



Hospice volunteers write life stories of the dying

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When Barb Markley's mom was dying of a chronic lung disease, she agreed to speak with a hospice volunteer about her life.

Now whenever Markley is grieving, she can listen to a recording or flip through a book and feel better.

"I can not only hear my mom's voice, I can hear her sense of humor, and it just fills a little bit of that void of missing her so much," she said.

Markley's mom, Barb DeRousse, left her stories through Lumina, a program offered by BJC Hospice that preserves the life experiences and values of the dying. Volunteer writers meet with the patients and agree on a project, like a book of stories, a scrapbook that's mostly photographs or a series of letters that are passed on to survivors. Some other hospice groups offer similar services.

Markley, 62, of Manchester, chose to give her mom privacy when she met with the volunteer, so the end result was a surprise.

"There are pieces of life about my mother that neither my brother nor I knew, and it's just like having a moment in time with her again," she said.

Suzanne Doyle helped found Lumina in 2006 and named it for the metaphorical image of light and the patients, whom she considers luminaries.

"Many folks think of themselves as very ordinary, so it's hard for them to believe that they matter so much that their words, their stories should be passed on, but that's the belief the program has," said Doyle, 63, of St. Louis.

Lumina has about 15 volunteers who go through intensive training not only to practice writing and interviewing skills but also to explore the impact of death and dying on the patients and on their families.

"This is hard work," she said. "People go out into the families and sit with dying people for many hours. The intimate dialogues between the patients and the people who are creating something have been remarkable."

Doyle, who has written half a dozen stories herself, said one of her most memorable patients was a woman in her 70s who had been disabled most of her life. She and her adult daughter were estranged, but the daughter agreed to sit in on one of the interviews and wrote out a series of questions she wanted her mother to answer. Her mother agreed and created an audio CD.

"It was an incredibly mending experience for the daughter to really find out that her mother loved her," Doyle said.

Another volunteer, Olga Smith, 77, of north St. Louis County, said the stories told are important to the history, not only of the family but the community.

"I'm the daughter of immigrants, and I wish that when Mom and Daddy were telling their stories I had recorded them," she said.

She has worked with a range of patients, from a man in his late 90s, who told stories about his job as a rural mail carrier, to a 39-year-old mother who barely lived long enough to finish letters to her three children.

"I showed her the envelopes with their names on it, and she was able to say, 'That's pretty,'" Smith said. "A few days later, she passed."

Volunteer Ruth Edwards, 87, of Overland, said the training was difficult on her emotionally, but she seldom talks to the patients about their illnesses. Instead they talk about their childhood, travel, recipes or other interests.

"I think it's very helpful to the patient, and I've enjoyed the life experiences of other people, too," she said.

For volunteer Peggy White Davis, 48, of Dardenne Prairie, the program is a chance to be more creative than she can be at her job as a technical writer.

"This work that I do after my 8 to 5 job is incredibly meaningful because it allows the heart to come out," she said.

Markley, who recently commemorated the one-year anniversary of her mother's death, said the Lumina program has given her the strength to move forward.

"It helps me know that my mom would want us not to grieve so much but use the things we learned from her and continue on in our own journey," she said.