Adams County hospice care provides quality of life at the end of life

By Karen Hendricks
Beatrice “Betty” Lee Frealing was an active pillar of the Gettysburg community through the age of 91, until she began experiencing health issues in the fall of 2012. Her daughter, Beverly Stanton, a sociology professor, says she didn’t associate her medical knowledge—including warning signs of congestive heart failure and early-onset dementia—with her beloved mother.

Looking back on her mother’s last six months of life, she wishes she had done things differently and placed her mother in hospice care earlier. Before she passed away on May 8, 2013, Frealing spent the last 10 days of her life in hospice care—a time that Stanton describes as “crucial” to her mother’s and family’s quality of life.

Hospice care is defined as specialized care designed for patients diagnosed with terminal illnesses or conditions that their doctors believe have progressed to the point where they have six months or less left to live. Although hospice is a growing segment of the healthcare industry, there are many misconceptions and stereotypes that healthcare professionals are trying to dispel. Those families whose loved ones have received hospice care are also speaking out and, in many cases, trying to alleviate other families’ fears about end-of-life care.

Building Bridges to Hospice Care

“The things that scare us the most are the things that we don’t understand,” says Angie Pickel, hospice social worker for the nonprofit Lutheran Home Care & Hospice. “So, it’s scary when someone we love is dying.”

“But hospice is the bridge—the educators, the support—to step up, form a plan, and help people through this,” she says. “There is nothing more special than being invited into people’s lives in such a delicate time, providing support.”

Hospice care evolved in the 1970s due to the prevalence of cancer patients needing specialized end-of-life care, says Pickel. Although there are still a significant number of cancer patients, she says today’s hospice clients include a wide spectrum of diagnoses including dementia, and heart and kidney disease. Pickel believes the need for hospice care is escalating, especially as baby boomers enter their 60s and 70s.

“While the number of people receiving hospice care is increasing, at the same time people are coming into hospice care much later in their disease process,” says Gil Brown, president and CEO of Hospice of Central Pennsylvania, an independent, nonprofit hospice care facility in Harrisburg, Pa. His patients hail from a seven-county area including Adams County.

According to Brown, hospices measure length of stay in two ways. “Our average length of stay is close to 60 days, but our median length of stay is 11 days. That means 50 percent of patients are with us for less than 11 days—not an optimum hospice experience.”

Brown says the figures point to a need for more education among the public, so they’re more aware of the safety net hospice can provide. “Hospice can provide comfort—physically, spiritually, and emotionally—to help patients and families enjoy their final weeks and months together.”

It’s a Team Effort

“One of the biggest misconceptions is... people hear ‘hospice’ and they think ‘death,’” says Ginny Davis, community relations coordinator for Lutheran Home Care & Hospice. “Due to the quality of hospice care, many people actually thrive, but I want to stress that hospice is care, not a cure. The biggest thing I want to stress though—hospice is not only for the patient but for the family too because of all the services provided.”

On a regional level, Hospice of Central Pennsylvania, based in Harrisburg, Pa., annually cared for 1,400 people in 2014, up from 1,200 patients the year before. These figures include a small percentage of Adams County residents.

Lutheran Home Care & Hospice, Adams County, treats 24-30 patients at any one given time. “There are some very good studies that show people who receive hospice care at the end of life live as much as three months longer than people who don’t receive hospice care,” says Gil Brown, president and CEO of Hospice of Central Pennsylvania.
Here in Adams County, Pickel says at any given time, Lutheran Home Care & Hospice is treating about 25 hospice patients. She is generally the first point of contact, meeting to talk about each patient’s goals, with the patient and the patient’s family members. As a result of that conversation, hospice care is customized for each individual patient through a team approach.

Davis says hospice services are provided by “a complete team of professionals,” through counseling, medical equipment, personal care, meal preparation and light housekeeping, direct clinical care, skilled nursing, volunteer services, or medication costs related to the terminal illness. Assistance with financial and funeral plans can be included in hospice care. “We help pull all the end strings together so the family is not overwhelmed,” says Davis.

Stanton especially encourages families to rely on these vital services offered through hospice. “One of the things I want people to know is…hospice isn’t only for people in their last week of life,” she says. “People should call hospice four to six months beforehand, to help the family, help the patient, and not be caught unaware.”

“I taught biology. I know pre-med, but I didn’t associate these things with my mom,” she adds. “When you’re in the trauma, you’re the caregiver, keeping the medicines going, paying the bills, going to doctor appointments. You’re too wrapped up in these things. People need to know about hospice and these resources, and feel freer to use them. Hospice is a wonderful thing.”

“Like family” is how Gettysburg resident Maureen describes the hospice workers who cared for her husband. Albert, after his diagnosis of pancreatic cancer from 1997-99. “The doctors said he would probably be gone within three months...everyone who knew him through Lutheran Home Care & Hospice called him a ‘miracle man.’ They took great care of him—as if he was a member of their own family.”

Maureen says she is grateful that hospice workers taught her so many skills that allowed her to take care of Albert—everything from medical procedures and how to change dressings, to advice on how to handle the times when Albert became upset. “It was 16 years ago, and I’m still very good friends with the first nurse who took care of him,” Maureen says. “I can’t praise them highly enough...they are special people.”

A Transformative Journey

“A lot of my job is life review—what needs to be finished up in people’s lives, telling their stories,” Pickel says. “It is an emotional time—there are certainly families and moments that touch you. You become humbled. It’s such an honor to meet incredible people from all walks of life—scientists, veterans—they are a treasure.”

She recalls helping a hospice client travel across the country so that he could say goodbye to friends. “He was an orphan early in life, so his ‘family’ were his friends. Even though he was very sick [with lung cancer], he needed to say goodbye to them, so I helped him travel to California and New Hampshire. I learned that ‘family’ isn’t always blood.”

Pickel says she approaches hospice as a journey, not an end. “It’s not a straight and narrow path; it’s full of hills, valleys, and curves,” she says. “But you don’t have to go alone. It’s a journey where I can go along and make sure your loved one has the best care possible.”

*Last name omitted for privacy
Paying for Hospice Care

Hospice is covered 100 percent by Medicare or Medicaid for those 65 and older, according to Ginny Davis, community relations coordinator for the nonprofit Lutheran Home Care & Hospice. "Hospice is covered by most health insurances," she says.

"And because Lutheran Home Care & Hospice is a nonprofit, if someone is without insurance we will work with the family, and we never turn anyone away."

Davis notes that for insurance purposes, hospice patients' first step is receiving a diagnosis from their physician stating they believe the patient has six months or less left to live. Although patients may live several days or weeks after entering hospice care, Davis says many patients actually live longer than their six months' diagnosis, and costs are still covered through end of life.

Lutheran Home Care & Hospice is offered throughout an 18-county area in Pennsylvania; services are not offered in Maryland due to different state regulations.

Dispelling Misconceptions on Hospice Care

The healthcare industry is working to dispel numerous misconceptions the public has about hospice care, says Angie Pickel, hospice social worker of Lutheran Home Care & Hospice.

"Some of the biggest myths are that hospice takes away medicine. This is not true—we look at medication lists from a comfort standpoint. Sometimes it might be best to stop drugs for a chronic disease, because someone doesn't have a long lifespan. But we don't stop all medications."

She says another misconception relates to being admitted into hospice care. "People sometimes think once you're in hospice care you can never come off. We do have hospice 'graduates' who go out of hospice care and then come back in later. That can happen."

"Also, if you still want to travel, we are here to help you do that."

"When hospice staff comes in, sometimes people think all we're going to talk about is dying. Although we support those who are dying, hospice is really about living and transitioning into death."

Touching Lives

A volunteer corps of more than 100 Adams County residents helps Lutheran Home Care & Hospice flourish. Bereavement Coordinator Kim Sentz says volunteers contribute handmade items that literally touch hospice care patients and families.

Burden bears, delivered by nurses or aides, are accompanied by a pamphlet that encourages patients to "lay all your burdens on your bear" whether through conversation or prayer. Additionally, prayer shawls made through a network of area church volunteers are offered to patients needing comfort during spiritual times of prayer.

Perhaps the most treasured of all handmade items are called memory bears. "We send a letter out after a loved one dies, offering to make a memory bear from an article of clothing—a shirt, sweatshirt, any item that was special to that person," Sentz says.

One very special volunteer, a woman named Bobbi, lost her husband in hospice and wanted to do something to give back. She began making the bears, developed her own pattern, and it's taken off. She has now made more than 300. The reaction from families [has been]... a lot of tears, excitement, and amazement because of the details she sews into each bear," Sentz says.

Bears themed with racing apparel, wedding dresses, fishing lures, jewelry, flannel shirts, even a mini guitar have all been created to memorialize loved ones.

"Most people put them on a bed or mantel, a place of honor where the bear can still be a part of the family," Sentz says. "I think it's a sense of comfort, that it's a part of their loved one that they can always treasure."

Pickel recalls, "I had a widow who wanted her husband's mechanic's shirt made into a memory bear. Unbeknown to the sewer, a stain was on it. When the woman looked at that bear, that stain had a connection to her—she remembered her husband putting around with grease, and she cried. These bears are precious to everyone for different reasons. They help solidify memories and feelings."