



Breast Cancer Survivor Perspective

Hosted by: Anees Chagpar, MD

Guest: Wendy Chambers, Patient

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Welcome to Yale Cancer Answers with doctors Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week in honor of Mother's Week, it is a conversation about breast cancer survivorship with Wendy Chambers. Wendy is a 2-time breast cancer survivor, and Dr. Chagpar is a Professor of Surgery at the Yale School of Medicine.

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Chagpar So, Wendy, tell us the story of how your breast cancer journey started? So, start the beginning - Once upon a time, I was perfectly well and then....

00:52.700 --> 01:03.000

Chambers Okay. That's a great place to start. About 10 years ago, I was diagnosed with DCIS, stage 0, on my right breast.

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Chagpar How did that start? I mean, did you just go for a mammogram, is that how it all started?

01:08.000 --> 01:41.300

Chambers I did. I went for a mammogram. My mother had had breast cancer when she was in her 50s, had a very successful treatment and it never returned and she lived into her late 80s, but I was diligent as are my sisters about going for mammograms. So, I went for a mammogram and I had never seen anything before, just some denseness, but it looked as if somebody had thrown coffee-grounds on top of my mammograms and that is when they explained to me that that was what ductal carcinoma in situ could look like. And so, that is in fact what I had.

01:41.300 --> 01:50.500

Chagpar So, they see these coffee-ground like things on your mammograms and then what happened? They called you back and they did a biopsy?

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Chambers They called me back, did a biopsy, did discover that it was DCIS, stage 0, it had not moved outside of the ducts, which is great and then they started to talk to me about a treatment plan.

02:03.400 --> 02:55.100

Chagpar Okay. So, what did that feel like? I mean, do you really kind of put yourself in that scenario. I am thinking about all the women and girls and mothers out there, especially now that we are talking about mother's day, who may be thinking about they have not had a mammogram, maybe they are scared to get a mammogram because the worst thing about getting a mammogram aside from the fact that some people think it is a little bit painful or tender is the news that you could actually have a cancer. So, what did it feel like when they first saw those calcium spots and then they told you needed to come back and then they told you needed a biopsy and then you had to wait for the results? Tell us like what was going through your head, were you totally calm during all of that or was there some anxiety going on?

02:55.100 --> 03:39.100

Chambers So, it is terrifying. And the first time and the second time, which I know we will talk about, this is really what I find to be the very scariest part. So, when you are not sure if you have cancer or not and it is just people being overcautious and it turns out to be nothing or if it is really going to be something. That is terrifying because you need to wait, you need to let go of control and we are all busy. I mean, I have had a big career at that time, I had children, a husband, 2 dogs, you know, life was really busy and wonderful and you know I do not think cancer ever happens at a good time right?

03:39.100 --> 03:41.000

Chagpar Yeah, it does not make an appointment on your calendar.

03:41.000 --> 04:33.000

Chambers Exactly, exactly. So, it is a terrible time because you really just need to wait and you do not know what you are waiting for. You are of course praying that it is nothing, but in my case, you know it turned out to be something and then I think it is still a very difficult time because you do not know, you do not understand the treatment, you need to really learn a lot about them, rely on your doctors to get the right guidance and then you are making decisions between things that you have never thought of in your life and it is really hard to pick the right one, even though, you know, you have the guidance of doctors, but it is scary. So, for me that time between diagnosis and deciding your treatment plan and then getting going was really the very scariest time, both times for me.

[04:33.000 --> 05:10.100](#)

Chagpar Yeah. And I think that that is true for a lot of women with breast cancer is just that waiting, not knowing, thinking about could it be - could it not be, and then you get the diagnosis; the biopsy comes back and they say it is ductal carcinoma in situ, and for a lot of people, when people just say that, it sounds like jibberish. And then, they are worried about well am I supposed to be worried, like is this really bad? is this not really bad? is worse than not having anything? Tell me about that and how you kind of went through the process of processing that information.

05:10.100 --> 06:02.300

Chambers So, like anything, it is like learning a new language. I did not know what the acronym DCIS stood for and if something is stage 0, then how can it be anything because 0 has no value, and so, I really tried to think my way through this and muscle my way through it and just learn, and try and embrace just like if I was in a country, it is like the bus to drop me off in a new country and i did not speak the language. And I had to kind of figure it up bit by bit. So, I asked a lot of questions, I actually overread I think in hindsight, but at that time, it seemed to make sense. I googled everything, I read every clinical trial I could get my hands on because I was really going to take control of what was happening.

06:02.300 --> 06:12.800

Chagpar Okay. So, did they call you to give you that diagnosis and then they set you up to see the surgeon, is that right?

06:12.800 --> 06:35.300

Chambers Exactly. They called me with the diagnosis and then they set me up with the surgeon that I did not know obviously because I had had no experience before and this was when I was living in New Jersey, so I made an appointment and then I got in very quickly which was wonderful and I went to see him to see what the next step was along with my husband and my then sixth grade daughter.

06:35.300 --> 07:01.800

Chagpar Okay. So, tell us what that appointment is like. There you are, you know, what seemingly was a bombshell had just hit your life and you were in this topsy-turvy new country, new language, new everything, going to see the surgeon, what was that like? And then, what happened during that visit?

[07:01.800 --> 08:46.200](#)

Chambers Well, so I took a notebook because I could write things down, I went in armed with a whole bunch of questions from research that I had done and things people had told me and things people told me to ask, I had talked to some other people who had gone through different kinds of breast cancer to get their point of view, so my notebook had a whole bunch of questions in it and I went in so I could write things down because I just knew, you know with this language being so new to me that I would not remember all my questions and I would not remember what the answers were. It is also why I took people with me not just because they loved me and this was scary, but so that they could listen and hear and ask questions too. So, what was it like? It actually for me was well still scary - cancer is a frightening diagnosis and I actually found it kind of empowering though because I had some answers on what was next and it also provided some personality and size I guess is the best way to put it of my cancer, you know. It was not as big just even in terms of severity as I was worried it would be, so it kind of gave it a face which was really important to me and then they had a treatment path that they wanted to talk to me about and it was not just this is what you must do, it was here is why we want to this - a lumpectomy and here is why we think radiation and here are the pros and cons of each, so instead of it being all put onto me, it was more of a guided dialogue I guess is the best way to put it.

08:46.200 --> 09:48.000

Chagpar Yeah. And I think that that's right, you know, a few key points that I think a lot of patients can learn from what you have said is, the value of taking a notebook and writing down your questions and bringing loved ones or if not loved ones - a second set of ears, a friend or somebody who can help you because it is a lot of information in short period of time. And then, the idea that although you are facing this diagnosis, I find a lot of patients actually find that visit really as you said empowering in the sense that they can now get a sense of control, like I can see this thing, I can deal this thing, I can understand what it is and I now know how I will take care of it and I am empowered with all of these options. So, then what happened after that? You met with the surgeon, it sounds like you had decided that you are going to do a lumpectomy and radiation, and so, then what happened?

09:48.000 --> 11:25.500

Chambers Right. Well, it is interesting and if I could come back to something you had asked me earlier that I did not answer, oh! well, I will move on. So what happened when we decided to do that treatment plan? It made a lot of sense to me and we just got it scheduled so that we could go ahead. Oh! I remember, in doing all of the research, I also had a mindset as I was approaching this first cancer in that I was going to attack it, I was going to beat it, I was going to control it, i was going to control everything about it. One, it was an inconvenient time and two, I just really felt that that was the right approach to have. I think it is important to share with you, I am big into pop culture and I kind of felt like Linda Hamilton in caring her shotgun in the terminator well, I was going to crush this and beat it and push it back. And that it is an important thing to keep in mind, so as I approached this treatment then, that was kind of my mindset even though I was being empowered and being led by doctors. So, the

doctors then talked to me actually about a clinical trial rather than just regular if you will, radiation that sped up the number of treatments, cut them in half. Well, given this was so inconvenient and given how I wanted to attack it, I actually decided to do that clinical trial and also thinking that if it worked, then I am not only helping myself in half the time, but I am also helping others as well.

[11:25.500 --> 12:11.600](#)

Chagpar You know, we talk a lot on the show about clinical trials, and the fact that, you know, nationwide only about 5% of people enroll in clinical trials even though we know that people who participate in clinical trials tend to do better than people who do not because we are always looking at treatments that are either more effective or shorter in duration or have fewer side effects, and the sense of altruism that, you know what not only can this potentially help me but help other people, tell us about your thought process in that going through thinking about whether or not you wanted to participate in a clinical trial; did you have a sense of oh! my God, am I going to be a human guinea pig, like did that ever go through your mind?

12:11.600 --> 13:19.500

Chambers It did a little bit, but I think the interesting thing about this particular trial that I decided to participate in, is I knew exactly what was going to happen, I was not going to be in the sample that thought they might be getting the treatment but did not get the treatment, I do not know, blind, double blind, the placebo whatever the language is, it was twice the radiation and half the time. So, I knew exactly what was going to happen and so, I did not feel quite so much like a guinea pig. We talked a lot about the side effects and would there be twice the side effects or twice as bad side effects or whatever, and the treatment team that was working on this trial, reassured me that that should not be the case; and so, I felt that it was, I guess, if we call it a risk rather than a regular treatment plan, I felt that the risk was warranted and not that high, and so, I decided to go for it. As I had mentioned, my life had been put to the side for a moment and I wanted to power through this, so it actually selfishly kind of fit better into my schedule to not have to go to radiation twice as long. So, that was another decision too.

13:19.500 --> 13:57.400

Chagpar Yeah. I mean, I think that is true; a lot of the times clinical trials either fit into people's schedule better, maybe the side effects are better, maybe you are getting therapy with an oral pill instead of an IV and a lot of trials these days are not versus something that is a black box, oftentimes you will know exactly what arm you are in, and so, a lot of patients might really want to think about asking about clinical trials. We are going to learn much more about the rest of your story after we take a short break for a medical minute. Please stay tuned to learn more about Wendy's experience with breast cancer right after this.

[13:57.400 --> 14:11.000](#)

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14:11.000--> 14:56.600

This is a medical minute about genetic testing, which can be useful for people with certain types of cancer that seem to run in their families. Patients that are considered at risk receive genetic counseling and testing so informed medical decisions can be based on their own personal risk assessment. Resources for genetic counseling and testing are available at federally designated comprehensive cancer centers. Interdisciplinary teams include geneticists, genetic counselors, physicians and nurses who work together to provide risk assessment and steps to prevent the development of cancer. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

14:56.600 --> 15:33.800

Chagpar Welcome back to Yale Cancer Answers. This is Dr. Anees Chagpar, and I am joined tonight by my guest Wendy Chambers. We are talking about her experience with breast cancer. And, before the break, she was telling us about how about 10 years ago she was diagnosed with stage 0 DCIS, which kind of threw her life into this upheaval, but she was determined to take control of this, have a lumpectomy, enroll in a clinical trial, get her radiation and power through it. So, Wendy, you had the lumpectomy, the radiation, and you never regretted going into that clinical trial?

15:33.800 --> 15:35.300

Chambers No, not at all.

15:35.300 --> 15:36.300

Chagpar And then what happened.

15:36.300 --> 15:38.500

Chambers Then, my cancer was gone.

15:38.500 --> 15:40.900

Chagpar Did they need to give you any other treatment?

[15:40.900 --> 16:05.000](#)

Chambers No they did not. They offered tamoxifen and AI, and I opted not to do the tamoxifen after understanding that my percent of recurrence for this type of cancer went from, I do not remember the stats exactly, but something like you know 4% down to 2%, I think, you know something like that, and so I opted to be finished and not continue with an AI.

16:05.000 --> 16:29.000

Chagpar Okay. So, another good point is ask the questions, ask the numbers, how much benefit am I going to get with this treatment and talk to your doctors about that. Okay, so you were done and you must have felt such a sense of like relief, hallelujah, celebration, what did that feel like when you hit the gong the last time in radiation?

16:29.000 --> 16:49.100

Chambers It was great. I mean, it was great. I really felt like I had done all I could that I had been taken really good care of and that I was finished. My mother had had cancer, I had cancer, check - I am done and now it is time for me to get back to my life.

16:49.100--> 16:53.700

Chagpar Okay, so you get back to your life, but you are still having checkups, is that right?

16:53.700 --> 17:03.800

Chambers Absolutely. I went every 6 months for 3 years at the facility that I was being treated at before when we were still living in New Jersey, and then I graduated to once a year.

17:03.800 --> 17:03.800

Chagpar Okay, and so, you would go for your checkups and how often were you getting your mammograms?

17:03.800 --> 17:10.500

Chambers I was getting my mammograms every 6 months.

[17:10.500 --> 17:18.400](#)

Chagpar Okay, so you were getting your mammograms every 6 months, you were getting checkups every 6 months and then you graduated to a year and then what happened?

17:18.400 --> 17:32.000

Chambers Then, I just kind of forgot about it, which was extraordinary. It was a blip on the radar that I moved past and almost 5 years went by...

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Chagpar And then?

17:32.200 --> 18:11.500

Chambers And then, I actually was, I had been so diligent, I had also changed my diet where it made sense, I was exercising more, I have always been active, but really making a concerted effort to try and make even better choices and I was putting lotion on after a shower one night and I felt something in my left breast. Now, the DCIS had been in my right breast 4-3/4 years earlier. So, I felt something in my left breast, actually felt more than one thing and I had had a mammogram because I was so good about going, about 8 months before there had been no signs of anything.

18:11.500 --> 18:33.500

Chagpar So, you feel this and you are thinking what is this, could this be, this cannot be anything I just had a mammogram 8 months ago, I am being followed really carefully, I am eating right, I am exercising, I am praying to whatever entity is out there, this cannot be really a lump.

18:33.500 --> 18:47.700

Chambers No, and I knew, I mean I knew how could it be anything but, because it felt differently from anything that I had felt before but that was not supposed to be what was going to happen, my cancer was not supposed to come back and it was supposed to be gone forever.

18:47.700 --> 19:07.000

Chagpar Right, I had willed it to be gone except that you now felt this lump. So, what was going through your head at that point? Like, were you like oh! my god, I have got to get into see a doctor or were you in a bit of denial like this cannot be anything, this might be just a cyst, I am just going to watch it?

[19:07.000 --> 0:19:55.0](#)

Chambers That is an incredibly great question to ask me because that was the beginning of June and I had my annual appointment with my surgeon and oncologist at the end of June, and I was leaving for a business trip for China the next morning and then I was doing a family trip with my husband and our wonderful kids in Scandinavia over the course of the next couple weeks, and then coming back and going right into my doctor's appointment and so, I thought well, nothing is going to happen between now and the next 2 weeks. So, I called them and let them know, I made sure everything was scheduled and they said, we will see you in 2 weeks when you are back from this whirlwind tour. So, I did not go in right away, but I went in within a couple of weeks.

0:19:55.0 --> 20:02.300

Chagpar Okay. So, you go in, you have now had a fabulous time traveling the world and you go in with a bit of trepidation I can imagine?

20:02.300 --> 20:13.400

Chambers Absolutely. And I said to the woman who was doing my mammogram saying you are going to see something and I need you to tell me that this is nothing.

20:13.400 --> 20:14.400

Chagpar And did she?

20:14.400 --> 20:33.400

Chambers She did the mammogram and she said I do not think we are going to tell you this is nothing, I think this is something when I was talking to the radiologist, and I knew, I mean I absolutely knew, but I did not know the extent of it and I did not know what we were facing yet, but I had a feeling we are about to start this again.

20:33.400 --> 20:38.700

Chagpar Okay. So, you have your mammogram and they see something, and then what happened?

[20:38.700 --> 21:23.000](#)

Chambers Then, so well, they suggested I do some additional diagnostic work and that there was really no reason for me to continue keep going back to New Jersey, yeah they loved having me but I should find a place in Connecticut, we had just moved to Fairfield County, I did not know anybody, I did not have any doctors, I did not have a GP or anything, so what actually the first I did is I googled radiologists and that actually is how I found the radiology place that is affiliated with Smilow and that is how my relationship with Smilow really began, but I really was, you know I googled it and that is what came up.

21:23.000--> 21:47.200

Chagpar Okay, so here you are, you are in New Jersey, you get a mammogram and they see something, but you have moved to Connecticut and they said, you know what you are going to need treatment, you better find treatment closer to home. So, you find a place on google in Connecticut, you have never heard of them in your life and so what did you do? You just called them up and said I need to come in and see you?

21:47.200 --> 22:23.700

Chambers Yeah, and they said we can get you in next week and then I burst into tears. It was a nice woman said, okay how about 3 o'clock today? So, I went in for it, the mammogram, and spoke to the radiologist and she said you really need to have a biopsy done and it just so happened that the person that came into do the biopsy was coming in the next day. So, she said I am getting you on her calendar for tomorrow, so come back. So, I went back to Fairfield for the biopsy the next day.

22:23.700 --> 22:24.900

Chagpar And then what happened?

22:24.900 --> 23:02.200

Chambers They did the biopsy, we got the results relatively quickly, I think within 24 hours because again there was a sense of urgency once the doctors realized what they were working with to get this identified and keep me moving. So, after the biopsy the doctor that did the biopsy called me at about 6 o'clock at the end of that day and said you know it is testing positive for cancer and can you see my friend who is a surgeon at Smilow up in New Haven at 9 o'clock tomorrow?

23:02.200 --> 23:03.100

Chagpar And you said?

[23:03.100 --> 23:13.300](#)

Chambers Okay. You know, I did not bother to question why they were moving me so quickly, I was just really grateful that I was in such good hands.

23:13.300 --> 23:19.300

Chagpar Yeah. And so, you drove down to New Haven and you met with the surgeon?

23:19.300 --> 24:21.900

Chambers Yeah, I did and again my husband and my daughter were with me. You know it is funny when you are going through this, you are often the only person in the room not wearing any clothes from the waist up and I did towards the end of my treatment set a rule that nobody gets to come in the room with me unless they take their tops off too, but that I was joking obviously, but yeah then I showed up and you know found out that everybody, all the professionals thought my cancer was really serious and we talked about what would be next, we made an appointment with an oncologist, we started talking about surgical options with the surgeon who is the first one I saw. I was given a giant binder that I called my chemo101 binder that had all questions that I might have or many of them that would be answered, and I left Smilow with this binder knowing that I had cancer again.

24:21.900 --> 24:24.200

Chagpar Yeah, and this time it was not stage 0?

24:24.200 --> 24:53.500

Chambers No, it was not. Well, we did not know at the time before surgery, but they thought it was at least stage II. They found 3 tumors, not 1 in my breast, I thought I had felt a second one but there were 3 and they were big and they were not there a year ago. And we went back to those mammograms and things and they just went there, so my cancer was back and my cancer was back with a vengeance, it was a different cancer I do not know, but ...

24:53.500 --> 24:57.300

Chagpar It was in the other breast, either way it was affecting you.

[24:57.300 --> 25:18.200](#)

Chambers Yeah, either way. So, that really was not supposed to be what was going to happen. But here I am and I am here again and you know at least stage II and it turned out, I mean after surgery that it was diagnosed as being stage IIA because of the size of the tumors in my left breast and there was some nodal involvement as well with my lymph nodes.

25:18.200--> 25:45.100

Chagpar So, before they started with surgery, you had mentioned that you had seen a medical oncologist too and had a lot of questions about chemo and this big binder that they gave you, did they talk to you getting chemotherapy first or was that something that they were planning after surgery or I mean, I am sure that the C-word aside from the C-word cancer other C-word chemo or both the words just drive fear into the souls of people?

25:45.100 --> 27:23.500

Chambers Totally. Well, surgery and radiation were known entities to me right and I had managed to avoid that scary terrifying chemo, but this time it was staring me in the face and that was recommended. So, to answer your question, the treatment path for me that was recommended was mastectomy. We talked about, the great news is there was no cancer in my right breast - yay. So, that one was hopefully won and done, and so we talked about removing one breast and I had a very serious conversation with the surgeon about doing a double mastectomy and as I said to her, going down to the studs and starting over again because I had had cancer now, a past cancer and a current cancer, and so we talked about then doing a double mastectomy with reconstruction. We talked about the different types of reconstruction. We opted because i had had radiation before not on implants but on doing the DIEP flap reconstruction and then after we were doing that, I mean we were talking about all this my heavens on the first day and the subsequent days before any of this happened, but we were then quickly following up after surgery and reconstruction with chemo and then radiation was on the docket potentially but they wanted to wait to see what kind of cancer and the extent of it once they got in to do the surgery and then in fact they did recommend radiation post-chemo. So, it was surgery and recon, and then chemo and then radiation.

27:23.500 --> 27:40.100

Chagpar Yeah and for a DIEP flap, for our listeners who might not know what that is, is that is essentially where they take your tummy tissue and they rebuild a breast. So, I mean, the glass half full side of that story is that you get a tummy tuck, that is a big operation.

[27:40.100 --> 28:12.700](#)

Chambers Right. I mean and it is funny because that is the first thing people will say to me, well it is a 13-hour surgery, I was sound asleep, it was more difficult for my family and for me personally, I greatly appreciate that my breasts are made out of me, I did not really need a tummy tuck, but it is an added benefit, I can still rock a bikini and I am not embarrassed by the scar, it is just I earned it and so it is really what worked for me.

28:12.700 --> 28:20.000

Chagpar And now that you have this second cancer, were they thinking about, you know, genetic predisposition, how did that play in?

28:20.000 --> 29:18.400

Chambers Absolutely. So, I did not do it until I think I had a lot going on and so I did not go I do not think until after I finished chemo, I do not remember exactly when but I did go see, what are they called, genetic counselor or genetic advisor and I was worried about me, I was more worried about my daughter, I was worried about my sisters, I was worried about their kids. So, I did it. I absolutely did it. You know, I put it on the list of things to do and I am not positive for the BRCA gene and I was not positive for anything else, and I have one of the any of the other markers and one of my sisters actually also had the test and she is negative. So, we feel really good about us and about our kids and about the future of cancer and its prevalence in our family.

29:18.400 -->

Wendy Chambers is a 2-time breast cancer survivor and a mom, Happy Mother's Day. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.