Living with life’s end

by Cheryl Keffer
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Hospice isn’t a place. It’s more of a frame of mind.

And Hospice of Baltimore, a non-profit based at Greater Baltimore Medical Center, wants to spread its philosophy about how to take care of people at the end of their lives.

So the organization is sending its representatives out into the community, visiting Baltimore County’s senior centers for a year-long look at the aspects of hospice and end-of-life care.

“We focus on the patient and the family – on comfort – and not on aggressive treatment,” said Theresa Proctor, a clinical social worker, to a group of seniors at the Overlea Center. “We want to (facilitate) a peaceful, comfortable end-of-life experience.”

In this society, “it’s not common” to view death as a natural part of life, Proctor said.

And while hospice organizations are not around to hurry things along, they’re also not going to prolong the process.

“We’re not here to keep the body breathing at all costs,” she said.
But as a team, the hospice workers – always comprised of a registered nurse helped by a social worker, nursing assistants, and others like chaplains, bereavement counselors, and physical therapists – provide spiritual and emotional support.

Patients are encouraged to remain as independent as possible, but hospice will bring in resources as needed.

What they won’t do, Proctor said, is gloss over what’s going to happen.

With hospice care, the end result is death.

“I’ve gone into houses before where everyone is trying to keep up a cheery disposition,” Proctor said, where the adult daughter might take the hospice nurse aside and say, “Mom doesn’t know she’s dying” and the mother – when the daughter’s out of earshot – says, “My daughter doesn’t know I’m dying.”

“We don’t often go along with it. We try to create a situation where everyone can express their feelings without judgement.

“It’s my job to get them together and talk about it.”

Opening up also gives people the chance to say “I’m going to miss you,” she added.

But at the same time, Proctor says that hospice workers are never ones to discourage patients or families to give up hope.

There was a case recently where the staff was preparing relatives for a family member’s imminent death based on symptoms being displayed, but it didn’t happen for another week. “It was seven more days they got with their loved one,” she said.

Grief support for the family is available for the following year – 13 months, really, because “the anniversary can get you all discombobulated again,” Proctor said.

The organization also offers grief services to the public, without the requirement of having a family member in hospice. Programs (luncheons, retreats, and workshops) are scheduled throughout the year. Most recently, Hospice of Baltimore offered a “how to prepare for the holidays” workshop.

Hospice care includes visits from staff; medical equipment and supplies, medication to control the symptoms of the terminal illness, and respite care for family members and caregivers.

Inpatient care, when needed, is also an option, whether in the hospital or in hospice-run facilities.

Hospice of Baltimore uses its Gilchrist Center when a patient needs extra care and can’t stay at home. The center is also available for people who don’t want to die in their own home.

While a majority of patients have cancer, it’s not the only life-limiting illness that affects those who take advantage of hospice programs.

Hospice care can also help those with heart disease, lung diseases like emphyema, kidney or liver disease, ALS (Lou Gehrig’s disease), end-stage AIDS, and advanced dementia.

Patients must have a life-limiting illness – with a life expectancy measured in months rather than years.

Usually the doctor has said there is nothing else that can be done or a patient has said “no more” treatments, according to Proctor.

At that point, either the patient’s physician can refer him/her to a hospice organization or a family member can request a referral.

“A lot of times doctors want to keep trying,” Proctor said, “but family members can ask for hospice care. We really value the patient’s choice.”

Note: This introductory program on hospice will be offered again at Rosedale Senior Center, 1208 Neighbors Ave., Monday, January 28 at 11 a.m. and Parkville Senior Center, 8601 Harford Rd., Tuesday, January 29 at 1 p.m.

**How you can help hospice patients**
Volunteers are an active part of many hospice programs, and the ways volunteers can help are almost endless.

Those who would like to interact with patients can:
• Help with writing a letter or memoirs to leave behind
• Be a good listener or share a book
• Visit to give a caregiver time off (to run errands, go to a doctor’s appointment, shower, etc.) or help with cooking and housework
• Provide services to bereaved families by writing notes and cards, visiting, and attending support groups

Those who may want to help, but not directly with patients or their families can assemble information packets and mailings, assist at special events, or opt to work at the hospice organization’s office, answering phones, and greeting and directing visitors.

Hospice of Baltimore requires that volunteers be at least 18 years old and complete a comprehensive 18-hour training program to acquaint them with hospice’s mission, services and programs. Training focuses on communication and interpersonal skills effective in working with patients and families, and helps volunteers explore their own perceptions and feelings about death and dying.

Volunteers can be a valuable set of eyes and ears to the hospice team, since patients often feel better talking with a volunteer — whose role is more like that of a friend or neighbor — and sharing things they might not share with medical staff or loved ones, according to a Hospice of Baltimore brochure.

To apply to become a Hospice of Baltimore volunteer, call 443-849-8296 or visit www.hospiceofbaltimore.org.

Understanding grief
As part of its 2008 initiative, “The Courage to Move Forward,” the Baltimore County Department of Aging, in partnership with the Hospice of Baltimore, will offer the presentation “Understanding Grief” at Overlea Senior Center, 4314 Fullerton Ave., Wednesday, February 6 at 10:30 a.m.; Seven Oaks, 9210 Seven Courts Dr., Wednesday, February 20 at 1 p.m.; Rosedale, 1208 Neighbors Ave., Monday, February 25 at 11 a.m.; and Parkville, 8601 Harford Rd., Tuesday, February 26 at 1 p.m.

March’s topic in this series will be on advance directives and living wills.

For more information, please call (410) 887-2594.

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One Response to “Living with life’s end”

1. Bailey Barash Says:

January 20th, 2008 at 6:36 pm

Hello -
I just read your article about hospice. Thank you.
I wanted to let you know I am a documentary maker and hospice volunteer in Atlanta, Georgia.
I’ve produced a short documentary about end-of- life decision making, palliative care, caregiving and hospice.

It’s called 203 Days.
You can view it in its entirety at the following University of Connecticut website along with a study guide.

http://fitsweb.uchc.edu/Days/days.html

It is an unflinching look at the day-to-day interactions between patient and caregiver, in this case an 89 year old woman who is living with her daughter.

203 Days just won the First Place 2007 Film Award from the National Hospice and Palliative Care Organization (NHPCO).

If you’d like more information please go to my website

http://bbarash.com/bb_203days.htm

I hope this film is helpful to people who want to know more about some of the most common experiences for caregiver and patient at this difficult time.

Bailey Barash