

Advocacy
Wendy van Besien
Tape 2
THE CAUCUS EDUCATIONAL CORPORATION

Q: ... just give me your name and a spelling and your age.

WB: Sure. Wendy van Besien, V-A-N, capital B-E-S-I-E-N, and I'm 40.

Q: How and when did you find out you had breast cancer?

WB: I was 37 and it was November. It was my birthday month and I hadn't yet made an appointment to go see my OBGYN, which I normally do every time, you know, for my birthday. And I said, Well, maybe I should just give myself a breast exam, which I had never really done before. And when I proceeded to do that I felt a lump on my right breast. And then I went in the shower and the lump didn't go away -- like I was hoping it was going to go away. And I called my OBGYN that morning, got an appointment like within the week. He said, I don't think it is anything but maybe you should go get a mammogram. I hadn't yet even had a mammogram. And from there I went to get a mammogram. I had a breast ultrasound. And when I was looking in the radiologist's eyes, when he was administering the ultrasound, I knew that something was wrong. Intuitively I just felt like this is not right, there ... he's spending a lot of time on something that wasn't supposed to be anything.

And sure enough, I went to the breast surgeon and they said, We really need to do a biopsy. And within, like from the day I found the lump to the day that I had the biopsy, it was like

five weeks. And then, you know, I was under and we came out and she said, Wendy, you have, you have breast cancer.

Q: And what was your first reaction?

WB: Really my first reaction was, It can't be me. She must have made a mistake. It must have been the woman that was on the operating table before, maybe the woman that was after. It just, it couldn't be me.

Q: And what was your next step, your first step?

WB: Well, the next step was ... my husband was with me and I looked over at him and, you know, coming out of the anesthesia, so it's ... it was difficult to kind of, kind of comprehend everything that was happening to you. Like the doctor's sort of talking about the sensital(?) node biopsy and, you know, next steps, and I was ... I couldn't get over the fact that she had just said, Wendy, you have breast cancer. But very quickly Steve and I got ourselves together. My parents were actually home, I have two little girls, my parents were home watching the children while I was getting the biopsy, so of course, you know, we needed, we needed to make that phone call. But then both Steve and I got on each of our cell phones. Because the one thing I knew was that I felt the doctor, original doctor was very good, but I knew I was going to go at least for a second, if not third opinion, and we needed to find the best and the brightest in the New York area.

Q: So you started working the phones?

WB: I started working the phones, even before we left the hospital. He was on his cell phone and I was on mine.

Q: And what were you looking for? Yeah, how'd you go about choosing a doctor?

WB: Well, I think the key is the ... the only thing you have really to go by is reputation. So what we tried to do is I tried to tap into people that I really respected, other doctors that I know in the area, doctors that I know outside of the area, friends or family that had, had gone through breast cancer with doctors, did they use ... and I went into like the public press. Okay, who was being written about and why were they being written about? And I decided on a couple of different doctors. And ultimately we chose Chip Cody out of Sloan, Memorial Sloan, to do the breast surgery.

Q: How difficult was that, that whole process? I mean, that's a very academic, intellectual process, and here you are going through all sorts of physical and emotional upheavals.

WB: It was really hard. I mean, although it was hard in one sense in that psychologically I had to deal with the fact that I, that I had just been diagnosed with breast cancer. On the other hand, it was more of an academic exercise in that I had a goal. And my goal was to find a doctor that I really connected with and that could ... would be my doctor for life. And for me that was a quest that I wasn't, you know ... I wanted the A team. I was going to have the A team on my side.

Q: That was for the surgery though.

WB: Correct.

Q: Okay. Were you given the option of lumpectomy, mastectomy and ... how did you go about deciding that?

WB: I was given that option, although my breast surgeon recommended to go with a lumpectomy.

Q: Let me just ask you to go back. You were given the option of ...

WB: Okay. I was given the option of a lumpectomy or a mastectomy, and he recommended that I go with the lumpectomy. And in the end what really swayed me to have a lumpectomy versus a mastectomy was I looked at survival rates, and I was educated that the fact of the matter is regardless of whether you get a mastectomy, a lumpectomy, survival rates were about the same.

Q: How long or how much digging did you do to find out about survival rates?

WB: A lot.

Q: (Overlap) what is the key?

WB: A lot. I mean, I tried not to use the Internet, because I think the Internet can give you just a lot of information without the context. And the sites that I really went on were like the NIH site, National Institute of Health, or the National Cancer Institute, or Living Beyond Breast Cancer, where there was a lot of really good information founded in either trials or anything that was really kind of researched.

I asked every doctor that I went to. I went on those sites to figure out survival rates. I also used a book called "The Susan Love Breast Book," which I thought was phenomenal. It was a great research and she explained the survival rates very well. And survival is really based on three things. It's based on the size of the tumor, whether or not you have lymph node involvement, and then the type of cancer.

Q: Post surgical ...
(Background Conversation)

Q: Post surgery ... then did you have to go back and ... is that how you ... how did you find Rick Michaelson?

WB: I found Rick Michaelson, again, I began the search of okay, who is a really good oncologist and who is someone that I could really connect with and what ... and then wanted to be a part of my medical team. And so I got a few names and he was one of them. And then when I went to interview him there was such a warmth about him and there ... he has such great knowledge, and he is incredibly compassionate, that as long as he and I could really think eye to eye on the treatment I knew that I wanted him to be my doctor.

Q: What were you looking for, looking for in an oncologist and somebody that would follow you post-surgically?

WB: I wanted someone that was ... first and foremost I wanted someone that was incredibly smart, incredibly knowledgeable in the area and would keep abreast of all the issues surrounding breast cancer. I mean, it seems like every six months there is new data that's coming about, new data about treatments, about, you know, causal factors, and I wanted someone that could keep me informed. Because being diagnosed at 37 I knew I had a much more life to live that not to live. And so that was the first I would ... I needed.

The second thing I needed was someone that wasn't going to necessarily be condescending but was going to educate me and not feel that the numerous questions that I have were stupid or not relevant. And Rick always answered my questions completely with a lot of grace and just ... and really helped me get educated on the whole oncology part of my treatment.

Q: I noticed when you were in there today, and I know you did this from the get go, you walked in with a notebook,

taking notes and asking questions. How important it is ... is it to go in with a bunch of questions and then to keep track on going?

WB: Right. I think it's incredibly important, and I've gotten ...

(Background Conversation)

WB: I think it's incredibly important to take notes and keep a notebook and ask relevant questions, and write them down. And the reason I think that is is when you get in front of a doctor regardless of who it is, you know, your mind can go blank. There's a lot of different things. First of all, you're the ... you're on their turf, not your own. So already you can feel a little bit uncomfortable. And depending upon what their demeanor is, you know, you might feel more or less comfortable to ask questions. But if you have everything written out ahead of time and if you've done your research you can kind of just check it off.

And I always for the most part took my husband with me, and he was really the note taker. And the reason I had to note take is it's very difficult to ask a question, listen to it, and write the answer to. And I wanted to make sure that I chronicled everything about my treatment as I was going through, as I was going through the treatment, because i wanted to make sure that I made the right decision and that I was able to always look back on my notes.

Q: And how helpful did it prove to be over the long run?

WB: Tremendously helpful. I was able ... I also kept a timeline of, you know, when I first found the tumor to when it was diagnosed, to the type of tumor and the size, and all the pathology reports. What ends up happening, as you go and interview different

doctors you need to take all this information because it's in their best interest to have an idea about your entire case so that they can give you their recommendation on how to proceed forward.

Q: Well, what kind of options were you offered post-surgically?

WB: When I went to see Dr. Michaelson he suggested that there were two types of chemotherapy that he thought was relevant. One could be CMF, which is over a longer period of time and has less side effects, and the other is a chemotherapy called AC, adriamycin cytoxin, and that is a little bit more potent over a much shorter period of time with some more severe side effects. And I chose to go the AC route. Basically a part of my team was also a Dr. Raymond Chang, who was a complementary and alternative doctor. He is an oncologist by training but I wanted him a part of the team because I wanted to make sure that I had explored all avenues. And after speaking to several different people and having Rick's advice as well, you know, we decided to go with the AC.

Q: And how many treatments, how often?

WB: It was four treatments every three weeks.

Q: And how difficult was it for you to tolerate?

WB: In the beginning it wasn't as difficult, just because what ends up happening with chemotherapy, and this is for any chemotherapy, it kind of builds up into you ... in your system. So the first two really weren't terrible. You feel bad for about 48 hours because you have so many, you know, chemicals in your body and it's doing what it's supposed to do, which is to kill all the bad or the negative cells. But the third and the fourth treatment got a little bit

more difficult. I needed some Neupogen shots, which is ...

Neupogen is a drug that helps to increase the white cell count .

Q: And reactions? Did you lose your hair or ...

WB: Yeah, I lost my hair. They say that you're going to lose your hair between 18 and 21 days and it was pretty much that. You know, and ... and that was very hard. Because what it does is it symbolizes or it signifies to the outside world that you're going through cancer. And for me, you know, I had this little lump. It was only a centimeter. I didn't feel sick. But yet the treatment makes you feel sick. But that is ... that's I think the paradox of, of the whole, the whole experience.

Q: Do you have any pictures of you with no hair?

WB: I do.

Q: Ooh, I want to see them. How did the girls react? Because it was really interesting what you told me.

WB: Right. The girls ... you know, it, it's interesting. My children were eight and five at the time. Very difficult for them to understand what is cancer and what does it mean. I mean, my ... initially my eight year-old said ... she got this frightened look on her face. She goes, You can get it from smoking, because she equated it to be like lung cancer. And so, I had to really break it down for them and explain that it was ... Mommy had some bad cells in her body and we needed to take the bad cells out, and that Mommy was going to take medicine to make sure that the bad cells don't come back. And that was really the basis of our conversation.

But, you know, at some point, you know, am I going to get it? If I hug you am I going to get it? You know, you go through that type of thing. And especially I remember one time, it was after my first treatment and it was right after I lost my hair, and,

you know, mentally you have to grieve. And so for me it was, it was about grieving. And Steve drew a bath upstairs and I had my bubbles and I had my glass of wine, and all of a sudden my little one pops in, she goes, Oh Mommy, you look like you're having fun. And then my other one pops in, Oh, can I come too? And, you know, we all kind of took a bath together. And what that symbolized to me was that regardless of who you are, you're always going to be the mom ... how you look.

Q: How did Steve react?

WB: He was a wonderful partner throughout. I mean, he was very supportive. He went to all the appointments with me. But I think like anything else, when a partner or spouse is going through something, you're pained and you grieve, and he had his own grieving to go through.

Q: You mentioned Dr. Chung?

WB: Chang.

Q: Chang.

WB: Chang.

Q: Why and how did you decide to look at alternative complementary therapies?

WB: I guess because when you think about the East and Western medicines they really do approach healing differently. And I felt like ... I never really asked, Why me? Because I thought that that was just negative energy, it wasn't going to get me anywhere. But what I did want to ask is, How can I create a lifestyle that's going to help prevent this again, and are there other means out there that I don't necessarily know, that can help me through treatment and then thereafter? And, again, I did my research. I went in public files. I talked to some doctors. I also talked to Dr.

Michaelson and said, I'm thinking about this, do you have a recommendation? And he has worked with Dr. Chang before.

Q: So what did Dr. Chang recommend?

WB: Dr. Chang ... put me on this herbal tea, just to help boost energy. Ultimately when you're going to through chemotherapy there have been some studies that you don't want to take any antioxidants or any medicine because what it does is is interacts with the efficacy of the chemotherapy. And, Dr. Chang, to his benefit, you know, that's what he does. So he was not going to put me on any protocol. But after I finished the chemotherapy he put me on a controlled fast ... to kind of wipe out the toxins in the body, as well as he took blood and now I'm on a regimen of taking supplements on a daily basis.

Q: And what's the drink that we're going to see you making?

WB: I'm going to make a green ... I just did green juice. I just used spinach and kale and carrots and whatever fresh food I have in the house. And I just ... it just is a great energy booster.

Q: I'm not sure every woman ... obviously the point is the advocacy. What should every woman do when and if diagnosed? What would be your let's say top three points?

WB: Right. I think the first thing is you need to grieve, because you have to go through it. I think the second point is you have to be educated. You need to get yourself up to speed. I mean, once I was diagnosed I didn't really understand the difference between chemotherapy and radiation. But afterwards, you know, I know now. And I think because I had a lot of data and a lot of knowledge, when I went in to speak to the doctors, which is my third

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... which is the third point, which is make sure you find doctors that you can really talk to, that want to spend time with you, that take their time with you and answer all your questions.

Q: Okay. Anything that we missed?

WB: I don't think. You're very thorough.

(END OF TAPE)