BREAST CANCER

A Husband's Perspective

by

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Note: This article is dedicated to my wife, Sandy, who has been through it all and who has allowed me to grow and understand what healing really means. This article is the product of a great deal of discussion between us.

Seven years since my wife had been diagnosed with breast cancer. Seven years during which she went through radiation, chemo, a lumpectomy and more follow –up visits then either of us care to remember. To quote my wife, I have had more people touch my breasts in the past seven years then I thought legally permissible. Breast cancer took over our lives, it was the topic of our breakfast, lunch and dinner conversations, it followed us into the bedroom and it became the unwelcome guest on our vacation. It would not go away. It was several years before we began to live again. We were back at the gym, my wife was doing her Pilates, we were working, traveling and enjoying life. We had pretty much moved Breast Cancer to the back burner – when - in July of 1991 it all came crashing down. Breast cancer was not finished with us.

I was sitting in my room at the Hyatt Westlake hotel in Thousand Oaks California, when my wife called. I knew something was wrong as we never talked this early. No sooner had we said hello then my wife informed that the results of her most recent follow- up exam were not good. It appeared that Cancer had returned this time to her left breast, Stuck in California there was nothing I could do, except try to be reassuring and let her know I would get the first flight home on the following day. My wife, however, was clear, that I stay and finish my work as there was nothing I could really do to help. She would call the surgeon and get us an appointment for the following week. We spoke several more times that evening and again on the following day. We were scared as we both felt we had seen the last of Breast Cancer. We had six years of clean check-ups and neither of us thought this one would be any different. Now it was back to the surgeon and the oncologist. We knew the drill and it wasn't pretty.

This time a lumpectomy would not be sufficient. This time my wife would need a mastectomy as she would the following year when cancer paid a return visit to her right breast.

- 4/23/92 "Infiltrating Duct Carcinoma Right Breast"
- 7/25/91 –" In Situ Carcinoma Left Breast"
- 5/11/84 "Lobular Carcinoma in Situ Right Breast"

Do not underestimate breast cancer it will be life altering for you both. It is the challenge we, as husbands, lovers and significant others face when breast cancer strikes. How do we help and what should we do? This article hopes to answer that question. I am not suggesting that we did all of the following, some we did, and some we did not.

THE DIAGNOSIS

It comes at you in stages: first, the radiologist (mammogram), the biopsy and then the confirmation after the biopsy. There is nothing worse than hearing the radiologist say that there may be a problem or the surgeon saying it is malignant. As her partner, you need to be there. It's not a time to send your wife's sister, mother or a friend while you are away on a business trip. Texting is not helpful and Skype and Face Time are not much better. Do *not* treat this as just another doctor's visit. It is not. For the biopsy, have someone in the waiting room with you. Do not go alone. If it is bad news, you will need a shoulder to lean on and that will not come from your computer, smart phone or I Pad. You will need a real person, someone who cares about you both and if at all possible has been through this. I did not have someone with me and it was a big mistake. I was lost. If not for the surgeon who was not only a great doctor but a first rate human being, I am not sure how I would have made it through that day in 1984.

COURSE OF ACTION

At this point, several decisions have to be made. First, the course of action, second, the doctor and third, the hospital. These issues are interrelated and it is hard to separate them. Although the surgeon usually dictates the hospital, he or she may have privileges at more than one; in that case, pick the one best for you. We selected one known as ideal for this type of surgery. As for the surgeon, we decided to stay with the man who did the biopsy. We liked him and his sense of caring and concern around the biopsy convinced us he was the right choice. Future events served to validate our initial assessment.

It is very likely that you will hear a variety of opinions about the appropriate course of action. You will need to evaluate lots of data, much of it conflicting. Even the doctors will not agree. The Internet was in its infancy when my wife faced breast cancer, and now there is even more data, books and web- sites ready to answer your every question.

BASIC GUIDELINES -

- <u>Be an active participant</u>. Don't make it seem as if this is your wife's decision and hers alone. Both of you will live with the aftermath. This is not a time to be emotionally and physically absent. And remember, being a participant is not done via social media. It requires your physical presence. Nothing less is acceptable.
- <u>Research!</u> Read everything you can about the disease. Pay particular attention to that data that most relates to your wife's situation. If her cancer was caught early, make sure you collect data about early breast cancer.
- <u>Selecting the doctors</u>. Come to meetings with the doctors well prepared and knowing what questions you need answered. If the doctor is not willing to answer your questions in detail, he or she is probably not the person you want to get involved with. It is not only the doctor's technical skills that are important. Is their personality consistent with what is important to the two of you? Is the chemistry right? Remember, there are many very good surgeons. You don't necessarily need the most well known or the "biggest". Once we determined that several of the surgeons we spoke with had the requisite skills to do the surgery, we looked for the one with whom we felt most comfortable. He became our surgeon and a great deal more over the years, as he was someone we trusted and could talk with. He always had time to spend with us. The same was true of the oncologist.
- <u>Talk to others</u>. You probably have more friends than you realize who have been down this road. Meet with them. Make sure the husband or significant other is involved and talk with them about your fears and concerns. Try to find people who have used the doctor you are considering.

THE SURGERY

Reality sets in, it is. your wife's breasts that are in jeopardy - the breasts that have given you a great deal of pleasure and enjoyment, that have nurtured your children and, most importantly, been an integral part of your wife's persona, are now at risk. No matter how minor the surgery, once the radiation is finished, your wife's breast or breasts will never be the same. Don't think otherwise. This period will require the most from you. It is long and difficult. What should you do?

- <u>The bandages</u>. Be there when the bandages are removed and be ready. If it is a mastectomy, it will not be pretty. It will be tough on your wife. She will need all your support. Prior to having the bandages removed, prepare yourself by speaking to the surgeon and with others who have been through this. This is a time to be experienced only by you and your wife - a very personal and private moment - as intimate as it gets. Clearly the surgeon will be present and you might find it helpful if a counselor is present or available. No friends and family not at this moment. There are no magic words for this moment, only make sure to communicate your love and caring.
- Go for counseling. Probably the biggest mistake we made was not going for counseling after my wife's initial lumpectomy. We both figured the breast cancer was caught early and only involved a lumpectomy and radiation - not a serious problem. We figured a good vacation would take care of everything and went off to the south of France, my wife's favorite place. Big mistake! This so-called vacation became two of the most difficult weeks we ever spent together. We eventually came to realize that we had not really dealt with all of our feelings and concerns. On the surface all seemed good but that was far from the reality. That our marriage survived continues to amaze both of us. You should both seek counseling, and it is wise for your wife to go to an allwomen's breast cancer group. My wife eventually found a hospitalbased group run by a psychiatrist that proved to be the turning point for us. I should have gone to a husbands' group, which would have helped me more fully understand and appreciate what my wife was experiencing. We should also have found a couples' group, which would have allowed us to discuss what we were going through and to understand the impact on our relationship. .
- <u>Go to the follow-up appointments</u>. There will be many, both with the surgeon and, if chemotherapy is involved, the oncologist. Be at as many of these as you can. On several occasions I couldn't attend and friends went in my place. This seemed to work, but it would have been better if I had been able to attend them all. Being there would have allowed me to more fully appreciate what was happening and to be more supportive.

- <u>Return to work</u>. We convinced ourselves that my returning to work was critical and so I did. This was one of our better decisions, as it brought back a sense of normalcy to our lives. More important, it gave us a second topic of conversation -- breast cancer now had a competitor for our time. I did cut down on extended business trips so that I could be home at night, but I was not able to be at some doctor's appointments. It was difficult for both of us. For me, I was away and feeling guilty and my wife did not have all the support she deserved.
- <u>Hire help</u>. You cannot be sure how people will react to chemo. My wife did not have much trouble, but at the beginning, having an LPN available when she returned from her chemo treatments and for several days after was very comforting. They were helpful and knowledgeable and helped us to put things in perspective.
- <u>Making love Part I.</u> As with everything else, this will not be easy for either of you. Be as loving and supportive as you know how. Anticipate a new state of normal. Whatever happened in the past is not likely to be today's norm at least not right away. The nature of the issue will be a function of how much surgery your wife underwent. For us, the lumpectomy and radiation were not as difficult as the mastectomy. With the former, my wife's breasts were still in place, albeit feeling and looking different. The mastectomy was an entirely different story; neither of us was comfortable at first. In a way we were like two teenagers exploring sex for the first time.
- <u>Making love Part II</u>. Be clear about your own feelings. Talk about how you both are feeling. Are you comfortable looking at your wife's or significant other's new chest, one that is missing a breast or maybe two? Is she comfortable being naked in front of you at this most intimate of moments? Don't kid yourself that everything is the same it's not. Don't push. This isn't a one-night stand. Allow your wife to find her own pace and keep talking.

CONCLUSION

It is important to remember that your wife's recovery is operating on two levels. The easiest to see and understand is the physical. Healing is moving along - but don't let the fact that the bandages have been removed and the doctor says that everything is fine fool you. There is a separate track, (and probably a far more important one) that is going on in your wife's head, and that will take a lot longer to heal. The physician will take care of the first but it will be up to you to ensure the success of the latter. This is a journey that you need to traverse together, with understanding, sensitivity and love.

RESOURCES

To aid in your search for help and guidance we have listed some of our favorite books and websites. This list is not meant to be all inclusive. The internet is replete with websites and Amazon and Barnes and Noble have dozens of books. Among our favorites are;

<u>Books</u>

Breast cancer husband: How to help your wife (and yourself) during Diagnosis, Treatment and Beyond, by Marc Silver and Frederick Smith, Rodale Press, January 2004.

Just get me Through This! The Practical Guide to Breast Cancer by Deborah Cohen, M.D. and Robert Gelfand, Kensington Press, May 2000.

Dr. Susan Love's Breast Book: 4th edition 2005: Da Capo Lifelong Books, September 2005.

The Breast Cancer Survivors Fitness Plan (Harvard medical School Guides); Carolyn M. Kaelin, Francesca Coltera, Josie Gardiner, Joy Prouty.; McGraw Hill; August 2006.

Web Sites

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Breast cancer research foundation - http://www.bcrfcure.org

Susan G. Komen For the Cure- http://cms.komen.org

American Cancer Society - <u>http://www.cancer</u>.org

National Cancer Institute- <u>www.cancer.gov/cancertopics/types/breast</u> This site has just about all the medical information you will need.

Webmd - <u>http://www.webmd.com</u>. Go to the health center on breast cancer. A very helpful site.

My treatment decision-<u>http://www.mytreatmentdecision.com/ -</u> A very personal website that highlights individual women and the decisions they made.