

Rebellious Wellness ^{over} 50

Bari Ross



Episode 38: Double Standards of Care and Patient Advocacy with Bari Ross

Gregory Anne: [00:00:00] Welcome back everybody. To another episode of Rebellious Wellness Over 50. Today, we're going to have a heartfelt and deep conversation about a couple of things that are important in health care, in our lives and health as women. My guest is Bari Ross, and she's going to talk to us about cancer,

cancer care, surviving cancer. And we're going to talk a little bit about the kinds of care that certain people get and maybe others don't and what we can do about it. How to be patient advocates for people in our families and our communities.

Bari, welcome.

Bari Ross: Thank you for having me.

Gregory Anne: Tell me about you. You're a cancer survivor for many years now, head and neck cancer?

Bari Ross: This is my 11th year surviving, stage four B head and neck cancer.

Gregory Anne: Oh gosh. I didn't even know there was such a thing as head and neck as a generalized thing. I thought it would be more specific like a lymph node or an organ.

Bari Ross: Well, how they classify head and neck is that anything between the nose and the neck.

So separated from brain cancer, to separated from other parts of this area, specifically.

Gregory Anne: Okay. Yeah. And your experience as a cancer patient led you to get into the advocacy and family advisor role that you're in now, is that correct?

Bari Ross: That's correct.

Gregory Anne: Tell us a little bit about how that happened. What was the journey there?

Bari Ross: Yeah, my journey started in April of, 2009. My husband was already being looked at, suspected of cancer and where the journey led us is that we were both diagnosed with cancer within 72 hours of each other. I was diagnosed with head and neck cancer. And that started with a small swelling behind my ear that my husband noticed. [00:02:00] He was then diagnosed three days later with acute lymphoblastic leukemia.

So it became quite a journey for both of us. That two years was crazy. We were in Phoenix. Our daughter was in Atlanta, which is where we are now. And she happened to be working for the Winship cancer center, which is part of Emory university. She brought us here. We were both treated successfully.

But during the treatment, there's a whole lot to learn when you're going through any, any disease, but especially cancer, because it's a foreign language. The doctors are speaking and talking and you don't know exactly what they're talking about. I, and my husband, we were trying to learn about each other's cancers as well to see what we needed to do.

But during the treatment, it became very apparent to me that I needed to learn the language that they were speaking on my behalf. What chemo meant? I had chemo. I had radiation and I had a major surgery to attack my cancer. Fortunately, they all worked, but everybody doesn't get that kind of care.

I did learn that first of all. And I probably learned that before I came to Emory, I actually learned that in the doctor's office out in Phoenix, because when he gave me my diagnosis and I started asking questions, And he said, "well the best guy out here that deals with what you have, they don't take your insurance.

And the second best guy I know, he doesn't take your insurance, but I found somebody in a book that takes your insurance. And I don't know anything about him, he's in the book and he can't see you for six weeks."

So that's when I told him, " You [00:04:00] just gave me a diagnosis of late stage cancer. You're having an insurance conversation and I need to hear a save Bari's life conversation."

Gregory Anne: Good point.

Bari Ross: And you're not touching on that anywhere. And he looked at me and says, "well, that's just a fact it's just a fact, this is the best I can do for you." So I call my daughter, she made arrangements,

I was brought to Atlanta. And so with my husband a few days later, we got to Emory, which is a research hospital. It's, world-renowned, it's one of the best in cancer. But when we got there, what I realized is, they have something in all medicine called standard of care. And that's just the basics.

And if you, or somebody with you, doesn't know how to ask questions, how to advocate, how to almost be an activist for you, you're going to get the standard of care. And your possibilities of survival drop significantly. And one of the things that Emory and a lot of the big centers, MD Anderson, in Texas, Dana Farber, the world renowned, the top 10, they brag about, if you come to us, you have a 25% higher survival rate than if you just go to your local regional hospital

for cancer care. And part of that is that they are leading edge, they're research centers. They have billions of dollars coming in from the U S government, the national health Institute. So. I learned quickly that I needed to be an advocate, but more importantly, through my treatment, there were months,

I couldn't even talk because of the radiation to my throat and the operations and all of that, [00:06:00] so that I had to get my family to advocate. And they had to learn

the language as well. And what questions to ask and where to push, because they have to be pushed. I mean, they're doing standard of care, you know, it's a hospital and if you don't ask, you don't get, you don't care.

So my family, I had to, I had to impose upon them to learn the language and to ask the right questions and to ask for the right people on my behalf. What I also learned is that caregivers are important. They are extremely important and they don't get the respect or the consideration that they should.

Caregivers are amazing and my daughter was taking care of two of us and she was pregnant and she had her own family. Okay? And she's trying to balance several balls in the air. And it became apparent that she needed help as well. So we had to reach out to other members of our family, members of her church, other members in the community to come and help.

To do simple things like drive me to radiation five days a week, or to make sure that I was being fed through a feeding tube. So everybody had to learn how to do that in the circle, and the hospitals didn't give us any information on that. We had to learn how to do that ourselves.

But when I got through everything and was considered, in remission, I really just started thinking about how many people go through this with no help, no instruction, no education, no patient education, no caregiver education. [00:08:00] There were lots of times when things were happening to me that even my caregivers didn't know. Everything doesn't require

a rush to the emergency room. Because you get to the emergency room and it's something the person just needs. To be infused with, water or liquids. One time I went to the emergency room and sat for six hours in the emergency room only to find out I was dehydrated.

Gregory Anne: Oh gosh.

Bari Ross: Yeah. And that was part of the problem. And if we had known that I was dehydrated or had any clue what that looked like, I could have been hydrated at home. So when I got through the worst parts of the treatment, I started thinking about how many, many families, I mean, many of the people who had questions, many of the people who I was just sitting outside in the doctor's office had questions.

I just started thinking, how this could be addressed in a big way? And in small ways, and Emory was just starting something called patient family advisors. And

they were looking for people who were interested in this. And one of their requirements was you had to be out of treatment for two years.

I was only out of treatment nine months and I literally demanded change. I said I can't wait two years, I need to do this now. And you all need to help me do this. So what I'm doing being the patient advocate there was that. The need was so much more than I even thought because I'm in the head and neck cancer world and people were coming in, in the breast [00:10:00] cancer world, in the liver cancer world.

And the cause cancer is very specific. The treatments are very specific. People think that, oh, you have cancer and it's one disease when it's lots of different diseases that affect any place on your body. If you have a cell, you can have cancer. And to date. I do know that there are between 185 and 200 different kinds of cancer, even in the same place.

So there's probably about eight or nine different breast cancers and we just think breast cancer. Right? And so in getting involved in Emory on a bigger scale, outside of my head and neck cancer world and outside of my husband's leukemia world, it became even more apparent that the ball was being dropped in a lot of areas in terms of patient care, not so much in terms of patient care on the medical level, but in terms of patient communication, in terms of patient follow-up, in terms of what happens to your patients when they go home, And you don't see, beyond the walls of the doctor's office or the operating room.

So, I also was fortunate enough to be asked to serve on a national panel about patient advocacy, through the national cancer Institute in Maryland or Washington DC. And when I got there, it became even more apparent how wide spread this problem was, but also how different treatment is for African-Americans and people of color and how different the overall response to it was.[00:12:00]

And I started pushing, like trying to push hard on that and I didn't get resistance, but I also didn't get acceptance. What I got was "It's on the list" and we're doing this and this and this. And so it's on the list. It's on the list of 10. We have a list of 10 and this might be 11 or 12.

Til COVID hit. And once COVID hit last year, almost year before last now, and it became apparent in the news, in the numbers, how disparate the treatment was and how, disparate the science was with regards to African-American and people of color. Our numbers in COVID were way out of balance.

It's like two to one, three to one in some cases that African-Americans and people of color were dying from COVID, more so than the other population. And then the

doctors, the hospitals, the scientists, once it was discussed and out there on the daily news and in magazines and newspapers, they started looking into it.

It moved up on the list from number 12 on a list of 10 to maybe number four, but it definitely got a different look and a different focus and a different call to leadership.

One of the reasons the numbers I do understand was so disparate on COVID was because people of color tend to have many, many more underlying conditions. So they just don't show up with COVID. They just don't show up with cancer. They show up with cancer, diabetes, and high blood pressure or COVID obesity and diabetes, which they've known for many, many years. [00:14:00] The scientists have known this. And when I go through the NCI meetings, they've known this, but there was never a cry, never a realization or never a care, that this was the case because nobody was advocating for it.

So the numbers are the numbers, but if you don't have anybody questioning you pushing, advocating for it, then it's just a number.

Gregory Anne: Yeah. Yeah. And it's a shame that it took something like COVID to bring those numbers to light, but at least now we're having the conversations, as you say. Last week, we had an episode with a woman who is a readiness and resilience

expert. She used to work for FEMA, and now she works for both corporations and individuals. And we were talking about the importance of communication for people when people don't know what's happening or what's about to happen and their stress level goes up, they do worse in an emergency situation. So I would imagine that as a patient who doesn't understand what a doctor is saying, they get brushed off, the doctor's in a hurry.

Maybe they don't even want to deal with you because you got some kind of weird thing on top of your cancer. It must be very bad for the disease healing process for them to be in the dark or to not understand the conversation, would you agree?

Oh, I totally

Bari Ross: agree. I think, again, I'm a numbers person.

When the doctor comes in to see you, he has eight minutes and four of those are on the computer. Like I said, the language barrier is big. " Oh, you have squamous cell cancer of the" ... And they're talking doctor language and one of the things we've been pushing as

advocates is translate it if you can, translate it to English or at least translate it down to a level where the patient or the caregiver can understand. And allow them to ask questions because the stress level goes up for everybody. And one of the things that we've [00:16:00] learned is that people will give up right there.

As you say, the healing, they will give up right there in the doctor's office. I don't understand what he's saying. I don't even know what this is. What am I fighting? Why am I fighting? And I've heard people say that, well, he said this and this and this, but I don't want chemo. And what, why don't you want chemo?

"I don't know, because I heard somebody said they had it," and then they're not going on what's going on with them, but a bad circumstance or a bad discussion with somebody that had it. They might've even had a totally different kind of chemo than what they're going to get.

Gregory Anne: Yeah. and it's so easy to be scared off, quote unquote, by something like you even say on your website, "you have cancer" are the three words that nobody ever wants to hear.

And immediately for most everybody, it strikes fear in the heart, doom and gloom. How is this going to end? What if it doesn't end the way I want, I'm going to go through weeks of radiation, right? You start recording in your mind what's going to happen, even though you don't know what's going to happen.

Like you said, it could be a different cancer. Might have different treatment, different outcomes, but I can see why, especially somebody who's not fluent in doctor speak. And most of us aren't, don't have somebody in the room with them listening with them so that they could take notes. Process. Maybe ask a question, like you said, and nevermind the medical bills, right? You started out saying we don't take your insurance. He doesn't take your insurance. Nobody else takes your insurance then what?

Bari Ross: Yeah. And that's a whole nother question again, you know, a lot of people don't go to the hospital, especially in the African-American community because they either don't have insurance or their insurance is not the Cadillac insurance, you know?

And then they think, oh, you know, I'm going to have to pay all of this money. I'm going to go through all of this. And your whole family's going to be impoverished if I'm sick or if I have to use [00:18:00] up all the money? And one of the good things about university hospitals is that they're not free, but that they do have other programs and that they do have other resources that your local regional hospital may not truly have.

And so I encourage people to go to your nearest university hospital I've really pushed that for financial reasons, as well as they have the leading edge care. They have clinical trials. Your regional hospital does not have clinical trials. They have, if you're interested in experimental medicine, they have special specialists and their specialist within, I called them special specialists and most special specialists

aren't at every regional hospitals they're at the big research centers.

Gregory Anne: You talked about being on a national panel and I know that the Winship Program is in Atlanta. Are these becoming more common? These patient and family advocacy kind of organizations within hospitals for anybody that might have cancer, that's not in Atlanta say?

Bari Ross: The patient advocacy are becoming not just for cancer, but for all patients, period.

I also sit on a panel at Emory that's patient advocacy over all of Emory healthcare. And then within that team, there are those of us from cardiology, gastroenterology, a transplant. I'm represent cancer. So it is becoming bigger, it's becoming nationwide.

It's definitely again in the university hospitals or research hospitals. And we have started to reach out to the rural communities. Yeah. Cause it's important. Yeah.

Gregory Anne: Oh, absolutely. I [00:20:00] mean, I feel for people even with this whole COVID and vaccinations and getting care for the people that may not have a car, but they live far out of a town , an urban center .

I know that there were efforts to bring the vaccine or treatments to people. But it's good to know that it's happening outside of just the idea of COVID, cause nobody should be left out.

Bari Ross: When it comes to healthcare, I think nobody should be less powerful.

Gregory Anne: Exactly.

Now you wrote a book about all of this. Tell us about your book. What's the title?

Bari Ross: My book is "Stronger with Two." And, um, it is about my journey and my husband's journey because on podcasts, I don't get to talk about his journey, but I was able to interview my husband, which was interesting.

I wrote it from, this is what happened to me, this is what happened to him. And then this is what happened to us. And, uh, "Stronger with Two" comes from when we got married we were each other's second. And when we got married, my 85 year old father came to the wedding, gave me away.

And when we were leaving, he took us aside and he said, you guys stay together. You will always be stronger with two.

Gregory Anne: Aww

Bari Ross: Yeah. And that's where I got the title from, but, and it proved to be the case. It really proved to be the case because I just remember a few times, my treatment was so much different than my husband's.

He had leukemia subsequently he's had a second cancer. He had lymphoma. Okay. But when we were going through it at the same time, his treatment was chemo, my treatment involved chemo, radiation at the same time, because my cancer was very aggressive.

And then I had a major surgery. And there were times when he would be finished [00:22:00] with his chemo and come home and have to take care of me. It was just an thinkable.

Gregory Anne: I can't even imagine your husband having to care for you. And I think when we talked before this podcast interview, I think you must've said that it taxed your marriage for both of you. Not all a bed of roses taking care of each other every minute of the day.

Bari Ross: Oh no, no, no, no, no, no. It was taxing on marriage.

From several angles. First again, I'm trying to tell him about my experience and he's looking at me and as he's feeding me through the tube, and the chemo that I took made me nauseous all the time. I couldn't eat, but the of food, the smell of certain things would trigger the chemo and then I would get nauseous. And he couldn't understand because he wasn't having any of that.

He'd go for chemo, but he actually go for four or five days and stay in the hospital and get chemo 23 hours a day. Yeah, for what he had, he was hospitalized. He'd go, he'd stay, he'd come home for a week, go back, stay five or six days, chemo back and forth. So our communication broke down. Our communication broke down, our empathy broke down for each other at some point, because he was like, "well, I'm doing so much better,

I'm getting stronger, I'm doing better and you're not." And he was right. I wasn't, I wasn't recovering as fast. And then I kept having setbacks, infections, going back and forth to the hospital. I kept having setbacks and he was moving. And [00:24:00] so his empathy, he and my daughter, as a matter of fact, were like, "well, you should be doing this by now.

And according to what we read on web MD, by now you should be able to eat and you should be able to swallow." And I was getting so angry at both of them. I was just getting frustrated and it was like, don't even come into the room. "But we have to come into the room to feed you."

So it got very challenging 'cause I was languishing. I wasn't moving as fast as everybody thought I should. And finally, I asked the doctor, I said, could you just speak to them and tell them that what they're reading on web MD or wherever they're reading it, that I'm not there.

I am so not there. And we don't know when I'll be there. It actually, I was on a feeding tube for a year. Yeah, I couldn't swallow. I had to go to swallowing rehab because all of the muscles that you use to swallow had weakened. People who have no concept of head and neck, who can't even imagine not being able to swallow or eat or talk, getting them to understand, or at least empathize, it was a job. It was. Yeah,

It was very frustrating. And when I actually went to the swallowing therapist to learn how to swallow again and to build those muscles back up and I could see that they had atrophied and that there was just, no, I mean, you just take it for granted, you swallow, but there's a whole 'nother process going on in your body associated with that.

Gregory Anne: And who knew there was a swallow therapist?

Bari Ross: Oh, yeah, there is. Oh my God they're incredible. They have these incredible machines, these incredible techniques or whatever. Yeah. But you just don't know until you need to?

Gregory Anne: Yes. Well, so [00:26:00] even if somebody isn't a trained patient advocate, would you say that it's important?

If you have anybody that can go with you to those doctor's appointments to bring somebody?

Bari Ross: Oh a hundred percent. I say a thousand percent, but what I've learned is because of COVID right now, where they say only the patient can be seen, that it is

having an impact because when you are going through a major issue like that, whether it's a heart attack, cancer, whatever it is, you need somebody in there.

Who to take notes, to ask questions, to talk to you, and explain to you what they're hearing, what the doctor is saying. So, you know, like almost like a translator, you need somebody in there who is not as emotionally involved as you, as the patient is. So, yes, it is important for somebody else to be with you when you're there.

Gregory Anne: Which means women, don't be afraid to ask for help.

Bari Ross: That's right..

Gregory Anne: We don't want to ask them "Come sit with me at the doctor. It sounds so silly, but really it's very, very important. It makes a huge difference.

Bari Ross: For men too, because one of the things I used to see , once I got better and I started doing the advocacy, I would go into the infusion center and I would see young men there with their fathers,

and it was just like, this is, you know, most of the time it's the wife sitting by the husband or vice versa. But I started seeing these young men with their fathers and it was just so uplifting and when they're with their daughters or in some cases, their granddaughters. It is really necessary for somebody...

If you need somebody for you not to ask, is [00:28:00] you're really doing yourself a disservice and the other members of your family, because you have all the information and they need some information too, about what's going on with you.

Gregory Anne: Absolutely. Well, Bari, this has been a really great conversation.

We've touched on a number of important subjects. Patient care, standard of care, who gets care, and how to be your own patient advocate. And also have the involvement of other people who can help us on the journey through anything. Like you said, it could be cancer, it could be a heart attack, transplant, whatever it is, even if it seems like "I can do this."

I think it's really important that we have those people. And I think doctors these days, I have spoken to a few anyway, on this podcast, they're happy to have another person listening. It's all around a good thing.

Tell people where they can find you, your website. You're on Instagram. What's the name of things?

My website is BariRoss.com. The name of my book is "Stronger with Two." I'm on Instagram stories. It's Stronger W2, and Facebook, Bari Roberts Ross. The book is available Amazon it's Kindle and it's paperback.

Bari Ross: And, uh, thank you.

Gregory Anne: Terrific. Thank you very much for being here. I appreciate it.