

## **Community View Psychosocial Care for People with Cancer:**

### **The Cancer Support Community Model**

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In 2007 the Institute of Medicine released “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.” The report lent credence to what Cancer Support Community had been saying since its inception as The Wellness Community in California in 1982 – that the psychosocial and emotional needs of people with cancer should be addressed along with the physical needs in order to treat the whole person. In 1982, successful Beverly Hills and NYC based real estate attorney, Harold Benjamin was searching for emotional support for he and his wife Harriett who had just been diagnosed with breast cancer. He found limited support in the community through the cancer advocacy organizations that offered support groups usually in a church or community center; sometimes as a self-help group and sometimes professionally facilitated. He also found the hospitals would provide support in the hospital setting however he wanted to avoid going into the hospital.

His idea, novel in 1982, was that there should be a warm, inviting, and comfortable place away from hospitals where people with cancer and their loved ones could focus on the emotional recovery of the many psychosocial issues that being diagnosed and treated for cancer brought to the table. With his own money he purchased a “little yellow house” in Santa Monica and enlisted several licensed mental health practitioners to devise a program for the complete psychosocial care of people with cancer and their caregivers. He named it The Wellness Community with the idea that people would be well despite cancer. The program that was developed in 1982 remains relatively unchanged today: weekly support groups for people in active treatment (defined as within 18 months of any kind of treatment for any kind of cancer) monthly support groups for specific cancers, educational programs to help people learn how to be their own advocate, and healthy lifestyle programs to deal with the stressors of cancer; like yoga, t'ai chi, mindfulness based stress reduction, etc. All programs were to be facilitated by licensed and specialty trained mental health clinicians or trained instructors and specialists in their field. The services were to be offered to anyone at no-cost to the participant, caregiver, and family member; no insurance cards and no co-pays. Due to the location's close proximity to the movie and entertainment industry many high profile people with cancer enjoyed services at The Wellness Community in Santa Monica.

One person, Gilda Radner, an original Saturday Night Live performer used The Wellness Community in her very public bout with ovarian cancer. Many people heard of and participated in the programs, and wanted one in their community. In Delaware, two women Ellen Hamilton and Cindy Dwyer were looking for a way to find support for their own cancer experiences but also to support a good friend Mary Moller who was battling ovarian cancer. Hamilton and Dwyer contacted founder Harold Benjamin and after three years of planning, The Wellness Community Delaware (name later changed to Cancer Support Community Delaware) began offering services in a loaned office near Trolley Square in April of 1996. With corporate and foundation support, the help of many individuals, and grants from the Delaware Health Fund and the State of Delaware, Cancer Support Community Delaware now provides our services statewide in three

homelike locations in New Castle, Kent and Sussex counties, with a small satellite location recently opened in Middletown.

Cancer is an illness with many facets: physical, emotional, existential and spiritual. All of these facets are incorporated into the support program discussions. The weekly groups are comprised of people with cancer which are currently or recently in active treatment. The isolation that people can feel when diagnosed and treated for cancer, despite having excellent family, friend and faith support is impacted when everyone in the room has heard the words “you have cancer.” People with cancer are sometimes surprised that the people they thought would be supportive of them either cannot or will not for various reasons but, sometimes, complete strangers step up and become important supporters during the cancer experience. Frequently these are members of a support group. Another key psychological issue after cancer is the loss of control the illness can bring. The word “cancer” can challenge our existence. “Will I survive this?” is often an early thought after diagnosis no matter how favorable the statistics.

Death can be perceived as the ultimate loss of control and in our present society; discussions of death and even expressing feeling about death can be discouraged. The groups provide a safe place where people can go to express this and many other concerns with folks who understand and share similar feelings. Cancer treatment can generate feelings of being out of control throughout the process. Once in the care of the health professionals it is easy to lose sight of your own identity; from the hospital bracelet to the sometimes difficult treatments self-image can change. When these feelings are discussed within the group context a sense of control can return. Finally there is the question of hope. Even people with late stage cancers can find hope; if not of being cured, then of comfort and improved quality of life. Hope is not the same as being positive. While it is nice to be able to maintain a positive outlook there can be some difficult moments during cancer treatment that positivity might not help- maintaining hope, however, might.

In addition to the emotional concerns addressed by CSCDE, more research is indicating that effectively coping with stress and remaining as physically active as possible can improve outcomes and certainly impact quality of life. With that in mind, Cancer Support Community Delaware offers multiple physical activities and stress reducing programs: yoga, t'ai chi, mindfulness based stress reduction, as well as writing, art and poetry classes to compliment the emotional support. Social events such as movie nights and pot luck lunches can also help folks deal with the isolation of being treated for cancer. Another important aspect of the program is the use of art/music/movement in helping people better deal with or even reframe some of their emotional concerns about cancer. Of course, not everyone survives cancer and we have two important bereavement programs; Living with Loss is a six session program that discusses normal grieving and gives people support in the first few months after the death of a loved one; The Next Step addresses the needs of those who are a year or so after the loss and still desire to meet with others who are dealing with longer term bereavement issues. The idea is for all of the programs to give those with cancer and their caregivers a safe place to discuss anything that can improve their quality of life, the opportunity of meeting others who are struggling with similar issues and mechanisms to cancer survivorship. Here are some thoughts participants shared about Cancer Support Community Delaware:

“My support group has become my second family.”

“The staff has made the group, from day one, a place to feel free to express whatever we needed to and have given us an outlet to

figure out how to move forward. The weekly groups consist of multiple types of cancer which allows us to hear very different points of view which can help our level of understanding.”

“I gain a safe place to speak about what we are going through without judgment. I feel support and try and give support to others which also helps me. I’m glad my husband has his own group to talk about what he is going through.”

Cancer Support Community was founded for one reason: to give people with cancer and their loved ones a safe place to do whatever they need to do to gain support during their most isolating experience.

Our hope is that we provide a doorway into complete cancer survivorship. We define a cancer survivor as “anyone who has heard the word ‘you have cancer’ and is still breathing”. Many people are so overwhelmed with the physical details of cancer treatment that they do not experience some of the emotional side effects until active treatment ends. While we are here for people during all phases of treatment, most of our participants come to us as active treatment is ending. Because of the advances in the diagnosis and treatment of cancer there are approximately 13 million cancer survivors in the United States at the present time. As the treatment for many cancers is becoming more like a “chronic illnesses” the need for support continues to grow. There are predictions of up to 18 million cancer survivors by 2025. Please remember to recommend our high quality emotional support programs to those who are in active treatment and beyond.

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