you so much for having me.

MEREDITH: It's an honor to have you here. It's so true, people do not think about this first, the burden that they're going to experience financially.

MONICA: That's absolutely right. And it shouldn't necessarily be the first thing that they have to think about. But it is an unfortunate reality that after someone experiences a cancer diagnosis, they are going to have to deal with the financial and the practical pieces.

MEREDITH: So what made you start this particular program? Triage Cancer.

MONICA: So, my colleague and I really saw that there was a gap in the resources available to individuals in the cancer community, in that there wasn't a lot of education around these practical and legal pieces. And a lot of times people will say, you know, I don't understand, why is there a lawyer in the room at a cancer conference? But the reality is so much of what they have to deal with after a diagnosis when it comes to finances and work, the practical pieces of life are in fact rooted in the law.

MEREDITH: Why isn't there much education when it comes to this?

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MONICA: I think honestly, it's just that the community is always trying to meet the needs, and it hasn't been a big enough need for there to be an organization created until now. That's where Triage Cancer comes in to play.

MEREDITH: So exactly what does your organization do then?

MONICA: So we provide education around all of the practical and legal issues and that really runs the gamut. It could be anything from understanding health insurance, how to choose health insurance plans, your employment rights. So if you want to take time off or work through treatment, what are your rights to do so? Finances, estate planning, all of these things are rooted in the law.

MEREDITH: And what is the biggest burden facing somebody when they get this diagnosis of metastatic breast cancer, a financial burden?

MONICA: Well, I don't think there's one. I think really it is a multitude of issues. And we even have this term now that they're using, financial toxicity, to really address or describe the financial burden that comes after a diagnosis.

MEREDITH: So describe that when you say financial toxicity.

MONICA: Yeah. So, physical toxicity is something that's been talked about for years with treatment. So what are the physical side effects of cancer treatment? And in 2013, some researchers out at Duke looked at this financial burden and they coined this term financial toxicity to describe how the financial burden can be just as significant as the physical burden.

MEREDITH: What is your specific role?

MONICA: So I'm a cancer rights attorney and I'm chief operating officer of Triage Cancer. So I co-founded the organization in 2012. And so really, that means that we do everything from create the educational materials to provide a lot of in-person education as well.

MEREDITH: When you talk about educational materials, tools that people can use, navigating their way through the financial aspect of disease, tick through some of those tools for us.

MONICA: Yeah, well, one of the things that's...one of the reasons it's so hard to address financial toxicity, it's a multifaceted problem. One of the biggest contributing factors is health insurance. And what we know is that having health insurance isn't enough to solve the problem. People have to have adequate health insurance, and they have to be able to know how to navigate that health insurance.

MEREDITH: But do you need to have that health insurance, that adequate health insurance, before you're diagnosed?

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MONICA: Well, certainly that's ideal, but that is not how things always happen. Most of the time, people don't really know how to pick a health insurance plan. We always say that there should be a class in high school on adulting, and one of those things should be understanding health insurance. But most of us get our first jobs, we're handed a pack of information. We pick a plan and that's the plan we have. And so one of the things that we try to do at Triage is give people the tools to make choices around, how do you pick a plan that's going to minimize your out-of-pocket costs? And how do you then navigate that plan once you have it? Now, what we tend to see happening is someone will get a diagnosis, and then they'll have a lot of out-of-pocket costs, because they don't have an adequate plan. But what we try to remind them is we get to make these choices every single year now, thanks to the Affordable Care Act. So, yes, you may have lots of out-of-pocket costs for this plan year, but starting the next plan year, you can make some different choices to try to minimize those. And I think that's particularly relevant for individuals in the metastatic breast cancer community who are going to have ongoing treatment. You are not stuck in the plan that you have now.

MEREDITH: So that is the good news.

MONICA: That is the good news, yes.

MEREDITH: Even if you're paying a lot this year, presumably the burden will lessen, in the years that follow.

MONICA: Yes. There are choices to be made that can lessen it. So that's one example of the types of materials that we provide. We have what we refer to as quick guides. They're one-to two-page documents that try to explain these complex legal topics. We have animated videos that are in English and Spanish. So if somebody doesn't want to read a quick guide, they can watch a video. We know people learn in different ways, so we try to provide these resources in multiple mediums. And then we also host a separate website completely that ah, is in a "choose your own adventure" format.

MEREDITH: What does that mean?

MONICA: So, basically the website will ask questions and based on how the user responds to those questions, it will take them to the most targeted information. So, for example, if somebody is on Medicare, then based on their answers to questions, that will only provide them information about Medicare. They don't have to sort through information that's not relevant to them. And that website is Cancer Finances dot org. We also are proud to partner with so many organizations in the cancer community who are doing fabulous work on their own. And so we think collaboration is really the key to all of this. If there are great resources available, there's no need to reinvent the wheel. But when it comes to the practical and legal issues, yes, we certainly hope that people can get what they need in one place, because we know how overwhelming this all is to begin with. And we don't want to send people on a wild goose chase.

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MEREDITH: And when you think in terms of dollars and cents, because you've seen the landscape before you, what are we talking about? What kind of numbers are they facing in terms of year-to-year trying to survive this and live with it?

MONICA: Yeah, there's a lot of costs that people don't necessarily think about. So even if someone has a phenomenal health insurance plan, they're still going to be out-of-pocket costs. You're still going to have to pay your deductible before the insurance even picks up their share of the costs. There are going to be copayments and coinsurance. Even after somebody reaches their out-of-pocket maximum, which theoretically should be the most they're going to pay for the year, if they want to see people out of their network, they're going to be paying for those costs on top of their out-of-pocket maximum. And people don't even necessarily understand the concept of networks. And so they're really forced to learn a whole new language and a whole new set of skills after a diagnosis. But then there's some other treatment related costs that may not be covered by insurance. So, it could be things like transportation to the facility, parking at the facility. I live in Chicago. Parking at hospitals downtown is very expensive and those costs can certainly add up. If they want-

MEREDITH: So how do you mitigate those costs?

MONICA: Well, there are definitely some financial resources available, we often suggest that people be very creative when thinking about their finances. So, maybe you can carpool with other people who are getting treatment on the same days, if that's possible. Certainly in some places there is public transportation. Some hospitals, if the individuals mentioned to their health care team that they're having financial struggles, hospitals may waive some of those fees.

MEREDITH: How often does that happen?

MONICA: Well, more often than you actually think.

MEREDITH: Really?

MONICA: Yeah. What we tend to see the bigger problem being is that individuals aren't talking with their health care team about finances. We are in a culture where it's not our norm to discuss finances with our health care team. You know, how often do you ask your doctor? Oh, I need a scan. How much is that going to cost?

MEREDITH: Exactly.

MONICA: That rarely happens. And it's the only thing as consumers we purchase in that way. I always joke. Imagine going to a Best Buy and saying, pick me out a washer and dryer. Don't tell me how much it's going to cost until after it's delivered. It sounds ridiculous. But that's exactly how we consume health care in this country.

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MEREDITH: And why do you think that is?

MONICA: I wish I had an answer to it. Honestly, I just think it hasn't ever been part of our practice. But we want it to be because we know from health care providers that they are happy to discuss costs and to help patients navigate the finances. But they can't read minds. So if they don't hear from their patients that finances are a concern, they can't help them.

MEREDITH: How do you get them to talk if they have historically not talked to their health care providers?

MONICA: Well, we are very grassroots. You know, we go into communities and we host conferences where we talk about advocacy and what advocacy means and how you have to be your own best advocate, and how important that is and that there's no shame in discussing finances, even though, again, that is sort of part of our culture, that finances traditionally are not something that you discuss outside of your family. But it has to be, it has to be. With the rising costs of care and how expensive and burdensome this financial toxicity has become for patients, it has to be part of the conversation.

MEREDITH: Maybe some people are just scared. They don't want to know the answer because they're really worried they don't have the money available to them to get the best care they can.

MONICA: And that is absolutely valid. And many people couldn't afford cancer care without some assistance and health insurance is certainly part of that puzzle. But there are also lots of other types of financial assistance out there that I don't think a lot of people realize. So, there are community, state level, cancer community organizations that provide all types of financial assistance. The pharmaceutical industry has done a really wonderful job of trying to support patients financially where they can. I think that there's been an influx of enlisting the help of friends and family in crowd funding, which I think is a wonderful thing, with some caveats.

MEREDITH: What are the caveats?

MONICA: Well, disclosure is a big piece of what we talk about. And when somebody receives a cancer diagnosis, a lot of control is taken away from them. And we think that making the conscious decision about are you going to disclose, what are you going to disclose and to whom are you going to disclose, is an area where people can start to take some control back. You know, that it is a very personal decision. And some people are open books and shout it from the rooftop. And some people want to be a little bit more closed book. And all of that is fine and appropriate and people should feel empowered to make a decision that feels best for them. Crowdfunding is a place where we see some inadvertent disclosure. So very well-meaning friends and families may start a fundraiser, and those are all Googleable. And so if somebody doesn't want to be disclosing, then they've sort of outed those people.

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MEREDITH: I see.

MONICA: And there often isn't a lot of conversation around disclosure. So we want there to be more.

MEREDITH: Well, it certainly should include the patient.

MONICA: Yes. But we hear stories all the time where it doesn't. And again, it almost always comes from a really...

MEREDITH: Good place.

MONICA: Good place of people trying to help and feeling helpless. But again, there are some ramifications. And then also, if people are on programs that are need based like Medicaid or SSI, an influx from a crowd funding campaign could jeopardize those benefits.

MEREDITH: You talk about disclosure. That brings me to something a little bit different. A lot of people want to get back some sense of normalcy in their life, and in many cases, that's going back to work, getting that paycheck again. The 9 to 5 every day, just feeling like you're productive. So if you're thinking about going back to work, should you tell your employer and if you should, when do you do that?

MONICA: Telling an employer about your medical situation is a very personal decision. And some people will be open books and disclose everything to their employers. Some want to keep information a little bit more private. What I do think is important for individuals to know is that generally speaking, you do not have to disclose to your employer anything about your medical condition. That being said, there are some tools and legal benefits you might be eligible for. And if you are trying to access those benefits, you may have to share some information, but it doesn't necessarily have to be the specific cancer diagnosis. We have a quick guide at Triage Cancer on disclosure, privacy and medical certification that goes into a lot of detail about if somebody is trying to keep their specific cancer diagnosis confidential, how they can still access those rights and benefits but keep it confidential.

MEREDITH: And what happens if your employer finds out after the fact?

MONICA: Again, you're not under obligation to share that information with your employer. The lawyer definitely doesn't recommend lying on any sort of official forms, but your medical information is in fact allowed to be kept private.

MEREDITH: It's your information.

MONICA: It's your information.

MEREDITH: Do you spend a lot of time talking directly to patients?

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MONICA: I would say it's about 50/50.

MEREDITH: 50/50?

MONICA: Between patients and caregivers themselves, and then also health care professionals. We know that the health care professionals are on the frontlines. They're the ones sitting in the room hearing the stories the patients are saying to them about my employer did this, or I'm so worried about this. And we want to be able to empower those health care professionals to have the answers, or at least at the very minimum, be able to provide some guidance as to where to go to get those answers.

MEREDITH: So they're a bit wandering in the wilderness, too, along with the patient.

MONICA: Absolutely. The nurses, the social workers, the navigators. This legal information is not part of their training. So many of them learn on the job and do a great job doing so. But they're not really given a lot of support or tools to do so. And so that is part of what we do at Triage Cancer.

MEREDITH: Is there a personal connection for you to these particular patients, to breast cancer, metastatic breast cancer?

MONICA: I think like many of us, we've all been touched by cancer in one way or another. What I think is so unique about the cancer community is it is so many different communities. But yet they all sort of come together under common goals. And much of what we talk about is not cancer-specific. But really, I think that given the prevalence of this disease and how many people it is touching, it is so incredibly important for us to be doing this.

MEREDITH: And all this financial advice is ultimately priceless, when you think about it.

MONICA: That may be our new catch phrase.

MEREDITH: Any final thoughts that you have about, advice for people being diagnosed today with metastatic breast cancer, when it comes to the legal and financial burdens they will inevitably face?

MONICA: I think my biggest piece of advice is that, it's important to take a moment to gather the necessary information before decisions are made. Because many times once a decision is made and you're down a path, it's hard to change paths. Disclosure, for example. And that to know that there are a lot of resources out in the community to help you find that information and to make those decisions. Triage Cancer is just one of those resources, but certainly we are available and all of our services are free of charge to anybody who needs to access them. And we are always happy to help guide people as we can.

MEREDITH: Monica thank you so much for joining us.

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MONICA: Thank you.

MEREDITH: And our thanks to Pfizer for sponsoring this conversation. Finances can be overwhelming and stressful, especially when tied to a metastatic breast cancer diagnosis. Hopefully, the guidance shared today empowers you to have an open and honest conversation with your doctor and encourages you to look for support services. Visit [find your MBC Voice dot com](http://findyourMBCVoice.com) for more information. I'm Meredith Vieira. Thanks for joining us.

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