2016 will mark the tenth anniversary of The Ken Hamilton Caregivers Center (KHCC) at Northern Westchester Hospital (NWH). It is a testimony to the center’s impact that its caregiver-focused concept which seemed revolutionary in 2006 is no longer so. Founded by Marian Hamilton after the passing of her husband, Ken, the center provides wide-ranging support to caregivers, whom Marian identified as an “underserved population.” Discover how The KHCC provides a lifeline for caregivers, and how it grew from a few volunteers to being a model for caregiver centers throughout the U.S.

Marian Hamilton recalls standing in the lobby of a hospital, having just received the dreadful news that her husband’s aggressive lung cancer had spread. “I was hysterical in the lobby, crying, and not one person helped me. There was nowhere to go with my trauma.” Throughout the two years that Ken received excellent medical care, Marian persistently felt that “No one really thought about me, considered my needs, or even made me part of the care team.”

After Ken passed in 2004, “I felt compelled to do something for other caregivers,” says Marian. “I asked myself, ‘What would have helped me?’ The answer was an oasis where I could go to take care of myself, where people understood and could help me through an extremely stressful experience.” In 2005, she approached NWH about creating a caregiver center funded by the community. “As a Planetree (profoundly patient-centered) hospital, NWH totally got it.”

“As a caregiver,” says Marian, “the worry and fear about the health of your loved one is so pervasive, it’s overwhelming. You feel inadequate. You wonder, ‘Am I doing enough? The right thing?’” Adds Jerri Rosenfeld, LMSW, The KHCC social worker, “After a diagnosis, it can be an extremely stressful time, full of uncertainty and concern. Caregivers must spring into action without having emotionally processed what has happened. Caregivers may feel guilty for taking time for self-care, which can put them at risk for exhaustion, depression, and anxious feelings. At The KHCC we often refer to the caregiver as the ‘invisible patient’ who requires attention and support.”

Today’s caregivers have more responsibilities than in the past. “Hospital stays are shorter,” notes Jerri. “Caregivers may be anxious about some of the tasks they will be asked to do at home; while trained to perform these tasks prior to discharge, caregivers require continued support and encouragement post-discharge.” At one point, Marian had to give Ken medicine in an IV twice daily. “I had no medical training. And I was told that if I didn’t do it right, it could kill him.” In addition, diseases that used to be terminal are now chronic. “For the caregiver, that means no end in sight.”

Once NWH gave the green light to a caregiver center, The KHCC’s three volunteer caregiver coaches, trained in “active listening,” began working with families on the floors. “We go find them,” says Jerri. “The crux of our work is still on the floors.” In November of 2007, construction of The KHCC was complete, and caregivers found the respite Marian envisioned in a soothing oasis. Here, caregivers receive counseling from Jerri, the social worker, and support from trained coaches; they can rest, reflect and refuel; and use a library of community resources. There is a reclining massage chair in a private area; a desk area with computers, copier and telephone; and a kitchenette with healthy snacks.

The KHCC staff has grown from three to 34 trained volunteer coaches. The number of people served has risen exponentially: from 500 family interactions in 2006 to 8,500 in 2014. Over 10 years, The KHCC staff will have had approximately 52,000 family interactions, demonstrating the vast need for caregiver support.

Caregiver coaches often start the relationship in a patient’s room. When Jerri told one caregiver, “We’re here for you,” the woman jumped out of her chair to hug Jerri. “She couldn’t believe someone actually cared about how she was doing.” Often, a coach will take an exhausted-looking caregiver from a patient’s room to a Hospital lounge. “How are you doing?” they ask.
Heartfelt Thanks
Demonstrate Results

“While my dad received care at NWH, I was often in The KHCC using a computer, grabbing a snack, or just looking for someone to talk to so I didn’t feel alone. Having you all there, and knowing you would go above and beyond to help me if I needed something, was invaluable.”
- Peter

“Your quiet rooms were so peaceful and helped us take some time out for ourselves. The staff of coaches is so caring, loving, helpful, wonderful and understanding that it made it easier for us to get through this terrible time in our lives.”
- Linda

The KHCC has received the Spirit of Planetree Best Practice Award for Family, Friends and Social Support.

Coaches help caregivers start caring for themselves again, which reduces their stress. “We encourage them to take a break, whether it is to come to the Center for respite, a 10-minute walk, or to go to get a meal,” says Marian. “We give them permission to care for themselves.” The first time Marian asked a caregiver about herself, “The change in her was dramatic. I was suddenly validating her. She told me all about her life, what she had done. She realized she still was the person she once was.”

The KHCC relies entirely on philanthropy. Partnership with the community launched the program and continues to sustain it. “From the start, it clearly resonated with the community,” says Marian. Volunteers are the program’s “backbone.”

Since 2006, as people and hospitals throughout the country have shown interest in founding a caregiver support program, The KHCC mission has included sharing its model. A formal Replication Program, coordinated by Jill Gottlieb, helps hospitals replicate The KHCC based on their own needs. Currently, 11 hospitals have implemented similar programs, vastly increasing the reach and impact of the urgently needed concept. “We want to spread our model. We know it works,” says Marian.

If you are a caregiver, learn more about The Ken Hamilton Caregivers Center at www.nwhc.net or call 914.242.8128.

If you are a hospital or healthcare provider and want to learn about The KHCC Replication Program, contact us at 914.242.7920 or jgottlieb@nwhc.net.