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Survivor Perspective with Pattie McKnight

Guest:

Pattie McKnight

Breast Cancer Survivor

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week, we welcome Pattie, a breast cancer survivor. Here is Francine Foss.

Foss I would like to open up the show by having you tell us a little bit about yourself, how old you are, what was your life like and how you received your cancer diagnosis?

Pattie I am 50 years old, had a good life, and had no reason to believe that I would be a candidate or join this club. I had my mammograms yearly, because it was what I was told to do and kept with that program of yearly mammograms. They found a mass about 5 years ago, but it was diagnosed as being benign, so I just continued with my mammograms yearly and moved on. This year when I went for my mammogram, they again found something, and told me they were going to monitor it. I am not very good at waiting however, so I thought I could just go on my own to a breast surgeon and have whatever it was removed, and quickly found out that is not the way it works. I got a call from my doctor asking what I was doing, and I did not have a referral for a breast surgeon. I told her I was most comfortable having it removed. She reassured me that the spot on my mammogram was nothing but she would do a biopsy. I went for a biopsy where they were going to drain what they thought was a cyst, but could not drain it, and sent me for a second biopsy, and I think I knew that it was not going to come back well. On November 22, a week before Thanksgiving, I got a call telling me that the pathology had come back and I had breast cancer.

Foss So, had you gone quite a long time now with the lump at this point?

Pattie Actually, because it was an annual mammogram where it was found, and again me not being a waiter, it was pretty quick that I had the biopsy and then the second biopsy, so it was not that long of a time.

Foss And you were very proactive in this whole process?

Pattie I have to say I think that that is something that I firmly believe in and I have really never been sick a day in my life, but going through it with my parents I think you really have to advocate for yourself. I tell people all the time, the doctor see a lot of patients, but nobody really knows you like you know you, so it is your job to make sure if you feel something that is strange, advocate for yourself and get yourself up to front of that line and get it checked.

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Foss Did you have other friends with breast cancer, any personal history of it or exposure within your family or anybody that you knew?

Pattie I cannot say that any of my family had breast cancer. I have managed breast cancer walks recently, because of what I do for living. It was something that was brought to us as a charity to support through McDonald's. So I was running breast cancer walks and did run into people there and always thought how strong they were and how they had made it, and here I am trying to support you, but cannot really understand what you are going through. On Mother's Day, we would do a walk at the lighthouse, so I have supported the cause but never really had it touch close to home for me.

Foss What was your initial reaction when you found out that it was cancer?

Pattie I will tell you, I had a funny reaction I believe, when the doctor called me for a moment I almost felt vindicated because I was starting to feel like a nuisance pressing and pressing for this biopsy that the medical people really did not think I needed. So for a moment I wanted to say, I told you so, but she initially said to me, do you have any questions and I thought I should have hundreds of questions, but it took a minute to figure out what those questions were, because it had not touched home for me, or close to me, I did not know what I should ask. I asked what was probably a foolish question, but in my own way to find out where I stood, I said to her, it was the week of Thanksgiving and cold weather was coming, and I said I bought a brand new coat and it was very expensive, and she said, what is your question? And I said, my question is do I cut the price tags off or do I return the coat, and she said, are you trying to ask if you are going to make it through the winter and I said, yeah, and she said oh, you are not going to die from this, you can beat this. She put me at ease by telling me to cut the tags off my coat, which now sounds so crazy, but I could just not form that sentence to say to her, am I dying? So that is how I asked her.

Foss As a patient, did you really want to hear, you have cancer, but you are going to be okay?

Pattie I think so, but I was happy that she used the word 'cancer.' Because that is exactly what she said, you have breast cancer. There was no fluffing it up, you have breast cancer, and for a second I guess I wish she wouldn't have said that, but now in hindsight, after dealing with Dr. Chagpar, I do not know if it would have been fair for her to say that and would I have wanted her to give me false hope and tell me I'd be fine when she did not really know?

Foss So you got the bad news right before holiday and then you had to go through the whole holiday with your family. When was the next time that you got any more information about what was going on?

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Pattie I got the phone call about the diagnosis on Monday, November 22 and I was getting ready to go Christmas shopping and that day halted. My daughter came immediately over, she is a nurse, she came over and I was immediately surrounded by family, and all I thought to myself was it looked like I was at a wake, but with no food. Everyone came around, and were sitting waiting for me to need something or say something, and I really did not know what I was supposed to need or what I was supposed to say, but I was very lucky. I called Dr. Gary Friedlaender from orthopedics at Yale who is a trusted friend, and he immediately told me the person I needed to see was Dr. Chagpar at Smilow, and by Wednesday of that week, two days later, I was able to get an appointment and go meet with her. I went in to the next day, Thanksgiving Day, already feeling at ease with it because I met with her, and we talked for hours. She explained the diagnosis completely. She explained all of my options, all of the pathology, all the big scary words. We spoke for so long that I started to think she must have another patient, but she never made me feel like she had another patient. It was just me for the whole day, and then I remembered on Thanksgiving Day, her calling me and me thinking, what doctor does that? Who calls the patient on a holiday to tell me do not be anxious, if you have any questions just email me, just call me, we have got this, it is early, you have options. She really did a great job of putting me at ease right from day one.

Foss That is terrific. I hope that other women can have that kind of experience also.

Pattie I think that I was blessed, but I am sure there are lots of Dr. Chagpar's and Dr. Fusi's out there. They really did make me feel like I had it and then I put my trust in them and people would ask me and my family members, have you read this book or did you Google it? Or have you read this article? And I thought, that is not my role. My role is not to become completely educated on ductal carcinoma and what are my chances. My job was to find a team of doctors that I trusted and trust that they were educated in that and do what they told me to do, and that was the road I chose to take.

Foss As you said, it was a ductal cancer, but can you share with us what your treatment was, and what the outcome was?

Pattie First of all, something that I liked when I spoke with Dr. Chagpar from day one, was I had all these questions, how advanced is it, what treatment am I going to have, how long is it going to be, how much of life is this going to take, will it take my life? And she was very clear with me from day one and told me there are only two people that can answer a lot of your questions, one of them is God and he is not here, and one of them is the pathologist, and we have not gotten to them yet. She made it very clear to me how important the pathologist was because that pathology would determine my treatment, but the first step was to remove it, and then they would be able to answer

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a lot of those other questions. So, that is what I focused on first, getting myself booked for surgery, finding a plastic surgeon. She did describe a lot of different options, many many options. I told her I wanted to have everything out, as much as you can do. For me, the waiting and taking the lesser road now would not have been the right answer, so I opted for the biggest surgery, taking everything.

Foss That is a difficult question for most women, when they are posed with what do you want to do now? As you said, there were two very major options, one of them was a local, small procedure that could be followed up by a second procedure, and the other one was to have the whole thing removed, and then face the possibility of reconstruction. And you went down the latter road.

Pattie Yes, I did, I opted for a double mastectomy. Another piece of good advice that Dr. Chagpar gave me was to make my decision that was right for me and then be firm with it because there are a lot of opinions out there, there are many roads that women travel when they get a diagnosis like this and I do not think any are right or wrong, it is only a matter of what is right or wrong for you. So, I did make my decision, I knew that it was the right decision for me, but I did get some feedback, that is a long surgery, it was 17 hours, it was big surgery, I did not even know you could be asleep and have surgery for that long, and it was a bit of a recovery, but for me it made me know that I did everything that I could do at that moment, and that is what I needed for me, to do everything I could at that moment. I remember when I went back and she read the pathology, 10 days after the surgery, and she told me that they had found some ductal carcinoma in the other breast. They had only seen it in one. I opted for the double and I remember saying to her, thank God and she said why thank God and I said well now again I felt vindicated, because I felt like I needed to do this radical procedure. When people were saying you're stage I, you could get away with much less, but in my mind, I would be okay with the fact that I would not have to revisit this again. So, when they found it in the other breast, undetected on mammogram, I was happy because then I thought I have done right thing by doing it now.

Foss You have been your own advocate and it has really paid off for you?

Pattie Yeah, and sometimes it is not easy because you want to entrust a doctor but then you have questions, but she gave me the options, and I said to her, is this the wrong decision to be so radical and she said, none the options that I have given you are wrong, they are all options, whatever you choose is right for you.

Foss It is difficult to handle that when you are faced with that kind of tough decision. Did you feel that

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you got enough information and did you go to other sources like the internet to look up the difference between the radical surgery and the more conservative surgery, or did you kind of have a gut feeling and you knew what you wanted to do?

Pattie I cannot say that I didn't look it up anywhere, but I will say again Dr. Chagpar was very thorough from drawing pictures, to giving me reoccurrence percentages of what my recurrence rate might be. She really gave me almost a book when I left there of each option, what it would look like physically and what it might look like in the future, what the recurrence rates would be should I choose one option over another. I felt like I got an education just sitting there for the couple of hours I sat with her that she read it to me.

Foss How soon was it from that appointment to the time you actually had the surgery?

Pattie Well, that was a learning experience for me because I thought I could just say, next week, and I remember saying to Dr. Chagpar, it's Christmas and I have a lot of things to do and she said, cancer never comes at a good time, it is never an opportune time to find out you have cancer, but it can't be next week, you have to find a plastic surgeon first, and I did go to a couple. I thought that I would find the most compassion in women, so I started out going to see some women, but it was not a good match, and as a matter of fact during one of them I ended up walking out in the middle of the consultation, it just did not feel right, and I ended up finding a man, Dr. Fusi was amazing. As soon as I went in and he started to talk to me, I knew that he was the right person for me, so I picked a plastic surgeon and January 11 was my big day.

Foss We are going to have to take a break or a medical minute. Please stay tuned to hear more about Pattie's experience with breast cancer.

*Medical
Minute*

It's estimated that nearly 200,000 men in the US will be diagnosed with prostate cancer this year, and over 2,000 new cases will be diagnosed in Connecticut alone. One in six American men will develop prostate cancer in the course of his lifetime. Major advances in the detection and treatment of prostate cancer have dramatically decreased the number of men who die from this disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using two simple tests, a physical exam and a blood test. Clinical trials are currently under way at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for prostate cancer. The da Vinci Robotic Surgical System is an option available for patients at Yale that uses three-dimensional imaging to enable the surgeon to perform a prostatectomy without the need for a large incision. This has been a medical minute and more information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

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Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined today by my guest Pattie who is sharing her cancer story. We talked to Pattie earlier about the diagnosis of a breast cancer and the fact that she underwent a fairly radical surgical procedure. Pattie, for our listeners who might be thinking about the options of the mastectomy versus the local procedure, can you talk about the surgery, the recovery, and whether or not you are glad at this point that you made that decision?

Pattie First, I would tell you that I am absolutely glad that I made the decision that I made for me, but I am respectful of the fact that everyone has a different path with this diagnosis. For me it was being where I was told to be by Dr. Chagpar, which was at Smilow on January 11, it was the day of the big storm here in Connecticut, but that did not affect me. I will tell you that I think I had an easier time being asleep during the procedure than my family had waiting. That is a long time to wait for somebody that you love knowing that they are in surgery. They were great in communicating from the OR to the waiting room to let them know they had removed the lymph nodes, that the initial pathology was coming back, and that the lymph nodes were clear on both sides so they kept giving them hope that things were going well. It was long procedure, they call it a DIEP flap procedure and they did a radical tummy tuck and took my stomach tissue to try to do reconstruction. I also had to have chest expanders put in with the double mastectomy, and all this was done at the same time. I was told that I would be in the hospital for some days recovering. I spent one day in ICU, one day on the floor and then was discharged that Friday, so I was in the hospital for the day of surgery and two days following. They were great to me. I felt great, went home, had a follow-up appointment a week from surgery where any drains that were left from the surgery were removed and I just felt like it was back on with life, but it was a little slow moving. Again, I know it is different for everyone, for me it was not as bad as I thought. I think the picture they painted for me and I accepted was worse than what I actually had to deal with afterwards, but I just concentrated on doing what the doctor told me to do and not doing what they told me not to do and it worked for me.

Foss Did you have to go through any rehab after the surgery, and how long was it before you got back to work?

Pattie I did not have any rehab. I am lucky in that I have a sister who is an occupational therapist, and quickly after the surgery I started to notice that I had a shoulder that was not responding quite well and to me that was odd because I thought I had breast surgery, what does that have to do with my shoulder? I was told that they could explain the anatomy to me, but I did not need to know that, I just needed to know what to do to get my shoulder to reach above my head again, and she hooked some pulleys over a door and told me to sit there a few times a day and what I needed to do and I did that and my shoulder came back. I had taken a month off of work originally and told them that is what I thought I would give this disease, a month, and I thought that would be an aggressive

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goal, but I would say a couple of weeks after surgery I was up and about, a little stiff, not quite back to the gym yet, not lifting, but up and dressed and feeling like myself to the point that people would say to me, did you have your surgery? And I would say yes, and they would say, you don't look like you had any surgery, and I would laugh and tell them, don't make me take my clothes off and show you my scar because I have had surgery! But getting yourself up and getting yourself going, I think, goes a long way to recovery.

Foss How hard was all of this for your family?

Pattie I would say that it was harder on them than on me. I have a son and a daughter, and my husband, and I think they worried about me much more than I worried about myself. My daughter, being a new nurse, had just enough knowledge to know how it could have gone, so I think it was harder for them worrying about me and taking care of me, but that just motivated me more to try to get better, so that they would not have to worry about me.

Foss The big question that we always ask cancer survivors is how their life changed now that they are a cancer survivor, compared to what it was before.

Pattie I spoke at the Pink Picnic recently for Yale Cancer Center and I was thinking about just that question because I think that is a very important part. The first important part is that a phone call that you have breast cancer is not a death sentence, you can live through this, and then, what you take away from it is also very important. I do not see it is a negative in my life. I truly do think that I have emerged from my diagnosis very enlightened, and very enriched by the amount of people that have risen to take care of me and to love me and to do anything that I needed, and I was empowered with my own strength and the fact that I am able to give back to other people. You do not have to look very far to find someone who has it much worse, so that is how I have come out of it, realizing that even when I talk about my surgery, a lot of people have had it much, much worse, so I consider myself thankful.

Foss Can you tell us about the Pink Picnic?

Pattie The Pink Picnic was actually really nice. I was invited to come as a speaker. BJ's is doing a great job to raise money for different centers, Yale Cancer Center specifically, and I think that is an important way to give back to support the people that are raising money so that we continue to do research and to find the answers, so that women can continue to have options when they get this diagnosis. I was happy to speak at it, and happy to support somebody who is supporting this cause and always happy to do anything for Dr. Chagpar because, as I told her in an E-mail one day, my

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mom and dad may be the reason why I am on this earth, but she is the reason I remain, so I am forever thankful to her for what she has done for me.

Foss Can you talk a little bit about the whole issue of networking among other breast cancer survivors? Were you able to meet other women after your diagnosis and is that network active and working the way you think it should be working?

Pattie It is very active, and it definitely works. I think that it ebbs and flows though. It is funny because I have found myself meeting some women whose diagnosis on paper would have looked like me, exactly my path, and when I meet with them, I would find that they were not in as good a place as I was in and I'd feel guilty. I felt like I should say that I was worse than I was only because I felt so guilty that they were not having the same somewhat easy road that I felt I was having. But then, after the fact of talking to them, they would say that they were inspired by the fact that there was hope that they would get better by seeing me doing well. It is a little bit complex when we get together. It is complex, but I think we all feed off of each other, we all get something from each other, so it is a good thing, it is a good network and I talk to women now that are going into this procedure that I have had, and they have actually asked to see scars and I am more than happy to show them because I think sometimes when you see it, it's less scary than what you might imagine, so we are definitely there for each other and it is definitely a strong network.

Foss What kinds of resources are out there other than the resources at Smilow Cancer Hospital? Can you talk a little bit about what those are and whether there are other resources out there that you would recommend for women going through this?

Pattie I have to say it was one stop shopping for me. I am sure there are a lot of other things out there, but I found everything I needed at Smilow. Everything from people to places to get what I needed, to resources, just everything. Everything I needed was there, the connections with other women and I have gotten a lot through Dr. Fusi's office, through the plastic surgeon's office, a lot of women who have been through the procedure and have either been very successful or maybe they are having a bit of a tougher time and they are reaching out to you to hear your story, but you really can find everything you need to know right there.

Foss And do you recommend that women go to the internet?

Pattie For me I would say no, I think you can find anything if you look long enough, and you will either think you are dying or you will think you do not have it, so I do not recommend it, I am not comfortable with it.

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- Foss One of things that you have stressed in our conversation is the importance of the relationship with your doctor, and I wonder if you have advice for women in terms of finding the right doctor?
- Pattie Some of it for me is upbringing and my heritage. Growing up in an Italian household I was told to never question the doctor. The doctor tells you something, you do not ever get a second opinion, you do what the doctor says. I did not practice that in this insistence. Dr. Chagpar was the first that I found for a breast surgeon and I loved her immediately and trusted her immediately. I did search a little bit for my plastic surgeon, until I found one that was right for me, so I would say you have to find somebody that is skilled clinically, but also has that bedside manner that you can talk to because if you can't bring anything to your doctor, whether they are skilled or not, they are not going to be able to help with it, so you really just need to find somebody that you are comfortable with because it is a long process. I mean I just went for a six month check and I was anxious to go back and see Dr. Chagpar and to be quite honest with you, less concerned about what she was going to tell me and more anxious to go see this woman that had done this amazing thing for me, and the news was good at six months, but I have many more six months visits and I know whatever it is, if it is good I will celebrate with her, and if it is not good, she will get me through it.
- Foss How do you prepare for those scans, those follow-up visits where you are having something like a scan and you do not know the outcome of that?
- Pattie This was my first one, and it seems like it was just yesterday when I saw it coming up on my calendar, I just stopped thinking about it every day. And now I am starting think about it very day again because I need to go back for this check up, but I went in and again, she just puts you so at ease, she came into the room and the first thing I said to her is, look how beautiful the plastic surgeon did and I look amazing and forgot what I was there for, I was there finding out if I had another six months and I did, I got good news from her, but it is a little trying when you see that time come up on the calendar and it's time to go back again, but I think when you have success the first time, maybe it makes it a little easier. I always say, "I think I have got this," because that is how she makes me feel. She makes me feel like I have got it, as long as I stick with her and do what she tells me to do, I have got it.
- Foss: Do you believe that at any specific point in time you will not be worried about this? In other words, a year from now, or two years from now, or five year from now, or do you think that you are always going to worry?
- Pattie I do not know if I will never not fret about the six months visit. I may fret forever on that, but I can't say that I worry about it every day. I have actually been told by people that I do not give the disease enough respect, I am not sure what that means, but I do not want to really give it any more than what it has taken from me. It took the time it took for my surgery and my recovery and that

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initial worrying, but I am not going to live every day worrying about it. I did not worry about it until that point, and had no reason to believe I would get breast cancer, and I did. So I guess the worrying about it and spending everyday thinking about it is not going to prevent it from coming back. I will just have to do what Dr. Chagpar tells me to do that time.

Foss A lot of women make major lifestyle changes, they exercise, if they did not exercise they change there diets significantly, have you done any of that?

Pattie I have not done that since this diagnosis, but it is funny because I had done that a year or so before that. I just lost 50 pounds. I was eating better, I was learning to love the gym, so I thought to myself, this is an odd time for it to come when I am healthier than I have been in most of my adult life, but then somebody quickly said to me, but it is a good time for it to come when you are the healthiest you have been in your adult life. You are more able to handle that long surgery and that recovery. So, for whatever reason I made those changes a year before, I am thankful that I did. I find myself to be a little more adventurous, I just got back from a trip to Africa, I went bungee jumping off Victoria falls, and I tell that story because the gentleman that put me onto the edge of the bridge said, are you afraid, and I said, I had breast cancer, push me off the bridge and I jumped off the bridge and it was amazing, so I guess I am a little bit less afraid that you are going to step out into traffic.

Foss Now is that something that you would recommended for other breast cancer survivors?

Pattie It was amazing, I would definitely do it again, I would definitely recommend to live life because you never know, when you least expect it, there could be that call, so live life.

Foss Would you have done that before if you did not have breast cancer?

Pattie I do not think I would have, I have to say I got my diagnosis at 49 and within six months I went from never having a passport in my life to getting a passport, going to France, going to London, going to Africa, so while I do not like to think it changed me that much, maybe it did, it is easier for me now to yes, I am not going to wait till tomorrow and I am not too busy, yes I can do that today.

Foss Can you talk about a sensitive issue which is relationships when you have had breast cancer and you have had surgery, relationships with your partner and how that changes?

Pattie Absolutely, because that definitely does come up and my husband and I are married 28 years and it was funny because I made a lot of decisions in that office with Dr. Chagpar that first day and never thought twice, but other people obviously did because they asked me afterwards what my husband

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thinks, or even after my reconstruction I was so happy and people would say to me, what does your husband think or what will you do with your reconstruction, will you ask them to keep you looking the same or different, what does your husband think? And I thought that was such an odd question because in my relationship with my husband I never would have thought to ask him what he thought I should do with my body. I always assumed those were my decisions to make, and he would be there to support that, as he was, but again, whatever road you are on or whatever relationship you are in, for me it was never a question. I could have gone home with no reconstruction, or total reconstruction. He was completely supportive of what I decided to do and could not be happier.

Pattie is a cancer survivor. If you have questions or would like add your comments, visit yalecancercenter.org, where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.