

Empowerment Exchange – Breast Health Conversations

Hosts: Wanda Lucas and Barbara Kornblau

Podcast Transcript

- Wanda Welcome to the Empowerment Exchange, a podcast for the American Association on Health and Disability. The goal is to provide helpful information that is easily accessible. I am your host, Wanda Lucas, along with Barbara Kornblau. We invite you to listen to our conversation on breast health for persons living with disabilities. We will also discuss becoming your own best advocate when seeking health services. This topic, breast cancer, is especially important to our community, our nation. It holds personal meaning for me because I am a breast cancer survivor. I was diagnosed with breast cancer 12 years ago, and I have worked tirelessly in advocacy and feel a certain level of commitment to ensure that women receive the right information about breast cancer and breast cancer screening.
- Barbara Okay. Thanks, Wanda. And I'm a person with a disability. My mother was a breast cancer survivor, and I've been doing disability advocacy for a long time. I'm an occupational therapist. I'm also an attorney. I used to sue people under the ADA. And so I think, you know, Wanda and I got together to do this because we both have an interest in this area, and we bring unique skills to the table, and we like to talk.
- Wanda As you know, Barbara, I've delivered quite a few workshops about breast cancer for women with disabilities. And a lot of the people who've attended the workshops have actually been people or women who are seniors or older. So they have not always lived with a disability, but the reality is they are facing some new challenges because of their current disability. So they found the information quite good, and they were very welcoming of the workshop. Other targets have been to talk to women who have had disabilities maybe their whole lives or for quite a long time. And what we're trying to convey in these workshops is that we don't want women to stop doing certain health care screenings. We don't want women to ignore symptoms or forego regular medical attention or medical appointments because of their disability. We want to make sure that they're empowered to continue to take care of themselves.
- Barbara Yeah, you know, it's so interesting, Wanda, because as a woman with a disability, you go to the doctor, and everybody expects certain things when they go to the doctor. You expect to be weighed, you expect to get your blood pressure taken. When you're over 40 or whatever age it is now, you expect them to say that you need to get a colonoscopy, you need breast cancer screening. And for some reason, doctors don't look at women with disabilities in the same way. But with women with disabilities, they want this information, and they don't get it. And now, what's interesting is that when Obamacare passed – the Affordable Care Act – there was a provision in the law that the access board had to come up with guidelines, voluntary, they're not mandatory, but voluntary

guidelines to make medical equipment accessible. So theoretically, some of these things should stop happening. And women should become, you know, more, they should have more access, and they should be treated like everyone else. So hopefully more doctors will refer people, women with disabilities, to mammograms. But then when you get to the mammography place, then you have a whole new set of challenges.

Wanda Right. And, you know, I'm so aware of those challenges, and my first reaction is, that's not fair. And when I think about that, I believe that it's important to empower the women who should be receiving these kind of services and access to the, you know, treatments and screenings that they need to speak up and say, that's not right. This is what I need. Why aren't you giving me that information? And I would make the assumption, and I could be wrong, that when a woman with a disability goes in for, like, a regular health screen, the doctors make assumptions about what they will understand and what they won't. I mean, and they're so wrong in that. Like, they may take your blood pressure but not tell you what it is. They may take your weight and not tell you what it is. They may get your lab results and just say, oh, they're fine. But you need to know your information.

Barbara Absolutely. Well, and, you know, there's a movement now called the Patient Engagement Movement. In fact, there's a group called the Society for Participatory Medicine, and the American Association on Health and Disability promotes this as well where you need information because you're the only one who really cares about you. Advocating for yourself is just so incredibly important. When the doctor says, okay, these tests are good, you have to be able to say, well, what does good mean? What does good mean? Because as we get older and we're all aging, if you're 20, you're going to be 30. It's just a factor.

Wanda That's just a fact. That's so true. So we need to know ourselves, but also with that, I always say to women, you know better than the doctor. And what I mean is no one knows your body like you. So I always tell women, especially the younger ones, when it comes to breast cancer and breast health, you should know what your breasts look like. So you will know when something's not right. Because if you go to a physician, let's say you have a 2 p.m. appointment, more than likely that physician has rubbed on quite a few pairs of ta-tas by the time you get to that table. So he's comparing your breasts to somebody else, but he may not know your normal. So it's important for you to know your breasts, know what they feel like, know like on your body, feel like to the touch, know that one may be bigger than the other, and that's okay. But you have to be aware of what's normal for you. So you can say, hey, this breast looks a little red, because we know that's not normal and needs to get checked out. Or you could say, I feel some kind of mass in my breast. It wasn't there three months ago. I need to get it checked out. Where some women have lumpy breasts, but you need to know that.

Barbara I always thought, I'll be honest, I didn't think self-breast exam was going to, it always felt the same to me, and I kind of wasn't always on top of it, and I

thought, why am I doing this? And one day, and I can't even make this stuff up, I was taking off this t-shirt, and I accidentally rubbed my hand on my breast, and I thought to myself, oh my gosh, this feels like there's a tube of lifesavers in my breast. I mean, that's what it felt like, and I freaked out, and I called my doctor, and he immediately gave me a prescription, and I went in, and I told the technician I'd felt like a tube of lifesavers. People were kind of trying not to laugh, but then I was on the table getting a biopsy, and luckily, it wasn't cancer, but it really felt like that, like all of a sudden. It was just this big thing that just appeared, and I happen to have, I have polycystic breasts, so I have... lumps are normal to me, but not that kind of lump. So I mean, when there's something there, you know about it. It's going to be there, and you've got to be aware of what your body is. You just have to be.

Wanda So I want to applaud you for saying, for not only recognizing that something was different, but also kind of being in a position to describe it, like the role of lifesavers, and I think that's important, because that would tell, give somebody some information, but I also want to applaud you. You called your doctor, and that he listened to you. He took your word for it. He valued your statement, and he sent you for further testing. The problem is, a lot of times, that does not happen, so you were lucky in a sense that your doctor listened to you, because I know that sometimes women are told, oh, it couldn't be cancer. You're too young, and that's not true. That's not fair. That is not right, and a woman has to argue, well, I want to check it out myself. I want it checked out. I want to feel certain myself there's nothing to it, and you have to advocate for yourself.

Barbara Right, and you bring up a really important point, Wanda, that you have to be your own advocate, and I think, you know, women with disabilities, in a lot of instances, are used to being their own advocates when it comes to advocating for things like accessibility, and you know, I need a way to get into your restaurant. This isn't fair. You know, the city doesn't have, the ramp's not working. They didn't plow the snow, or whatever it is. We get used to some of that, and we don't always succeed, but, you know, we try, and some of us fight more than others, but when it comes to your health care, you know, if you can't get up the ramp to get to city hall to vote, okay, so you were denied your right to vote, and that's a terrible thing. I'm not putting that down. If you're denied a test, you could die, and I want to tell you another story that, this is very, an upsetting story to me, but I had a friend who was, had quadriplegia, low quads, so she used to catheterize herself, and she started seeing more and more blood in the catheter, and she called the doctor and said, well, you catheterized yourself. Blood's normal. She's like, not this much blood. I mean, she knew her body. She knew what was normal for her. And so she called me, and I made some calls to try and – I said, you've got to be seen. Let's start with a pap smear. And I called doctors I knew, and nobody wanted to deal with her because she can't transfer to the table. So finally, I spoke to one who said, well, if you transfer to the table and you help hold her legs up, I'll do the pap smear. And we did that. And it ended up that she had stage four cervical cancer. She died six weeks later at the age of 29. Debbie had a big mouth. You know, if she was wheeling down the sidewalk and someone was walking slowly, she'd say, can you get your rear out

of the way, please? She was not afraid of anything. But she couldn't fight the healthcare system. She couldn't advocate for herself. She needed help advocating. So, you know, the important thing is that you have to be able to advocate for yourself as if your life depends on it, because it may. And if you need help, you know, get a friend. Get someone who – you know, if you don't have a big mouth like Wanda and I, you know, you can get someone else who does to help you to advocate for yourself. And you can learn more advocacy for yourself.

Wanda But that's a great story. And let me tell you what I heard in that story. She was able to advocate for herself when it came to accessibility into a building or whatever. And I think what a lot of people need to understand is those very same skills should apply to your healthcare. The other thing that I see happening is we forget that the doctors work for us. So we need to demand, you know, their service, just like getting into that building. If you want to go to a restaurant, they say they're accessible. You get there, you can't get in. They're supposed to make allowances and find a way to get you in there. So when you get to the table, you expect a certain level of service. You should expect that from your doctors. Because the restaurant works for you, the doctor works for you. And so often I find people don't look at healthcare that way.

Barbara I mean, you're absolutely right. I never really thought of it that way. That's a great way of looking at it, Wanda, that you're a customer. Whether it's, somebody serving you food or bringing you clothes to try on, this is your health.

Wanda This is your health and you have to speak up. But the other thing your friend did that was really good is that she told someone else. She told someone else because sometimes people get tired of fighting. But you need to share that information. It's heartbreaking when people have been dealing with something for a long time and they never told anybody. You know, they need to tell somebody like you or I because we have big mouths, we know what to do, you know.

Barbara Exactly. And everybody's got a friend like us with a big mouth.

Wanda Exactly. Exactly. And even if they don't, there are other places they could call where people can step in and serve in their role.

Barbara The National Disability Rights Network, you can look up on their website and they have lawyers. It's like a public interest law firm that's paid for. It's free. And you can go to them and explain to them what's going on and they'll help you or find a lawyer who can help you to advocate if you're having difficulty advocating for yourself. But, you know, advocating for yourself, sometimes it makes you tired and it can be overwhelming. When you're dealing with the stress of having a medical condition, sometimes you just have to stop and ask someone else to help you because it's just too much. And I've done that myself with my own health and I do have a big mouth. I'm not afraid to see people, but sometimes it's just, it wears you down.

Wanda It wears you down and I understand that. And sometimes we just need to say, when you make an appointment, to tell that facility or that doctor, here's what's going on with me. I'm going to need a longer appointment and I want to know if someone can go in the room with me because I'll need help, you know, scooting onto the table, even though most of the tables go up and down, but you still may need some help. They're supposed to help you out, but they don't know you need help until you tell them. So I always tell people that when you make the appointment, say to them, I'm going to need some extra time or some assistance. Is there a navigator there? Is there a nurse there? Can someone help me with this particular part of my appointment? And that's perfectly legal, appropriate, and people should get that assistance.

Barbara That's an excellent point. And, you know, in some situations, they may call you down when they see you, but they may have to fight for that, too.

Wanda Well, they shouldn't. And if they say that...

Barbara They're not allowed to.

Wanda Yeah, they're not allowed to. They say that, so people need to tell somebody else what that person said to them. You know, they need to spread the word because that should not happen. You know, I can't imagine any of my providers, you know, being like that. I can't imagine. Because my thing is, if a provider said something like that to me, I would find another provider, but I would make sure everyone I knew, knew about that provider that wasn't kind. That's just me. Women with disabilities, because they're not always treated well, they tend to use that – I hate to say it as an excuse, but that's kind of what it is – to not get an annual exam, to not get a pap test, to not get the scheduled mammograms or whatever they're supposed to get because it's such a hassle. And I understand it, but it shouldn't be that way. But what we find is that women with disabilities are sort of similar to, say, African American women and Latina women who wait, like don't get regularly scheduled screenings for things like breast cancer. And when breast cancer is detected, it tends to be later stage or the tumors are larger. And that's the unfortunate thing. And I would say that it's probably due to them feeling less than welcome during an appointment or that the mammogram experience was so horrible that they didn't want to go back. And I understand it, but I want to say to women, don't accept that. Fight for your own health. Get those screenings. Everywhere in the Washington, D.C. area, the mammogram machines go up and down. If you're in a wheelchair, you don't have to be able to stand up. You should be able to tell somebody, that is too uncomfortable or I can't raise my arm this way. Whatever it is, your needs should be met during that screening.

Barbara Absolutely. And the other thing to keep in mind is that mammograms aren't fun for anybody. If you had an alien from another planet come down and you said, you want to what? You're going to squeeze my breasts between two plates? Are you kidding me? It's not fun for anybody. You have to go in there knowing that this is not fun. And then when you add to it the attitude of the technician or

whatever. So if you walk in and say, I don't know if you've ever done a mammogram with someone with a disability before or someone in a wheelchair, somebody blind, whatever your disability might be. If you feel uncomfortable about something, let's talk about it. Let's make this a conversation. Together we can do this and neither one of us has to feel too uncomfortable because we know that as the person who's going to get our breast squeezed, we're going to feel uncomfortable. But we don't want to feel uncomfortable with attitudes and stuff. So I think if you break the ice that way, that that's the best way to start. If you've never done this before, together we can make this work.

Wanda And it's a collaboration almost. It's almost like a dance. You do this, I do that. So I think that's a great, great point to make because the mammogram technicians are generally really great at their job. I don't think I would have chosen a career where I fondle women's breasts. But they tend to be very good and I find that they're very skilled at saying, letting you know what they're going to do next, which is always good. So if a person with a disability can create the dance, I think that's a great thing.

Barbara Yes, they can lead, so to speak. They can lead, right. Instead of the mammography tech leading, you lead.

Wanda The other thing that I find with every woman is hearing the word cancer. I'm finding that a lot of people don't know people that have survived it, that are living with it, which is sad. And if they get the letter that says their mammogram was abnormal, they truly freak out where it could be nothing, but you just want to get it checked out. Here I am 12 years later. They told me something was wrong. I got it checked out. Yes, I was diagnosed, but I went through treatment and here I am. So I'm hoping that women won't be as afraid to check something out. Like if they see something abnormal or the mammogram is abnormal, I hope they get it checked out.

Barbara Yes, because this is a very treatable cancer.

Wanda It gets tricky when a woman is very young or the type. It's a very complicated disease and I don't think I knew that early on, but breast cancer is very complicated with all these subtypes and you don't know who's going to respond and all that. But even with all that, I think women should get things checked out. So I talked earlier about like one breast that maybe gets red and the woman notices that. She shouldn't ignore it. Just get it checked out just so you know that maybe there's nothing wrong because not all breast cancer shows up like a hard mass or a woman who has a rash on her nipple. Well, that's not normal. So they should get it checked out. A woman that sees that the skin on her breast changes and maybe she starts looking like an orange. She should know that that's not normal, especially when...

Barbara Right, or a dimple or something.

- Wanda Right, or a dimple, the nipple dimples, one breast feels warmer, one gets larger, whatever it is, if it's different from what she knows about her breast, all we're saying is get it checked out. And don't take no for an answer from that physician.
- Barbara They may not say that to another woman without a disability, but whenever you hear a doctor say, don't worry about it, you need to worry and convince them.
- Wanda You need to worry about it. But there are probably some physicians that make assumptions about what a woman with a disability can understand.
- Barbara And you know, we do, there are women with different types of disabilities, there are women with intellectual disabilities, and even, you know, women with intellectual and developmental disabilities, they, you know, they're concerned about their bodies and there's, no matter what someone's IQ is, doesn't matter, you need, you know, a good doctor explains to people what's going on and listens when, you know, when a person says, I'm worried, I'm concerned, a good doctor should listen.
- Wanda The other thing I want to make sure women know is most of the people that get breast cancer don't have a family history of it. Say me, I have no family history of breast cancer, but I got breast cancer because I hear women say, well, you know, I felt this lump, but nobody else in my family has breast cancer, so I'm sure it's okay. Well, we don't know it's okay, just go get it checked out. A lot of times, men don't think they can get breast cancer, and even though they don't get it very often, men do get it.
- Barbara You know, my brother had a lump in his chest, and he had, he had a biopsy, and they were worried that it might be breast cancer, and he was lucky it was benign, but he felt the lump.
- Wanda He felt the lump, right, and he needed to get checked out, right. I hear a lot of things in the media. People will talk about cures for breast cancer or what causes breast cancer, but, you know, the reality is, again, breast cancer is a very complicated disease. We don't really know one particular thing that causes breast cancer, but we do know risk factors that are associated with people that get breast cancer, and some of those risk factors, like the number one risk factor any person can have for getting breast cancer is being a woman. Being a woman is one of your greatest risk factors for developing breast cancer, and so is, like, getting older. The older you get, the higher your risk for developing breast cancer, which is why, like, screening starts around 40, you're getting older, your body is changing, those kind of things. I've had breast cancer. It was treated, but I still get mammograms because I have a personal history of cancer, so I need to check to make sure it doesn't return or it doesn't show up in another place. We all know about adopting a healthy lifestyle, like eating habits, exercise, maintaining a healthy weight. All those things matter, as you know, but I'm not saying a person who's a vegetarian that has been very active all their life, I'm not saying that person can't get breast cancer because they can't. We're just talking about risk factors that kind of heighten your risk for getting breast cancer. I know

people that are less healthy than me that never got breast cancer, and I said, well, why me? You know, I'm not that bad, you know, but, you know, cancer, a lot of times, it's like a luck of the draw, unfortunately. We just never know, but the key is screening for cancer. We screen for all kinds of cancer, such as cervical cancer, breast cancer, as you get older, colon cancer, we check for heart disease more so than we did when we were 15, you know, so getting older is its own risk, but it's a privilege that's denied to many, so we never complain too much.

Barbara You know, it's important because a lot of doctors don't think of those risk factors necessarily with women with disabilities because, you know, like you mentioned weight, but if they don't have an accessible scale, they're not going to weigh you, so they're kind of not going to know that you've put on 20 pounds. That's not something that they may realize, so that's why advocating for some of these, you know, to be treated like everyone else, you know, get the same tests, and in fact, I would even ask when you go in for a physical and say, okay, doc, I'm 40, what are the standard screenings that you recommend to the average woman at age 40, and, you know, if you get a response like, well, I recommend everybody get a mammogram, but you don't need to worry about that, or, you know, you need to, what do you do for everybody? I want to do everybody's stuff for me.

Wanda Or even challenge the doctor, why would you say that?

Barbara Exactly.

Wanda What would they say, don't worry about it, if you're telling another 40-year-old person to get a mammogram, but here I am facing you, and you're telling me I don't have to worry about it, why are you treating me differently? I think we have to challenge our doctors. Working with someone shouldn't be that difficult. It's just about, like I said, creating the dance where the technician needs to make sure the person understands the tests involved. The technician should say, I will need you to raise your arm, you know, to this height. Are you able to do that? And the person can say yes or no, or what would help them raise their arm more. So it's just a matter of stating what's needed for the exam to take place completely to find out if that person can do that, and if not, making some adaptations.

Barbara Close. And when you get in the room, you can start that conversation. Exactly. You can lead that dance and say, you know, I have a shoulder replacement. My arm only moves in this position, this position, and this position. You know, you'll have to move the machine down. Let's figure out how we can do this.

Wanda You said it perfectly. Let's, meaning let's us, together, figure out how to make this work. And I think that's the attitude that the technician should have, as well as the patient. Let us work together. Very doable. Sometimes, women, well, a lot of times, women say they hate mammograms, and truly, I don't get excited about the day I have to get a mammogram, but I know the pain doesn't last

forever. But the other thing I tell people is when to schedule their mammograms, not when they're having a cycle, like maybe a week or two after the cycle is completed. I also tell them it's okay to take a couple of aspirins before they go, and also to see if they can avoid caffeine that morning. I'm not saying it will take away all the pressure, but sometimes those things can help decrease the sensitivity of their breath.

Barbara There are things that you can do to make it a better experience.

Wanda Also, I tell people that it's okay to bring somebody with you. I know there have been some extremes. Some people, you know, really have a hard time with mammograms, especially the first one. But, you know, it's okay to bring somebody, or to say, I need a break. Again, when you tell somebody, I need a longer appointment, maybe you need a five-minute break between x-rays. Do one breath break. I need a minute. Give me a couple of minutes before you jump to the next. But maybe some people need to take a step back, and I think that's okay. They shouldn't feel bad about it. They need to speak up about what will work for them, because you want that test done. Now that we've got people that get their mammograms, there are times when a mammogram comes back and it says it was abnormal. It does not automatically mean it's cancer, but I find that women don't follow through. There's that fear that comes in. I hope that women will not let the fear get in the way of them finding out the truth. True, it may be cancer, but they want to take some additional pictures of your breasts before they say, okay, yeah, there is something going on. And then once they determine that by the additional x-rays, what they call a diagnostic mammogram, then they'll do a biopsy. I remember when my biopsy was scheduled, I knew that that meant a needle. But what struck me was that she gave me her cell phone number, just in case I have questions later on. And yes, it did turn out to be cancer, but it didn't end my life. You know, my life wasn't over. And I'll never forget, and I still go to her, because she said, when she told me the result, I said, that's okay, I'm going to get through this. And you know what she said to me? She said, well, I met you, you are going to get through this. And I was like, well, okay, you know, so I went in.

Barbara You were a fighter.

Wanda I was a fighter. The other thing that I did, and I don't know why I did it, is I called my insurance company, my health insurance company. And I never had before, just to say, here's what's going on. I want to know what you'll cover. And they were amazing. We'll cover this. We'll cover this. And the thing that we really want you to know is, we'll pay for a second opinion. The point is, you reach a doctor that you're not comfortable with, you're free to get a second opinion. We will pay for that. When I had to go meet with the surgeon, I felt like I had my health insurance in a backpack armed for battle. I knew I was covered. You know, I knew that somebody was supporting me. And then I did my research, and I had lots of questions, pages and pages. And they were patient. They answered all the questions. I just had the best experience, because I was an engaged patient. I knew that I had rights. I knew that my insurance company

would cover everything that I needed. And I also knew that I could call them with any questions.

Barbara So having those tools at your disposal empowered you. A lot of these health insurance companies now have nurse case managers. Right. And it's more...

Wanda Or health coaches and those kinds of things
Barbara Yeah. All kinds of things to help you out.

Wanda And I think some very key points have been made about, you know, being your own best advocate. And I think it starts when you make the phone call to make the appointment. Here is what... appointment. Here is what I'm dealing with or facing, or here's who I am. Can you give me longer time? Can you provide someone to give me assistance? And speaking up if something, if you feel something is wrong. Do not take it, take the doctor saying, don't worry about it. Insist on getting the appropriate screening or test that you need, given your situation. Don't let their different treatment show up as denial of services or unfair screening or medical treatment. You deserve extra care, patience, just like any other patient.

Barbara Breast cancer doesn't discriminate, it doesn't look at, you know, it's not fair to hit this person, it's not fair to that person. Everybody's at equal risk of breast cancer.

Wanda The other thing that I forgot to mention is the latest thing that confuses a lot of patients is this whole thing around breast density. And generally as you get older, you lose that density, it becomes more fatty and loose. The firmness of a piece of fruit versus a bowl of jelly, jello. So that happens, it's a natural transition as we get older. But when women have those tight, firm breasts, it is harder to see any abnormalities in a breast. So like I say, if a young woman says, I feel a lump or I think something doesn't feel right, a lot of times an ultrasound or further testing is needed because their breast is so dense. So if a young woman says, is 25 years old and says, well, I thought I felt a lump, you know, the other day, and the doctor says, oh, you're too young, they should insist to get the mammogram, but also probably an ultrasound as well. An ultrasound may be needed to provide an additional view of the breast, especially when it is dense, as is typically found with younger women. The use of an ultrasound is not uncommon, so women should not become alarmed when the test is ordered.

Wanda [Outro] So that concludes today's Empowerment Exchange with Wanda Lucas and Barbara Kornblau. We hope our conversation has been informative and engaging. Thank you for listening.