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Doulas now helping terminally - ill with end-of-life issues

By MARCELLE HOPKINS
Columbia News Service

NEW YORK - Barbara Collins had some unfinished business to wrap up before she died. Collins, 61, had been bedridden for five years with multiple sclerosis. She knew she was near the end of her life and wanted to find her best friend from high school, Candy, whom she hadn't spoken to for 35 years.

Her new friend would help her do that. Saramaria Allenby, 41, is an end-of-life doula, a volunteer companion for the terminally ill.

A month after Allenby started visiting Collins in a nursing home in Brooklyn, N.Y., Collins mentioned that she needed to talk to Candy.

"I knew she was looking for reconciliation," Allenby said.

Allenby found Candy on Classmates.com and contacted her on Collins' behalf. The old friends began an e-mail correspondence through Allenby, who read Candy's letters to Collins and transcribed her responses.

They reminisced about smoking cigarettes out the back door of their high school theater and riding bikes around their Long Island neighborhood until well past dark.

They talked about their falling out 35 years ago - over a misunderstood phone call - and what had transpired in their lives since then. Three weeks later Collins died.

Allenby said she was glad to be able to help Collins find her old friend. That was part of her job as a doula.

The term doula, which comes from the Greek word meaning woman's servant, most often refers to women who help mothers through childbirth.

But the concept has been adapted to apply to another important part of life: dying.

Hospitals, nursing homes and community organizations across the country have begun training volunteers (both men and women) to offer friendship and support to the dying.

"Dying is as sacred as birth, and no one should go through that alone," said Allenby, who learned about end-of-life doulas during a chaplaincy internship at Isabella Geriatric Center in New York City.

Rabbi Nadya Gross, founder of the End-of-Life Doula Association, had been a birth doula in California in the 1980s before she moved to Colorado and formed a spiritual support group for people coping with chronic illness.

"The dying process is a normal part of life, and it shouldn't be something frightening and fought," said Gross, who leads a Jewish Renewal congregation in Boulder, Colo., with her husband, Rabbi Victor Gross.

Having served as a spiritual companion for several dying people in her area, Gross, 51, wanted to train others to do the same.

Through the Internet, she discovered a similar program in New York City founded in 2000 by the Jewish Board of Children and Family Services.

With guidance from that program's director, Harriet Feiner, and local Jewish chaplains, Gross graduated her first class of 27 volunteer end-of-life doulas in February 2005.

The idea of volunteers visiting the dying has been a pillar of hospice care since the 1970s. But doulas differ from hospice volunteers in that they can form relationships with patients long before the end of their lives.

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Doula programs pair volunteers with patients who have life expectancies of up to 18 months, while most hospice patients die within nine weeks of entering a program, according to the National Hospice and Palliative Care Organization.

Part confidant, part friend, part advocate, a doula's role changes with each patient.

Mark Lewis, a secretary at a law firm and a doula volunteer, found out that his patient was Catholic, so he bought her a statue of the Virgin Mary.

"I pulled out the statue and she smiled and said, 'Thanks,'" Lewis said.

"Then I pulled out chocolate Haagen-Dazs ice cream and she shrieked with joy. I'd never seen her so happy."

On a later visit, he noticed that she had hearing aids but had not worn them for several months. He bought batteries for them and helped her put them in.

As with birth doulas, end-of-life doulas offer emotional and logistical support to patients' family members.

At St. Mary's Hospital for Children in New York, doulas are paired with terminally ill children ranging from infants to teens. They offer much-needed relief for parents who have to work, have other children at home, live far away or are otherwise drawn away from their children's bedside.

"Parents feel a lot of guilt for not being here all the time with their sick child," said Doreen Sikoscow, manager of palliative care at St. Mary's.

"A doula allows them to break away sometimes and take care of themselves."

Befriending a dying person is no easy task. Most doulas are called to duty through a personal experience, good or bad, with death.

For Melania Eller, that experience was on the job. As a palliative-care nurse at a San Francisco hospital, Eller attended doula training to learn how to relate to her patients differently.

"It opened me up to be more intimate, less guarded as a nurse," Eller said. "I'm more touchy-feely with my patients now."

All doulas are quick to point out the hidden rewards in their experiences.

Allenby said Collins taught her that life didn't have to be complicated. "With her, I learned to enjoy the simplest pleasures: visiting a friend, holding a hand, eating something really yummy," Allenby said.

Lewis joked that, thanks to his doula services he now has "some bargaining chips with Saint Peter."

For Lewis, being a doula isn't mysterious or grandiose.

"Bottom line, you're just visiting someone who is alone in a very scary time in life," he said.



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