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The Power of Group Caregiving – Eileen’s Story
by Candace Wilson

I could always count on Eileen Miller to be an enthusiastic companion on my life’s journey. The year I turned 50 I had knee surgery. When I asked Eileen, who had also had knee surgery, to join me in hiking the rugged Washington coast, she didn’t hesitate. Except for an initial loud complaint about her 60 lb. pack, Eileen was undaunted by 6 days of scrambling over bear size boulders and beach logs, inching our way over headlands, and dosing ourselves nightly with Ibuprofen.

Eileen was so healthy. She was a vegetarian who grew her own organic vegetables. She was a physical therapist who took the right vitamins and supplements and limited herself to 2 cups of coffee each day. While training for the Danskin Triathlon in the spring of 2004, she developed a cough that wouldn’t go away.

What the doctors said was devastating: She had advanced lung cancer. She had never even smoked! How could this have happened? Surgery was not an option. She should immediately start heavy doses of chemotherapy and radiation to have the best chance. She would experience cumulative fatigue and other side effects. The statistics for survival were not very encouraging.

Eileen’s many friends immediately made her well-being our first priority. We arrived at her home to discuss the latest test results over impromptu meals and to offer encouragement and suggestions. Eileen loved all the support, but it was exhausting and overwhelming. She learned that the synonym for cancer is “No Control.” First she lost control of her health and body; then she lost control of her home and sanctuary. She felt like she was losing control of her life.

Then we heard about “Share the Care”, a model for group caregiving. Mary Ellen Shands, of Cancer Lifeline, a Seattle, Washington, support agency, led the organizational meeting for over twenty friends, co-workers, and patients. We were all eager to do everything we could to “help Eileen,” but Mary Ellen asked us what we might *receive* from participating. Each of us named at least one benefit. A daughter tearfully shared her gratitude for those who took care of her mom in a distant state. Now she would be able to help someone else. It was hard for Eileen, a generous giver, to accept that she would have to rely on us in the months ahead. Hearing that she had something to give to each of us allowed her to keep her self-respect.

Each of us volunteered for tasks we would do. It was a relief for me to say I did not want to prepare meals, knowing that there were others who did. We agreed to take turns as captains on a weekly basis.

Captains called Eileen each week to see what she needed, allowing her to be in control. We e-mailed and phoned the latest updates so Eileen wasn’t worn out by countless personal calls. Captains assigned tasks and responded to emergencies during the week. We cleaned house, drove Eileen to the doctor, provided meals, built a garden wall, washed the dog, and made runs

to the E.R. Because we were a group, we were each able to take time for ourselves, knowing Eileen would be well cared for. For 7-1/2 months, we functioned well and could have gone on indefinitely.

Eileen Miller died February 14, 2005, at the age of 57. Our Share the Care group gave her the best care possible. Since there was a plan, no effort was wasted. Instead of feeling inadequate and isolated, we worked as a team. When members of the group met after Eileen’s death, several spoke gratefully of the experience of community we had shared and what an unexpected gift it was. Eileen was a companion to all of us to the end of her life. I miss her.

SIDEBAR

Share the Care: How to Organize A Group to Care for Someone Who Is Seriously Ill by Cappy Capossela and Sheila Warnock, Fireside (Simon & Schuster), C. 1996, 2004.
Available from Amazon.com and Barnes & Noble.

Based on the authors’ experiences of caring for their friend Susan, the book outlines a model of group caregiving. The book is a complete handbook for groups and includes forms and detailed guidelines. Susan’s group lasted 3-1/2 years and included fundraising and travel out of the country for alternative treatments. The group structure allows time off for everyone and prevents burnout and isolation.

Before her group care experience, author Warnock cared single handedly for her mother, and became overwhelmed and exhausted. Her experiences have made her a strong advocate for group caregiving. She says, “This is not just about organizing people. It is deeper; it bonds people and provides quality of life to the patient and their family.”

Mary Ellen Shands Program Associate and Family Consultant of Cancer Lifeline, a Seattle, Washington support agency comments, “This experience is so powerful. It’s a chance to do something good and important in a world that is cynical.” Shands has worked as a hospice nurse and knows how isolated and worn out family caregivers can become.

Share the Care Foundation

Share the Care is now a nonprofit foundation, focused primarily on education & promotion of group caregiving. Day-long trainings are geared towards health professionals and clergy who may have opportunities to mentor groups.

To learn about forming a group or hosting a training, visit the website at www.sharethecare.org.