

The Heart That Keeps on Going

Nancy Friis-Jensen RN, CNOR

Frederiksberg Hospital, Denmark

The Heart Pillow is a project designed to help breast cancer patients. But it is much more than that. It is a story of women helping women and a story of a network that crosses many boundaries, venues, and settings. It is stories inside of a story.

The origin of the heart pillow is unknown. This network started when Janet Kramer-Mai, an oncology nurse at Erlanger Medical Center in Chattanooga, Tennessee, was diagnosed with breast cancer in 2002. Three of her aunts from Indiana made and sent her a heart shaped pillow to use after her surgery. The pillow fits comfortable under the arm and relieves pain from the surgical incision, protects against accidental bumps, helps ease edema and relieves shoulder tension. Exactly where the aunts received the pillow is unknown. Janet was helped so much by this simple idea, that she started the project at her hospital with volunteer groups making the pillows which are given immediately to the patients post-operatively.

The next chapter of the story was written when I attended the 2006 AORN Congress in Washington D.C. Though I live in Denmark and work in a urology operating room at Frederiksberg Hospital, I was born and raised in Chattanooga. During my trip to the USA, I took the opportunity to visit family. At the request of one of our doctors, I visited my old work place, Erlanger Medical Center and Janet very graciously agreed to talk to me about breast cancer treatment there. She gave me the pillow and highly praised its benefits.

Upon returning to Denmark with the pillow, I could not stop reflecting on the near contact I had experienced with breast cancer. A 38 year old colleague, who was a mother to a 3 year old girl and just given birth to her son 3 months prior, was diagnosed with breast cancer in

2002. I remembered the pain and lymphedema she suffered after surgery and the enormous feeling of helplessness I had unable to do anything for her. I really wished I had known about the pillow then and felt that this gift I had received should not be taken for granted.

My first contact was presenting the project to the American Women's Club in Denmark (AWC Denmark), a non-profit organization. They were very positive, supportive and willing to help. Since I felt it was important for the women to receive the pillows immediately post-operatively, and because my hospital does not treat breast cancer, I contacted our sister hospital, Rigshospital University Hospital, which operates 500 breast cancer patients a year. We agreed on a 10 pillow trial in August 2006 which was very successful. This began the continuing story of the heart pillow in Denmark.

The pillows were unbelievable popular to the point of some women requesting the pillows when they were first admitted. The power of "word of mouth" in our network system was really surprising and has been a major component of the project. AWC Denmark agreed to continue to help with making the pillows, giving financial aid and promoting of the project in their newsletter. A "pillow talk" group was organized and meets once a month to work on the pillows while enjoying each others company, refreshments, and discussing everything from the latest movies to the world situation.

In 2006, a representative of AWC Denmark attended a conference of FAWCO, Federation of American Clubs Overseas, with over 36 country members worldwide. She had a Danish newsletter with her which was read by a member of AWC Greece. This started a whole new story, and thru this network, the project has extended to Greece, Sweden, Norway, Finland, Rome, Vienna, Saudi Arabia, Kuwait, Lebanon, Amsterdam, and San Francisco.

Additional funding was supplied in October 2007 from Pink Tribute, breast cancer support association, which enabled the project to start at a second Danish Hospital, Herlev University Hospital, which also operates 500 breast cancer patients a year.

The project has been mentioned in two newspaper articles and four journals in Denmark. This has led to projects now being organized at five other Danish Hospitals plus many individuals helped with a pillow, including as distant as Greenland. Project starts are also planned in France and Mexico. Many new venues have been opened with individuals and new group involvement such as patchwork clubs, senior citizen groups, and Lion Clubs. It has been possible to receive a discount on the stuffing, reducing the cost of making the pillows to \$3.00 per pillow. At no time has fabric been bought for the pillows, all having been donated mainly by individuals wanting to contribute.

Time constraints and the magnitude of the project, necessitated the use of another networking tool. A website was launched along with a Myspace site. The websites have connected with 6 cities in the USA and places unknown and with church groups, Girl Scouts and individuals. The project has been presented at numerous conferences, including FAWCO in Seoul, Korea in March 2008 and AORN Congress in California in March 2008.

Several new benefits of the pillow have emerged along the way. It gives women, families and patients the opportunity of helping in a concrete and immediate way and helps ease their feeling of helplessness. Some women use the project as a form of therapy to relieve their own feeling of helplessness when facing a disease they can't control. It is a focus point of doing something and connecting with other women. And last, but not least, the pillow gives psychological comfort and something to hold onto tight when their world has just been turned upside down. With this "gift", they know they are not alone and others are thinking of their needs even though they do not know them personally.

In today's busy world and with the pressures of giving quality care in an economical way and timely manner, the pillow is an ideal solution which can be used in many settings – surgical wards, outpatient and ambulatory clinics, treatment facilities, etc.

In summary, the tools used in this project have been word of mouth, newsletters and articles, websites, and conferences and presentations. Cultural differences must be considered when starting and the individual projects adapted to meet this diversity. It must be realized that networking takes time, both in regard to expanding but most importantly to taking care of the established network. Many possibilities have yet to be explored, school community service and private company support, and public funding, just to name a few. At present, a smaller version of the pillow is being tried by patients to be used in cars under seatbelts and can be taken easily in trains, buses and when outside the home.

It is the intent that this will remain a “women to women” project, voluntary and free – a gift. There has not been and will never be any evidenced-based research preformed on this project. It is a question of getting back to basics and listening to what our patients tell us. If we are able to help just a few of the women who are suffering, then it is a success. The goal is to provide a pillow to every woman in need. My dream is that soon there will be no women in need.