

HOSPICARE

NEWS

OCTOBER 2003

Elvis Lives

Joan Jacobs Brumberg

Over the past year, Hospicare services have begun to have a considerable impact in nursing homes in Tompkins County. A growing number of families with loved ones in nursing homes are turning to Hospicare for additional support as the end of life nears. Also, studies indicate that an estimated 10 to 20 percent of nursing home patients are really appropriate for hospice services. Our staff, under the leadership of patient care director Mikki Megivern, is working energetically to find ways to collaborate with area nursing homes to support the physical and emotional comfort of patients with chronic and life-threatening illnesses.

The story of Mr. H., who died at Lakeside Nursing Home last year, is emblematic of the unique skills and spirit that the Hospicare team can interject into end-of-life care.

Mr. H. was a complicated patient in his late 60s. He had limited cognitive abilities and metastatic colon cancer that had resulted in a colostomy. He had spent a number of years at the Reconstruction Home before moving to a group home, where he learned to manage many activities of daily living such as making his bed and doing his laundry. When he became ill with cancer, he had surgery at the local hospital and then went to live at Lakeside.

Lisa Skeval, the Hospicare R.N. who cared for Mr. H., described him as a "sweet, innocent, childlike" person who was always happy to see her. He looked forward to the regularity of her visits. Most of all, she said, he liked his Hospicare volunteer Tom, whom he described to everyone as his "best friend." For Mr. H., who did not



continued on page 5

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A Message from the Director



It seems that everyone is talking about how short summer was this year. Having come through a long and bitter winter, followed by a cool, wet spring, perhaps we felt entitled to a season of slow warm days, to the steady buzz of cicadas, the sultry feel of summer air on our skin. And instead, the corn peaked in what felt like a couple of days, the tomatoes flooded in too soon after we planted them, and the season seemed to be over almost as soon as it started.

We could push and prod that metaphor to exhaustion. It might serve as a reminder of so many things: that we have no entitlement but to cope with what we are dealt; that good things pass quickly; that we must enter fully into each moment of our lives, not let them slip away without appreciating that we have had them. To torment a well-worn phrase, "thus hospice doth make existentialists of us all," no matter what our belief system about an omnipotent deity or the possibility of an afterlife.

We learn so much from our patients; perhaps that's part of what keeps us doing this work. One memorable woman sits in a chair with a pair of binoculars ready at her side in case the heron decides to dive-bomb the pond, or the 12 ducklings march lock-step behind mama along the garden path. Each day is to her a gift of time, an opportunity to engage with the world she sees around her. "I know I'm on borrowed time," she told me, "but isn't it marvelous!" She is not measuring what she doesn't have, or what comes in short supply; instead, she is reveling in the moment, extracting the rich juice of life from each day.

In a year when we have contended with a war, with generalized anxiety about the present as well as the future, when we had a blackout, and the economy seemed to tank, when new viruses froze the entry points to places around the world, I would be mocking even Pollyanna to claim that this is the best of all possible worlds. What is true is that it's the only world we've got, and we need to fix it when we can. That may push us to expand our willingness to act beyond our usual comfort zone. And, like our patient with the binoculars, we need to learn how to come to terms with what cannot be changed and still find those moments of connection, of pleasure, of love and beauty, that we can affirm, right to the end.



Nina Miller

Nina Miller

Profile

First in a series of profiles of members of the Hospicare Board of Directors by Gary Stewart

Don Stewart



The fact that Don Stewart's "favorite quote" (see box) focuses on chicken barbeques rather than high finance says a lot about this longtime Hospicare board member. Like most of his board colleagues, Don is devoted to career, community, and family. He also has a requisite uplifting perspective about life, and the challenges tied to death, that make a difference for Hospicare and its mission.

It's no surprise that Don's first exposure to Hospicare was through executive director Nina Miller, master recruiter. He says, "She convinced me to join the board, and I have never regretted it.

"Many of us have lost a family member or friend who suffered from a life-ending illness, who might have benefited from hospice services," Don said recently. "I myself have lost a younger brother and several close friends to cancer.

"I think I've been able to contribute to the continued success of the hospice movement in Tompkins County through my service on the board. But I've received much more in return by seeing the importance of the services the agency provides to our patients and their families. The real 'heroes' are our staff and the volunteers who work directly with the patients."

The Hospicare Board of Directors is a cast with character that brings distinct talents and connections to the King Road table. Don's expertise with money matters has been invaluable several times over the years.

Clichés aside, the agency can't put a price on his advice and insight. This was especially reflected during a landmark era in Hospicare's history.

"I joined the board during the construction of the Residence; it was the first in New York State. When the construction was complete and we admitted our first patient, we felt that the project was complete. But the first couple of years were difficult ones, as the community was not aware that the Residence was available.

"Because the cost of running the Residence with one patient or with full occupancy is the same, we had to watch our budget carefully. We had to close the residence temporarily to regroup and raise a contingency fund to support the operation so it would not be a financial drain on our home-care program. That was a very difficult decision, but we were able to bridge that period and now the residence is almost always full, with a waiting list."

For Don Stewart, the mission of Hospicare will always revolve around moving ahead, marking successes, and getting the word out. He notes with trademark practicality, "Our new Palliative Care Services are a critical addition that will allow us to help more people who might not be appropriate for hospice services. And we need to continue to increase community awareness of Hospicare, not only so we can serve more families in need of the support, but also to encourage the community to financially support the organization.

"Our fund-raising efforts," says Don, "are critical if we want to continue to provide this service to the community."

Thankfully, Don Stewart's efforts in this area have transcended chicken barbeques, though his humor, drive, and big-picture philosophies serve as a constant reminder: the little things count for a lot at Hospicare and for the people we serve.



Residence:

Ithaca, N.Y.

Family:

Wife Sis, a registered nurse in Cayuga Medical Center's emergency room, and sons Chris, a writer in New York City, and DJ, who attends graduate school in Chicago.

Occupation:

Executive vice president, Tompkins Investment Services, Tompkins Trust Company.

Pastimes:

Family, golf, and various other athletic attempts, including kayaking, hiking, and tennis.

Years on the Hospicare Board:

Started in 1995, president in 2000-2001, began a third term in 2002. Also serves on the board of the Hospicare Foundation.

Favorite quote:

"This chicken barbeque has the potential to be one of our most successful fund-raising efforts." *

*Footnote from Nina Miller: "Unfortunately, the chicken barbecue turned out to be the least successful fund-raising effort in Hospicare's history, and the board members who got up at dawn and labored over hot coals are still trying to get the smell of barbecue sauce out of their hair!"

Palliative Care Service Takes On the Work of the Ithaca Cancer Network

When the Ithaca Cancer Network was organized some years ago, it was done so by Pamela Carson. Some of you may remember Pamela, the former executive director of Educate the Children. When Pamela developed stomach cancer, she looked around the community for a support group and found that the only groups were for people with breast or prostate cancer.

Being a long-time activist, Pamela decided to organize a support group for people with any kind of cancer. The group was so successful that a second was offered, and a decision then was made to incorporate both as the Ithaca Cancer Network (ICaN), a service run totally by volunteers. Soon, Partners in Healing, a one-to-one support program, was added. With memorial and other gifts, ICaN assembled a collection of books, videos, and audiotapes for its resource center, available to the public.

In the past year, the ICaN board of directors realized that if, in fact, the program were to continue growing, it needed the energy and commitment of an organization with staff resources. At the same time, Hospicare had begun its expansion into palliative care, serving people at any stage of a life-threatening illness. After careful consideration by both boards, the Ithaca Cancer Network was incorporated as the Cancer Support Program at Hospicare and Palliative Care Services.

The first offering of the Cancer Support Program is a six-part educational series called Living with Cancer, which began in September and extends to the end of October. In mid-fall, a support group for people with any kind of cancer will be led by Jeff Collins, certified social worker at Hospicare and Palliative Care Services. The resource center has been relocated to the small conference room at the Hospicare Center, where material may be signed out during working hours or by special arrangement.

The Cancer Support Program will be funded by donations. For information about any of the activities of the Cancer Support Program, call 272-0212.



Raymond and Margaret McElwee Fund for Staff Development Established

Thanks to a generous gift, the Raymond and Margaret McElwee Fund for Staff Development has been established at Hospicare and Palliative Care Services.

"My mother was a true believer in Hospicare, and she was always grateful for the care they provided for my dad," said Pat McElwee, the couple's daughter. "And when mom died recently, they were there for us again. They made what could have been a nightmare into a peaceful and smooth transition."

The McElwees were active in community affairs and had a deep belief that staff members need both support and opportunities for growth in their work. "I know they would be pleased to have this fund established in their names," Pat continued.

Contributions may be sent to Hospicare and Palliative Care Services, 172 East King Road, Ithaca, NY 14850 and earmarked for the McElwee Fund.



Save the date!

Christmas in the Country, a benefit sale for Hospicare and Palliative Care Services, will be held on **Saturday and Sunday, December 6 and 7**, at the Rogue's Harbor Inn in Lansing. Sponsored by Merchants and More on Cayuga's Eastern Shore, the sale will include poinsettias, wreaths, antiques, holiday decorations, and unique holiday gifts.



Check their web site for more information:
www.cayugaseastshore.com.

have many visitors, the Hospicare team—his nurse Lisa, his home health aide, and his volunteer—became a family, not just in terms of medical advocacy, but in terms of his emotional needs in the last year and a half of his life.

Both Tom and Lisa knew that Mr. H. was a devoted fan of Elvis Presley. He had his own “boom box” and a pile of tapes that made it possible for him to listen to Elvis whenever he wished. Knowing this about her patient, Lisa sang him “Heart-break Hotel” and “Nothing but a Hound Dog” while doing her nursing care. She also admits that at the annual gift exchange among the Hospicare staff she connived to get an Elvis magnet someone had brought in as a fun present, because she knew that Mr. H. would treasure it more than anybody.

Mr. H.’s last birthday was memorable. His Hospicare team, including Wendy Yettru, the volunteer coordinator,

planned a special celebration that included hiring Steve Southworth, a local singer with the Rock-a-Billy Rays, to entertain at the nursing home. With wonderful cooperation from the Lakeside staff, a time was designated, a room set up, and a cake baked. Staff and residents sang and danced for over an hour at the “Elvis Serenade,” all in Mr. H.’s honor.

Mr. H. died within a few months, but according to all reports, he never stopped talking about the party and all his “good friends” who were there.

Lisa Skeval’s perspective on her experience with Mr. H. reflects the integration of her professional skills and her deep personal commitment to the unique individuality of each of her patients. Although she once thought Hospicare nursing would be “too sad,” Lisa told the story joyfully of her involvement with Mr. H., knowing that she

and the Hospicare team, together with the nursing home staff, had made a significant impact on his life.

“Our team offered Mr. H. special support, advocacy, medical expertise, and friendship,” Lisa explained, “and that was a great combination. The team approach makes Hospicare unusual. There are a lot of people in nursing homes who could benefit from calling us,” she concluded. “We enjoy working with nursing home staff, because we all want the same goal: increasing the comfort and peace of our patients.” In this case, Elvis was wonderful medicine, and Hospicare and Lakeside Nursing Home were willing to carry the tune.

Hospicare services are available to any nursing home patients who meet hospice criteria. For information call 272-0212.



Hospicare and Palliative Care Services Receives Grant from the Y Group

“Wait a minute, I know who that is!” That’s what you may say when you watch the new video made by Hark Productions to help explain palliative care to the public. The video was made possible through a grant to Hospicare and Palliative Care Services from the Y

Group. Our proposal was 1 of 20 entries, and we were delighted to learn that we had won. Created by film maker Kevin Hicks of Hark Productions, the “actors” in the video are members of the Hospicare staff, with guest commentary by Dr. Charles Garbo and testimonials

by two very courageous people who have used the Palliative Care service. Watch for the video on our web site, www.Hospicare.org, or call and we’ll arrange a showing for you.



Conference on End-of-Life Care for People with Alzheimer’s Disease

Hospicare and the Alzheimer’s Association are co-sponsoring a half-day conference for professionals and others working with people with Alzheimer’s disease. The conference is called “The End of the Journey,” and it deals with issues such as treating pain in patients

with dementia, recognizing terminality, and special issues of bereavement. There is a \$25 charge for the workshop, and preregistration can be completed by calling Florence Smith of the Alzheimer’s Association at 272-3491.



Camp Good Grief

Saoirse McClory



Following days of gray skies and frequent torrential rains, July 26th was sunny and beautiful as 22 children, between the ages of 6 and 14, arrived for Hospicare's second annual Good Grief Camp. This was more than double the number who attended in 2002, the camp's first year. They were directed to the gardens by hand-painted signs of Snoopy and friends. Several children descended excitedly upon the registration table, eagerly decorating their nametags and wriggling into their new t-shirts. Others held back, less sure they wanted to be there. One small child, held in her father's arms, said she felt "excited and scared at the same time"—a feeling, I think, shared by many of the children.

All of these children had experienced the death of someone close to them—a parent, grandparent, or sibling. Each was familiar with the pain and confusion of separation from someone beloved. Today they were going to meet other children with similar experiences. Together they would join in activities to remember their loved ones and be supported in finding words and positive ways of expressing difficult feelings.

The day began with the children decorating t-shirts for themselves. Some drew angels and flowers, others, dinosaurs, and some, broken hearts. As we sat in a circle and introduced ourselves to one another, Crossroads the Clown arrived atop a large

motorcycle. Orange mop hair sprang out from underneath his helmet, and his two-foot-long shoes slapped the ground as he made his way to where we sat. As he bantered with the children, asking them questions and answering theirs, the clown pulled from his bag silly hats and other objects that elicited squeals from the children. Soon Crossroads was deftly twisting balloons into animal shapes, juggling batons, and painting dragons, puppies, and swords on the children's arms and faces.

Sporting their new "tattoos," the children formed small groups, or healing circles, and began to talk about their losses. These circles were designed to provide children with an opportunity to talk openly about the death in a safe place. The children also were able to hear other's stories and so reduce the sense of isolation that a bereaved child may feel. In our group each child took turns holding a teddy bear as he or she told the others in the circle about the death of their loved one.

In a while the children were ready to "get to the fun stuff" (as one child in our group put it), and so the first healing circles were followed by canoeing on the pond, planting rosemary (symbolizing remembrance) in terracotta pots decorated by the children, and making memory boxes with pictures cut from magazines, stickers, and ribbons.

During a picnic lunch, the Cayuga Community Role Players enacted thought-

ful, improvised role plays, showing in one scene a third grader returning to school after the death of her grandmother and her interaction with her classmates. The role players stopped the scene and invited their young audience to comment on what was going on in the scene. How were these schoolchildren feeling? How could things have been better? Children in the audience raised their hands and remarked on what they'd observed. Some children referred to their own experiences of returning to school following the death of their parent or grandparent. They asked questions and offered advice to the role players, who remained in character.

Next the children rejoined their "healing circles," this time to talk about feelings. The younger children were shown cards of children in different situations exhibiting various facial expressions. What do you think this child is feeling? Anger? Frustration? Guilt? Sadness? Loneliness? And this child? Joy? Relief? Curiosity? Do you ever feel this way? What do you do when you feel this way?

The children helped each other find words for a variety of feelings and were reassured that all those feelings are very natural to experience when someone you love has died. The children were encouraged to find appropriate ways for dealing with some of the hard and painful feelings that may arise.

At 2:30 p.m. Beauty and the Beast Storytellers arrived, along with Ken Zeserson, who played guitar and sang. Many of the children remembered the storytellers from their schools and greeted them with gleeful recollections of previous storytelling sessions. Beauty and the Beast told fantastical tales in hilarious voices to the children, who joined in with energy and enthusiasm.

As the storytellers wove their magic, Jeannette Berretta and Christine Lloyd from the Wounded Healers Bereavement Support Group spent time with the children's parents and caregivers, who had been invited for the remainder of the afternoon. This gathering gave the adults an opportunity to talk about the challenge of dealing with their own grief along with the grief of their children and to receive support and guidance from others in similar situations.

As the camp came to a close, the children

20th Anniversary Celebration

wrote notes to their loved one who had died and tied them to a balloon. After planting a tree in memory of their loved one, they released the balloons together into the air and watched them rise up and float into the distance.

The day ended with ice cream, and each child received a packet of information about children and grieving along with a small bag, or "survival kit," to take home.

Each kit contained the following list to describe the items enclosed:

A lifesaver—to remind you of the many times others need your help and you need theirs.

A cotton ball—cushioned support of a friend for the tough road ahead.

A rubber band—a reminder to stay flexible.

A candy Kiss and Hug—we all need hugs and kisses.

An eraser—a reminder that every day you can start anew.

A paper clip—to help hold it all together.

A candle—a reminder to share your light.

A marble—to help keep you rolling (or in case you lose one!)

Sweet and sour candy—to help you accept and appreciate other's differences.

A happy face—smiling not only feels good, it's contagious.

A Band-Aid—for healing hurt feelings, yours or someone else's.

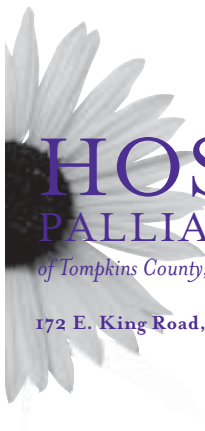
A paper butterfly containing flower seeds—to plant in your garden so that wildflowers will blossom year after year in memory of your loved one.

Grief is real for children, although they often express it differently from adults. Camp Good Grief aims to combine education and fun as a model for the continuation of healthy grief work. The children who came to this camp are wonderful teachers, and we at Hospicare are eager and grateful to learn from them. We hope to continue to develop and improve the services we offer to children in our community.

As one of the camp's staff members, I found it a lovely day: fun, helpful, sad, difficult, and very inspiring. Special thanks to the camp's sponsors and to Donna George, bereavement coordinator, and the mental health professionals and hospice volunteers who worked with her to make Camp Good Grief a moving and meaningful experience for all.



And a good time was had by all! Hospicare celebrated its 20th anniversary of incorporation on June 26th with a gala dinner, sponsored by the Tompkins Trust Company. Awards were presented to Judy Malloy and, in absentia, Jerry Nye for their tireless work in creating the Hospicare residence. Human resources chair Marcia Fort presented awards for service of five or more years to staff members Jeff Collins, Donna George, James Geuder, Mikki McGivern, Shirley White, Pauline Cameron, Michelle Anzalone, and Nina Miller. Dr. Timothy Quill, noted palliative care physician and author, gave a quietly inspiring talk. Thanks to all who made the evening so special: the Fingerlakes Strings, Hope's Way, Patisserie Renee Senne, the Plantations, Michaeleen's, the staff at Cornell's Biotechnology Building, invitation designer Dennis Kulis—and especially, our own Debbie Cady, who really knows how to throw a party!



HOSPICARE AND PALLIATIVE CARE SERVICES

of Tompkins County, Inc.

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Hospicare Wish List



Bird seed (our feathered friends consume huge quantities of it, to the pleasure of our patients and their visitors!)

A digital camera

Three-hole punches

Scissors

Videos for the Residence

An under-the-counter dishwasher

Lift chairs

Coag-Check—costs about \$1,000. This is a finger-stick device for checking blood clotting. It is easier and less painful for our patients than the usual method of drawing blood.

Microwaveable heating pads (filled with rice, cherry pits, etc.)

An ear (tympanic) thermometer

Visit us at www.hospicare.org

