



WomenStories, an Organization Which Created an Original DVD Series for Breast Cancer Patients, Designed to Provide Psychosocial Support

By Roslyn Romanowski, MD and Miriam Dow

MISSION

The mission of WomenStories is to inspire, inform and support breast cancer patients by documenting and sharing survivors' experiences.

HISTORY

WomenStories was founded in 1998 in Buffalo, NY when a small group of breast cancer patients found little psychosocial support available for them in the area. They envisioned a series of videos addressing different, non-medical issues of importance to breast cancer patients, which could be distributed to help other women. The video project was launched, and over the next 7 years, 10 separate programs were produced. Titles in the series include Initial Discovery and Diagnosis, Family Support, Intimacy and Chemotherapy, among others.

PRODUCTION

The video series was filmed with breast cancer survivors and their family members. Most women were from western NY, and efforts to achieve diversity were made throughout, for broad appeal. Distribution of videos began as soon as the first ones were completed. Outreach to local physicians, organizations and insurance carriers was the first step, followed by national efforts. Interest in the series is growing among educators, and it has been used in nursing and medical student education.

FUNDING

Funding has been solely through gifts from individuals and grants from corporations and foundations. WomenStories is a non-profit organization. Recently the video series was transferred to DVD, and all 10 programs fit on 2 DVDs. This has eased distribution, which is already international. The series is also available as streaming videos from the WomenStories web site.

CONCLUSIONS

Studies have shown that cancer survivors feel an increased need for non-medical and emotional support, a need which is not met by medical sources. The WomenStories series addresses this need in a way which makes psychosocial support available to a broad range of women, in many different communities. Future plans include longer versions of the programs, revised for closed caption broadcast on public television and translation into other languages. WomenStories is an example of a patient-inspired, patient-executed project which is successful at offering non-medical psychosocial support to women with breast cancer.

REACTIONS / RESPONSES

Evaluation findings from Memorial Sloan Kettering:

- The videos remove a sense of isolation and help the survivor watching it understand that she is not the only woman who has ever been diagnosed with breast cancer.
- The videos show strong-willed women who have progressed through various treatments and have found a new sense of purpose and way of living. By hearing the women speak, the viewer learns first-hand that it is possible to move beyond fear and anxiety and not let a cancer diagnosis control your life.
- Seeing the diverse range of women in the videos (in ethnicity, race, age) illustrates that unfortunately breast cancer can affect any women.

"We have found that using real patients conveys a story that the newly diagnosed patient can relate to in her decision-making process and also provide a powerful sense of hope and understanding. Good luck on a very exciting and worthwhile project!"

*S. Eva Singletary, M.D.
Chief, Surgical Breast Service
MD Anderson Cancer Center
Houston, Texas*

"This is an innovative, long overdue project, which I feel is extremely valuable in the community at large. As a cancer surgeon, I know the psychological and emotional aspects of cancer diagnosis are often overwhelming. Professional counseling from physicians and nurses is helpful, however, women often feel isolated and alone in their decision-making process. I feel that the ability for women to view other women going through the same issues as they are by whatever media is available will become invaluable in everyday practice. WomenStories has the commitment, the energy and the know-how to do this."

*Rosa E. Cuenca, MD
Surgical Oncologist
Northeast Texas Oncology & Reconstructive Surgery, PA
Mount Pleasant, Texas*

Available on line or on DVD at www.WomenStories.org

Titles in the WomenStories Series

Initial Discovery & Diagnosis of Breast Cancer

"She [the doctor] treated the whole family. And I think it was really, really important because it wasn't just me dealing with cancer. You know, there were three people in the house that were dealing with it at the time."



Family Support

"You have to follow their lead in terms of what it is that they want. You can't give a person something that you think that they need. You know you just have to be a family."



Intimacy

"I also began to define my own sexuality and I had to do that in order to feel sexual, and I'm still in the process of doing that.

What does intimacy really mean to me? What is my sexuality really about? And focusing on the kinds of things we do for each other on a daily basis, that are not so sexual per se, but they are so much a part of what makes us complete and what makes us intimate."



Surgical Choices

"When I look at it every day and at first I thought, oh my god I have this ugly scar but it's not ugly it's beautiful."



Young Women and Breast Cancer

"My diagnosis was unusual because I was so young, first of all, I was only twenty-four and I had started bleeding from my nipple and when I went to my doctors they told me it was normal, it was just hormones and I didn't believe them.

After months of fighting for more testing they finally did a biopsy and realized that it was cancer but this whole process took about a year to get the actual biopsy done and then I had to have a total mastectomy by that time."



Chemotherapy

"Those 45 minutes of my first chemotherapy session was probably the loneliest time of my life... But all of a sudden, I thought of all the things before me - How I lived, where I was, what I did... Even though it was the loneliest time, because I had to take this myself and I only could take it, no one could help me. It opened me up to wish that I could make the most out of this experience."



Recurrence & Metastasis

"A cancer diagnosis for me was hugely eye opening. I envisioned this decade starting at age forty as the next chapter for me in my personal growth and development and so the cancer diagnosis and, really what has been ten years of constant new diagnoses because I would say every two years there's been a recurrence of some sort, has just demanded that I live in the moment and because of my nature and my dreams it has encouraged me to seize each moment and just go for things, not second guess myself and not procrastinate, no time."



Hormone Treatment

"I learned about myself that, like it or not, I can take more negative things happening to me than I ever thought possible... What I found was by it being dealt to me hand by hand, card by card, I could play one card and then go on to the next, and then some of the cards were positive ones."



Radiation

When I was told that radiation was part of my treatment, I do not want to say I was thrilled, but I was happy the more things that I could do to try to get rid of the cancer that was inside of my body... I felt proactive by doing more and not so helpless in terms of being able to fight it.



Life After Breast Cancer

Cancer is not the end of the world. Cancer is not the end of your life. And having cancer doesn't mean that you can't reach other people, you can help a lot. You could be useful. You could do things to make other peoples life better. Cancer won't take that away from you, and the only regret that I have from cancer is that it took away my dancing and my sweets because I developed diabetes after that. But even though, I don't regret not to dance, because I could teach other people to dance.

