Patient Perspective for Breast Cancer Awareness Month

Hosted by: Anees Chagpar, MD
Guest: Anne-Marie Rosaler

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Welcome to Yale Cancer Answers with Drs. Howard Hochster, Anees Chagpar, and Steven Gore. I am Bruce Barber. Yale Cancer Answers is our way of providing you with the most up-to-date 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 breast cancer awareness month, it is a patient perceptive with breast cancer survivor, Anne Marie Rosaler. Dr. Chagpar is an Associate Professor in the Department of Surgery at the Yale School Of Medicine and the Assistant Director for Global Oncology at Yale Comprehensive Cancer Center.

Chagpar So Anne Marie I thought you know this month, October, is breast cancer awareness month and a lot of people are hearing a lot of buzz about breast cancer. You have been through this journey. Tell us your story that starts with once upon a time I was perfectly well and then…

Anne Marie And then…In early December 2011, I was diagnosed with early stage breast cancer.

Chagpar How did that happen? Like did you go for a mammogram, did you feel a lump, did you have nipple discharge, like you seriously start from the very beginning, because a lot of people that is the fear that they have is one day they are going to be diagnosed, but how does that happen?

Anne Marie I was very diligent about having my yearly mammogram because of my family history. My mom had breast cancer when she was 70. She did not die of breast cancer, but she was treated for breast cancer when she was 70 and I was concerned that with my family history, it was the fact that I was also on hormone replacement therapy, that I was in a higher risk group, and therefore, I made sure that I get my yearly mammogram and I am very, very adamant about that. You know, any of my friends I speak to you have to have your mammogram regardless of what you read in the paper.

Chagpar Yeah.

Anne Marie Because without that, I probably would not be here today.

Chagpar Because that mammogram found it early, is that right?

Anne Marie Yes. What happened is that I had just retired and just prior to retirement, I decided to transfer all my records from Atlanta where I was working to Yale, and why Yale because I wanted comprehensive breast center one-stop shopping. You know I knew because of Yale’s reputation, it was really important for me to have the best of care and I had my mammogram in June of 2011 and in June 2011, I was told that I better come back in six months to have something checked and sure enough. In December, I went back and you found something that needed to be biopsied and I was biopsied and diagnosed with what is it called invasive ductal carcinoma.

Chagpar Yeah.
Anne Marie And, I was so stunned because this is something that happens to everybody but not you.

Chagpar Exactly.

Anne Marie And, at the time, I did not know what road I was going to be on and I think that is the worst part is just the anxiety, what does that mean and what reassured me was in fact the way I was treated immediately, and I have full disclosure by you in a very reassuring manner. At that time, my mother was hospitalized in a very grave condition in France and that was my major concern was taking care of her and you told me you are not going to let cancer rule your life. You are going to go but your life, we are going to take care of you and I was the most reassuring thing. The feeling that I felt cared for, that was responsiveness and empathy and that made a world of difference and of course the support of my family and my friends. I was lucky to be in that situation, to be retired also, that was a very positive factor because I did not have to worry about children and work, and I must say that even though I was terrified, I can say in retrospect that even at that time after I had surgery after I had radiotherapy that I felt I had optimum experience was you know having breast cancer that I could possibly have and for that reason, I felt that it was important that I share that message with other patients because the terror I felt quickly whatever spot is the wait, you know waiting for mammogram result, waiting for the MRI results, waiting for the pathology report, you do not know what it all means, you do not know what road you are going to be on and after I have been through all these, I can say that it has been a very, I hate to say, positive but it was the best possible experience I could have was my diagnosis.

Chagpar So, let us take as step back. You go for your mammogram, they call you back in six months. What was that like? What were the thoughts going through your head when they said, you know we see something, but it might be nothing, come back in six months.

Anne Marie I was not so concerned because I had mammograms every year and every time I was called back because I had dense breast tissue, so I had to have a sonogram, they saw something and every time it was a cyst and you know and so I was.

Chagpar Thought okay.

Anne Marie Everything okay one more time and so I was stunned and terrified.

Chagpar Yeah. So then you come back in December and they say now, now we need to do a biopsy, and you have that biopsy and you said the worst part is the wait. So, how long did you have to wait to get the results back, and how did those results get delivered to you?

Anne Marie Well, that was not so positive. That was the only negative thought in my whole experience - well I think it took may be three days for me to get the results of the biopsy and the way I received the results is by a message on my answering machine. I just come back from walking my dog and I find this message saying that I had to come in for an MRI.

00:07:44 into MP3: https://ysmwebsites.azureedge.net/cancer/2017-YCA-1029-Podcast-Rosaler_319688_5_v1.mp3
Chagpar  Hmm, and who was that from, from your family doctor or your ob-gyn.

Anne Marie  No, this was from the Yale.

Chagpar  From the radiology.

Anne Marie  Yes.

Chagpar  Yeah.

Anne Marie  And so I knew instantly what that meant, and this is when I tried to call back and I get another you know I had a leave a voice mail message, but I had and that is what I find really very positive in my experience at Yale. I had your email, and I emailed you and you responded immediately. Not only you did respond to my email, you called me.

Chagpar  Yeah.

Anne Marie  And so, I think that is really important for when your patient to have a medical team that is responsive and we understand that you know medical teams, your doctors and your nurse coordinators are dealing with many patients and are very busy, but it means the world to a patient to have that kind of responsiveness.

Chagpar  So, you get called back and they say you need an MRI, and at what point did they tell you that you have cancer?

Anne Marie  Well, when you called me back, you told me that I had you know breast cancer early stage and you were reassuring us you could possibly be and you also warned me that the MRI and that something I tell all my friends or other patients I speak to that you know an MRI can come back with alarming results, lot of false positive, which happens with me.

Chagpar  Hmm.

Anne Marie  Which meant that I had to have another biopsy, an MRI-guided biopsy.

Chagpar  Hmm.

Anne Marie  Which was also another way to another anxiety provoking experience.

Chagpar  Hmm.

Anne Marie  And at that point, actually, I said that is probably the time when I was most scared because the other breast was involved.
Anne Marie: And we were talking then about possible double mastectomy. One thing that you know when I was diagnosed, you told me all my options. I mean, you laid out all the options with all the possible outcomes, all the statistics and so basically it was my decision based on all the facts that you laid out in front of me and I opted for a partial mastectomy, but then when the MRI results came, there was possibility of a double mastectomy.

Chagpar: Yeah.

Anne Marie: And so I think that probably was the worst part for me.

Chagpar: Yeah.

Anne Marie: And but then when we got the results of the biopsy, it was better than we had anticipated, so it was. Yes, but I remember those times are as very...

Chagpar: It is kind of up and down.

Anne Marie: Up and down, and the wait is really and not knowing which road, I think once you are on the path of action meaning taking treatment, then I felt better.

Chagpar: Hmm.

Anne Marie: When I knew what the path was going to be, there was still you know waiting for the results of pathology report following the surgery but once we went ahead with surgery, then I felt much better.

Chagpar: Right, because you had taken action to get the cancer out.

Anne Marie: Yes.

Chagpar: And, at the same time, you were dealing with your mom who was ill in France. What was that like trying to go through cancer treatment yourself and still worrying about your mom?

Anne Marie: In retrospect, I think in a way it helped me. It took my mind off, you know, my situation.

Chagpar: Hmm.

Anne Marie: And that was losing your mom is you know a major, major event in one’s life and she was force of nature.

Chagpar: Hmm.

00:11:57 into MP3: https://ysmwebsites.azureedge.net/cancer/2017-YCA-1029-Podcast-Rosaler_319688_5_v1.mp3
Anne Marie She was also volunteer. She was the head of the nursing section for the Red Cross in Monaco for many, many years until she was 87 when she attended a conference in Osaka, Japan for the Red Cross, and when she came back she had a stroke.

Chagpar I am so sorry.

Anne Marie Yes, and so the last three years of her life were really tough and so she was hospitalized. She was 90 when I was diagnosed and she was in the hospital, and that was I think probably the most stressful part of it all.

Chagpar Hmm.

Anne Marie And in a way she helped me.

Chagpar Hmm. And I think the one thing that is really important for people to understand and our listeners who may be going through this is that you know breast cancer never you know kind of picks a date on your schedule and says is this a good time. It always happens when other things are happening. It is an unanticipated event, and you have to make sure that you live your life. Your breast cancer treatment is there to help you live your life but you got to live your life and take care of the cancer at the same time, but do not put off you know going to see your mom who is ill or going in and accepting you.

Anne Marie And I did not.

Chagpar Yeah.

Anne Marie And you were instrumental in that in pushing me to go on about my life.

Chagpar Right.

Anne Marie And reassuring me that you and the Yale team where there to take care of me and that is all.

Chagpar Yeah. Well, that is fantastic. We are going to take a short break for a Medical Minute and learn a lot more about Anne Marie’s story in honor of breast cancer awareness month right after this.
This is a Medical Minute about lung cancer. More than 85% of lung cancer diagnoses are related to smoking and quitting even after decades of use can significantly reduce your risk of developing lung cancer. For lung cancer patients clinical trials are currently underway to test innovative new treatments, advances are being made by utilizing targeted therapies and immunotherapies, the battle 2 trial at Yale aims to learn if a drug or combination of drugs based on personal biomarkers can help to control non-small cell lung cancer. More information is available at YaleCancerCenter.org. You are listening to WNPR, Connecticut's public media source for news and ideas.

Chagpar This is Dr. Anees Chagpar and I am joined tonight by my guest, Anne Marie Rosaler. She is sharing today her story of survivorship with us in honor of breast cancer awareness month. Right before the break, Anne Marie, you were telling us about how you actually went back to France, right in the middle of all of your treatments. Tell us more about that.

Anne Marie In fact I was diagnosed in December and surgery was scheduled for the middle of January and in consultation with you, we agreed that we could postpone it to early February so that I could be with my mother and I went back and I spent about three weeks with her. I knew at that time that it was the end, but I could not stay any longer, so I came back for the surgery and I think three days after surgery, she passed away. And so when I called you and I said can I go back for the funeral and you said yes. So, I went less than a week after surgery, I went back to France for the funeral.

Chagpar Yeah.

Anne Marie And at that time, I did not have the results of the pathology report. I know you saw when I came back. After I came back, we got the good news which were that I would require treatment of radiotherapy, no chemo and that was a huge relief. And I went and met with the radiology, the oncologist who agreed that I could have the treatment close to me, because I would live about an hour and 20 minutes away from Yale, which I did, and I was so grateful and so relieved that to me going you know to my daily treatments was felt like a gift in a way.

Chagpar Tell me more about that.

Anne Marie To be honest, I was very worried about chemo and so the fact that I did not have to undergo chemo was a huge relief for me.

Chagpar Hmm.

Anne Marie And, yes I experienced you know like severe sunburn but other than that, I was fine.

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Chagpar Yeah.

Anne Marie I was fine and I was fine also because I felt things were slowly returning to normal. I was also grieving for my mother, so you know things do get back to normal.

Chagpar Yeah. I am so glad that you went back though and were able to spend some quality time with her before she passed.

Anne Marie Yes, but that was really a tough part, because I know she was dying.

Chagpar Yeah.

Anne Marie And, I could not be with her when she passed.

Chagpar Yeah.

Anne Marie So, that is something that I you know I deeply regret, but my brothers were with her, so that is my consolation.

Chagpar Yeah. And so you went through radiation treatments and you got back to normal. Talk more about that because a lot of people who may be looking at breast cancer and facing breast cancer may wonder whether things ever get back to normal.

Anne Marie Well, haha, they do, and it feels wonderful.

Chagpar Yeah.

Anne Marie Back that, you know it made me realize that you cannot ever take normal for granted.

Chagpar Hmm.

Anne Marie And that was, I mean, I think it was in a way wonderful feeling to get back to normal, so such a relief and things do get back to normal and normal feels amazing as the way it felt and I always that is why I decided to volunteer.

Chagpar Yeah.

Anne Marie Because I had that feeling that yes you can be terrified, you can be you know over, I mean have so much anxiety, but it will pass.
Chagpar Yeah. Tell us more about that, because I think it is so amazing and we are so grateful to see how patients you know they go through this time of tumultuousness with their own breast cancer journey and then they really want to give back in a positive way and you have really made a difference to a lot of patients. Tell us more about how that happened, how you made the decision to volunteer and what that experience has been like for you.

Anne Marie It is strange because I mean just I wanted to volunteer because I just retired and I knew that that was one of the things that I wanted to do was to volunteer, but I was not sure in what capacity. I thought Red Cross maybe and this was a natural.

Chagpar Hmm.

Anne Marie Because I felt I had such a positive experience or the optimum experience I would say I could have and I had felt so good and I saw these volunteers you know when I came pretty much every week or every two weeks at Yale and that it felt like a normal thing to do and when I remember meeting with the volunteer coordinator Annie Capland and she actually said to me very point blank she said are you sure you want to do this?

Chagpar Hmm.

Anne Marie She said a lot of patients that want to have anything to do you know with coming back and I said I need it. I felt it was a need, it was therapeutic for me because it kind of normalized the whole experience coming every week to see the team who cared for me but to also speak with other patients and try and help you know with my experience to reassure them that yes, things do get back to normal and it does feel wonderful.

Chagpar Yeah. And I know that a lot of patients really are so grateful to have other patients who have gone through it kind of helping to chaperone all of the other issues. You know you have got your surgeon telling you about the surgery and the radiation oncologist telling you about the radiation, but having another patient who has lived that journey and gone through the ups and downs in the rollercoaster of emotions must be so wonderful.

Anne Marie You know, I do not feel like I am doing very much, but sometimes I come across a patient and we hit it off and I have actually become friends with some patients, and when you are hit with the news, it is just so overwhelming and I remember getting that big binder.

Chagpar Hmm.

Anne Marie With a ton of information. I do not know that if any patients actually go through the binder. I know there is also a nurse coordinator, there is a social worker, there is a complimentary services, so there are lot of resources, but that is just so much. So it is good to be you know to speak to another patient who actually tells you, you know, what has helped him or her.
Anne Marie And for me, being with other patients speaking with other patients has also been helpful.

Chagpar Yeah, and then you went off and became a Zumba instructor.

Anne Marie I mean, I have always been a dance lover.

Chagpar Hmm.

Anne Marie So, I always tried to take as many classes as I could always and I discovered at my local gym that was in 2010, I discovered a fitness program called Zumba and I thought this is for me, I love it, and what was becoming really frustrated because they kept cancelling classes and I said the only way for me to do this on a regular basis is to teach, so I became a licensed Zumba instructor and it was so helpful in my recovery also, physically and emotionally, that I thought it might not be a bad idea to share that with other patients and that is how I decide, you know I asked if I could teach as a volunteer a class for patients and I have been doing that now for two years.

Chagpar Yeah, and do patients love it?

Anne Marie Yes, they do. Those who actually are adventurous. Haha.

Chagpar Haha.

Anne Marie Because Zumba scares a lot of people if it is too violent, too intense, but.

Chagpar It really is not.

Anne Marie It is not, because you adjust the intensity and I actually became the Zumba gold which is low intensity Zumba for that purpose so I could go back to Smilow - this is really no impact gentle Zumba as you have gentle yoga, and I have been enjoying it very much and the patients I think. You know it is a small group, but they are regulars and they like it a lot.

Chagpar Yeah.

Anne Marie It is Zumba therapy really.

Chagpar Yeah. You know I take Zumba at a local gym here too and I love it. It would be so nice if the healthcare workers could also take your Zumba class.

Anne Marie Yes, they also say they would love to, but they do not have time because they are working.
Chagpar Yeah, that is right, but talk a little bit about you know in survivorship one of the things that we talk about a lot is not only getting back to normal, but getting back to physical activity and exercise and so I thought that your idea to bring Zumba to patients was such a wonderful idea to really get people active to help them to exercise, to get down to ideal bodyweight. These are all things that a lot of breast cancer patients struggle with.

Anne Marie Yes, and you know when patients come to Zumba class, I also tell them you know if you do not like Zumba, I mean find something that you love to do. I think what is really, really important both physically and mentally is just moving. It is not to stay still ever, is to move, move, move, move. For me it is crucial and I hope that you know even patients who have come and loved it but cannot come back and I encouraged them to find classes at the Y or their local gym or to find something that they love doing, whether it is walking, cycling, swimming, you name it, just hiking. For me, walking my dog also has been very important.

Chagpar Yeah.

Anne Marie I walk my dog for an hour every day and physical activity and basically doing what you love.

Chagpar Yeah. And I think the other thing that you really engender in people and in patients is having a really positive outlook on the world. There is never a time I see you when you do not have a smile on your face.

Anne Marie Well, I mean one thing that cancer has made me realize first of all, which was very humbling. You realize that you do not know what it is like. You know, you may have had many friends and I do unfortunately have many friends who have dealt with cancer and not only breast cancer. You do not know what it is like until you deal with it yourself.

Chagpar Hmm.

Anne Marie And so, it made me realize you know how tenuous and how fragile, I mean normal is and I say to all my friends you know do not let this small stuff bother you.

Chagpar Yeah.

Anne Marie You know, you have to live your life with a vengeance and kindness is a lot easier in my opinion. Being kind and smiling is so much easier than being nasty.
Chagpar Yeah, and the number of patients that I have had who really have taken that outlook of a new outlook on life that it is precious and things that maybe scared them before, they will now take on or bad relationships that they were in, they now get out of or good relationships they get into and there is kind of almost metamorphosis that cancer has that really is very as you called it in our last segment positive. Talk more about that. How is cancer a positive experience because a lot of people who have not experienced yet think it is the end of the world but so many cancer patients come out of it and they say you know what, I did not like having cancer, but it was one of the most positive things that could have happened to me.

Anne Marie Yes, and you know I hesitate to say positive, but for me and you know I have full disclosure, you know because of my own personal situation being retired and having a lot of family support and friend support, having really top notch scare, it was still positive because it made me realize, you know that my life can, any life, can turn on a dime and so just treasure.

Chagpar Hmm.

Anne Marie Treasure you know everything that is good about your life and treasure your friends, your family and do everything that you love with a passion.

Anne Marie Rosaler is a breast cancer survivor. 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. You are on WNPR, Connecticut's public media source for news and ideas.