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Making memoirs: New projects help terminally ill patients share life stories

Mary Bergin
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Tell me about your childhood home, and take me on a walk through your neighborhood.

Describe yourself as a student in school, and the teacher who had the biggest impact.

What was your first car like? Who was your first love? When did you first realize you had met the person you'd marry?

Two new projects in Madison are making it easier for terminally ill patients to document their life story and leave a lasting, tangible, personal gift for the people they love.

The gift also works in other ways, by helping people assess their lives, make adjustments and feel more comfortable about their mortality.

A "Lifetime Legacies" class at Edgewood College trains students to produce their own life reviews, then interview and produce a life review for a person who is terminally ill. The two-semester class, part of the Human Issues Studies Program, has begun its second year.

A new program at HospiceCare Inc. soon will have volunteers producing life reviews for the families of hospice patients. The free keepsake will take one of four forms: a narrative booklet of memories, a booklet with a family tree and pictures, an audio CD of edited interviews, or a DVD of photos with music and/or interview excerpts.

Every terminally ill person has the need to go through a life review, internally or out loud, says Pamela Thomas, who is coordinating the new program.

"So often there is so much to mourn" because of a terminal diagnosis, she notes. "We also want to help people celebrate" the fullness and joys of their lives.

Called Legacy Links, the program will rely on volunteers to conduct interviews, collect other pertinent materials and process what they gather. A pilot program that began earlier this year at HospiceCare's Rock County office was deemed a success and has expanded, with eight trained volunteers so far. The Dane County program is just getting started.

"Looking back on their life, their experiences, from a perspective of wisdom often helps people not have regrets," Thomas says. The process also is a way to document family history and help relatives better understand the context of a patient's life.

There also is bereavement value, for the grieving person who is comforted by the sound of a voice, details of a story or collection of photos.

Volunteers who want to conduct interviews must complete 20 hours of patient care training, and the next session will begin Nov. 1. Contact Amanda Pischke at 327-7163 or amanda.pischke@hospicecareinc.com to register.

Six hours of life review training also will be required of these volunteers, plus others who will be the processors/editors of material (but they have no direct patient contact). Up to five volunteers could be involved in one project, Thomas says.

"We tell volunteers to find the 'extraordinary' in the 'ordinary' parts of life," she explains. "We will make our patients the hero of their own story."

A three-page set of questions guides interviewers. Volunteers learn how to be sensitive, active and effective listeners.

For more about the program, contact Thomas at 314-2951 or pamela.thomas@hospicecareinc.com.

Legacy Links also is in need of money in Madison. In Janesville, \$5,000 in donations came from the Community Foundation of Southern Wisconsin, the Alliant Energy Foundation, Janesville Morning Rotary Club and fundraisers by students at Edison Middle School.

Self-exams at Edgewood

At Edgewood College, hospice volunteer training is a prerequisite for taking the "Lifetime Legacies" class. The 14 students can use text, photos, audio and/or video clips to produce life reviews. Most will work in pairs. A few may do life reviews of people they already know.

Class development was a way for Judy Adrian, the instructor, to process and recover from her mother's death.

"We go beyond intellectual learning," she says. "People die -- that is a fact," but she wants students to realize how they can help, learn and benefit while witnessing a part of this process.

"The teachers learn as much as the students," says Neal Ewers, a teaching assistant and hospice volunteer. "It's a wonderful setting for us all to be open and talk about our fears and uncertainties" about death.

Adrian encourages storytelling as a method that "allows people to speak from the heart, build trust and talk about their own reality." Ewers, who is blind, is the class icebreaker who mixes humor with poignancy as he shares stories from his own life.

"We learn as we go, and it's wonderful," Ewers says. "I tell my story as an example of how you might tell your own."

Students include Kathie Keyes, a math major who enrolled because an aunt was a hospice patient, and Nanette Thompson, a nursing major who volunteers at HospiceCare's inpatient unit.

"It's liberating to help somebody else," Thompson says. "There's no way to measure the good" that she gains through hospice work. Keyes, in the throes of self-examination, says she's learning what triggers happy and negative emotions.

All Edgewood students are required to complete at least one Human Issues course or relevant independent study, says Kris Michelson, co-director of the program. Class topics are interdisciplinary ("Lifetime Legacies" embraces psychology, literature, sociology, values exploration), require ethical decision-making and involve learning through travel, community involvement or other engaged learning.

[Return to story](#)

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