Hospice programs open arms wider to help the dying

By Kyung M. Song
Seattle Times health reporter

Lisa Griffith is 48 and dying of lung cancer that has spread to her brain.

After months of radiation and chemotherapy, her oncologist finally declared in April that the treatments were proving fruitless.

Since May, a cadre of Providence Hospice of Seattle nurses, volunteers and even a massage therapist have been coming to Griffith's sunlit Seward Park home. They tweak medications to minimize her pain, secured her government disability benefits and are shepherding her through what she expects will be her final months.

"Hospice has been such a blessing," Griffith said.

And unlike most hospice patients, Griffith did not have to surrender her battle with cancer as a condition to receiving hospice help. Hospice admission usually is limited to terminally ill patients who have less than six months to live — and forgo all treatments seeking cure. The very idea for some people has been tantamount to a death sentence.

But that tradition has slowly been lifting.

The rules have meant that cancer patients on chemotherapy or kidney patients undergoing dialysis were shut out of hospice even as they faced likely deaths. And it has meant that only half of all Americans who might benefit from hospice services ever get them, advocates say.

But led by Providence, several hospice programs in the Puget Sound area have quietly stopped requiring patients to waive treatments that could prolong or even save their lives.

The goal is to expand hospice to more people and earlier so that they have ample time to attend to the multiple tasks of dying. Hospice helps ease patients' pain, put their financial affairs in order, gird them emotionally and spiritually and help
them say their goodbyes.

"We started looking for opportunities to say 'yes' instead of 'no,' " said David Bucher, executive director of Providence Hospice.

It was the recognition that cancer patients like Griffith often died in needless pain and fear that gave birth to the hospice movement during the early 1970s. Yet many Americans remain wary of hospice. Only about a third of the nearly 2.5 million Americans who died in 2005 were under hospice care, according to the National Hospice and Palliative Care Organization. Experts say the numbers should be twice that.

"A lot of doctors and patients say hospice is giving up hope," said Gail Loughlin, a nurse and clinical liaison at Providence. "But I like to reframe that. Hospice is perhaps redefining hope."

As part of that mission, Providence, the largest hospice program in the Seattle area, began switching to "open-access admissions" in 2004. For the first time, cancer patients could continue with palliative radiation or chemotherapy while under hospice's care. Providence gradually lifted restrictions on almost all other advanced treatments, ranging from blood transfusions to dialysis, provided that the primary purpose is to make the patient more comfortable.

Franciscan Hospice Services in Tacoma and Evergreen Hospice in Kirkland also have adopted similar open-access policies.

Open access

Providence's Bucher says open access is drawing more patients to hospice. Equally important, patients are enrolling sooner. So far this year, the average length of service for a Providence patient is 64 days, up from 47 days in 2004. Average daily census has more than doubled from 211 patients to 460 patients in that time.

Nationally, the average length of hospice service was 59 days in 2005, according to the hospice organization. But the numbers obscure the fact that half of all patients enter hospice less than a month before their deaths. That's far too brief, experts say, to get its full benefits.

But accepting patients who aren't ready to quit advanced therapies can be a financial risk. Medicare, the insurer for the vast majority of hospice patients, typically pays hospice a fixed daily sum regardless of what it does for each patient. That means expenses like equipment rentals, medications and expensive dialysis must be paid out of the per-diem reimbursement.

Open access isn't without its critics. Advocates of traditional hospice contend that loosening admissions rules blurs hospices historical focus on managing death.

"What is the purpose of hospice? Is it for patients who are dying — or not?" asked Daniel Callahan, co-founder of The Hastings Center, an independent bioethics-research center in Garrison, N.Y., and an expert on end-of-life issues.

Mark Rake-Marona, director of Franciscan Hospice, counters that open access is exactly where hospice should be headed.

"It's our mission to serve everyone and not put any stipulations on treatments," he said.

Once patients enter hospice, Rake-Marona said, even the most ferocious fighters among them eventually change their priorities.

"Most people do discontinue those treatments. They realize that it's a burden," he said.

Fearless
Griffith, the hospice patient, is fearless about facing death.

After her diagnosis in December, she endured four months of radiation and chemotherapy that battered her body and left it 60 pounds heavier from steroid treatments.

She has been working with a Providence Hospice social worker since shortly after her diagnosis. But she is also a practical, unsentimental woman: Griffith fled a meeting of the cancer-support group Gilda's Club "because there was too much hugging."

But her eyes mist when she talks about all that hospice has done for her.

"I don't want to be sick while I'm waiting to die," Griffith said. "Having hospice gave me confidence to continue to be positive."

Kyung Song: 206-464-2423 or ksong@seattletimes.com

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