



Interview Transcript: Marla

Marla is a physician, writer and onair health journalist.

Type of Cancer: Breast

Age at Diagnosis: 48

Year of Diagnosis: 2004

Treatment: Bilateral Mastectomy, Total Hysterectomy, Chemotherapy, Radiation Therapy and Breast Reconstruction

Date of Interview: January 2010

My name is Dr. Marla Shapiro. I was 48 when I had my routine mammogram and I was diagnosed with invasive breast cancer. I went through eight rounds of chemotherapy. Following the chemotherapy, I had bilateral mastectomies. Both my breasts were removed and I started a process of reconstruction. In addition I had a complete total hysterectomy and bilateral oophorectomy, both my ovaries were taken out. It's almost as if any body part I could possibly get rid of, I said goodbye to, that I no longer needed or I no longer felt were my friends.

From doctor to patient

Being a physician was probably the best thing and the worst thing simultaneously. People ask me if it was easier because I was a physician. The only thing that was easier is that I understood the technical language. That's what was easier. The worst part of it was that as a physician I could only think of the worstcase scenarios. I could only think of the exceptions to the rules. I could only see the dark side. Not because I'm a dark person, but because I've just walked in this field way too long. And that's not to say that I was expecting a bad outcome but it was hard to be reassured. Much, much harder to be reassured when you've seen... it's like looking at a diamond. You don't just see the front facet, I've seen the side, the back, the angles, the upsides, the downsides. I've seen it all, so it was very hard to reassure me and that made it impossible for me. That I could find no space where I could feel calm at the beginning. I was like anyone else, whether I was a patient or a doctor, fear was the predominant emotion.

Uncertainty

In the world of cancer there often is no certainty. There isn't even any certainty sometimes about which treatment protocol you should take. You can be offered this or you can be offered that because a physician feels that both of those treatment arms will give the same results. The uncertainty of making a decision, even though I live in a world of uncertainty as a physician—the timeline of having to make a decision relatively quickly, and recognizing that once the information is presented, all you can do is then reach inside and let part of the emotion of who you are help guide you. And that, for me, was difficult to do because I am very much an evidence-based physician and when there was no evidence to clearly say do this or do that, I recognize that I then had to figure out what felt right for me.

Big decisions

The decision to have a bilateral mastectomy was not easy. There was a lot of evidence that pointed in terms of this being the right decision for me and my situation. Emotionally, I talked to my husband and his attitude was, "You're going to do whatever it takes to keep you alive, you're going to do what's best for you." He came to all the appointments. He's not a physician. It's difficult for him to listen to sort of what sounded like mutilating surgery. And it is mutilating surgery.

My options afterwards in terms of reconstruction, which I chose, and the type of reconstruction you can have... decisions, decisions, decisions, decisions, and more decisions. It's so damn overwhelming. You know, I'm... never was someone who defined myself by my breasts, I'm way more attached to my brain and my ability to do the things that I love to do. But even having said that, it's not easy to make the decision to take both your breasts off. And I spent a lot of time talking to women who had bilateral mastectomies, which is, I think, a really good thing to do. Women showed me what they looked like without implants, women showed me what they looked like with implants, different types of implants, and that was helpful. But no matter how helpful it is, it's not easy. Don't expect it to be easy. I don't think it's supposed to be easy.

It's MY cancer

I remember one day where I was particularly... all those bad things that I was and just impossible to live with and very selfpitying because this was happening to me. You know, where my husband looked at me and said, "You know, you have cancer but you don't have to be such a witch." And it was a good thing for him to be able to say to me, "You know, we're living with this too. So you don't—the more that you withdraw and the more that you push us away, the more impossible it is for you, and certainly the more impossible it is for us." That, those types of moments were I began to realize that I was being incredibly selfcentred and selfish... I thought I was rightfully selfish: this was MY disease, I was the one having the biopsies and the surgeries, and I was the one with the chemotherapy and I was the one with all of the side effects, I was the one with the joint pain, I was the one going bald and lost my eyelashes and all the other horrible things that happen to you. But it was happening to them too. They were these passive bystanders who couldn't fix it for me, and wanted to fix it for me.

Thrifer, not survivor

Do not think of yourself as a survivor, think of yourself as a thrifer. You've been given this experience, one you wouldn't ask for, you're through the technical aspects of it, you're never really through it because you always have your checkups and you have the fear of recurrence and all the other things that come with the uncertainty of the uncertainty. The only thing that's certain about cancer is that you're uncertain about what's ultimately going to happen. But I didn't want to live there, I didn't want to live that way.

You can choose to make that the focus of your life or you can choose to not make it the focus and I think it's like anything else. When you are first diagnosed you can't get out of bed in the morning without the diagnosis physically smacking you in the face. Eventually, as time goes on, it's sort of not so much in your face but it's sort of beside you. And then it sort of gets to be a bit behind you. And then eventually, as time goes on, you find yourself getting up not thinking about cancer at all. Maybe days or weeks or even months that you don't think about cancer

until someone mentions it or you have an appointment or someone else's experience makes you think about it. But that's what happens. Time sort of pulls it from here, back there, which is where it should be, and allows you to not see it every living waking breathing moment like you do at the beginning. Because at the beginning, it's all there is.

Advice

And I think the best advice that I can give people is to feel your fear, meet your fear and try and leave the fear a little bit to the side. Don't let it define every single waking moment. Recognize that you've got a team that's there to help you with treatment and that you're on your journey of treatment, which is really important. You've gotten the diagnosis; OK, you've got the diagnosis and now you're going to move forward and you're going to move forward with the treatment and you're going to keep the lines of communication as open as you can with the people who treat you. Don't be afraid to ask any question, there's no question that's dumb, there's no question that you shouldn't ask and there's no thought that you shouldn't speak out loud. It's the thoughts that you don't speak out loud, that you keep buried inside, are the ones that are going to eat you alive.

And I would tell you that you have to recognize, although it took me a long time, that this is not a journey that you take alone. Let the world in, don't shut the world out waiting for this to be over and for life to be normal. Accept that this is where you are right now and accept all the support that you possibly can and don't just focus on the physical things that are happening to you. You need to talk about the emotional things that are happening to you and you need to recognize that this isn't only happening to you, it's happening to everybody else who loves you, around you. So, feel your fear but give yourself permission at times to put it aside, because there is a lot more ahead of you and you need to be present.

One more life experience

I said at the very beginning that I didn't want breast cancer to define me, and I don't think it has defined me, but it certainly has refined me in some ways and changed me in terms of who I am. How can you not have any life experience not impact on how you change, be it a breast cancer experience or a cancer experience or any time where you feel like your life is being threatened. With time, I began to recognize that this is one more life experience and that it is going to definitely change how I'm going to look at the world, make a difference in terms of who I was and I had to accept it, I had to go with it, I had to stop being angry at it. I had to move forward.