

# HOSPICARE

## NEWS

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MARCH 2004

### The Littlest Caregiver

BY JOAN JACOBS BRUMBERG

Late last June, Hospicare director Nina Miller handed me a striking photograph, the one you see above. Unfortunately, our newsletter's black and white format cannot capture the wonderful colors of the tie-dyed tee shirt or the matching purple bandanas covering the heads of both adult and child. Yet even in black and white, you should be able to see the affection radiating from both faces. I wanted to know more about the picture, especially when Nina told me that at the time it was taken the patient was cooing with pleasure, even though she had lost her ability to speak and was in the final weeks of her life.

The woman to the right is Nancy Cannata, a Trumansburg resident and Cornell employee who died in August 2003 at the age of 65 after a long and courageous fight with ovarian cancer. Although Nancy lived alone and had neither children nor siblings, the last years of her life were enriched by a caring and compassionate group of woman friends who called themselves the "five sisters": Pat Dougherty, Cheryl Martak, Lina Brooks, Alanna Downey, and Alanna Criner. They came together to help Nancy deal with her surgeries and her treatments as she faced a life-threatening illness. One of the "sisters" acted as health care proxy; another as the executor of her estate; others took care of



her house and belongings—most notably her beloved cats—whenever she had to be hospitalized. Another drove her to work in Ithaca when she so badly wanted to resume her job editing "Class Notes" for the *Cornell Magazine*.

Nancy had an enormous will to live and resisted turning to Hospicare until she had exhausted every possible medical intervention, including numerous surgeries and forms of chemotherapy. Pat Dougherty told me: "She laughed hard, cried hard, and enjoyed life." She was the kind of person who defined herself as a "hard-assed Pole," and she believed she could "beat her disease." In fact, she did live well beyond the prognosis she was originally given.

For over four years, Nancy struggled with her disease, and these friends were with her in good times and bad. "We all felt like her advocates," Pat explained. "I even went to the doctor with her and wrote everything down so she would have the information later." After Nancy entered the Hospicare Residence this past June, the "five sisters"—assisted by Hospicare staff—threw a birthday party for Nancy at her own home. Although she had to be transported there by a Gadabout bus on a gurney, she was thrilled and pleased by an impromptu musicale with people serenading her in her own dining room, the music coming from bowls and shakers as well as a harmonica.

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## A Message from the Director



Confession: I'm one of those long-term Ithacans who has never come to grips with winter. I have not learned to embrace the gray.

Outside my window, it is a typical Ithaca winter scene: snow on the ground, the pond frozen and bumpy with ice, tree branches exposed and barren, an occasional white-out when the wind whips out angrily. And most of all, gray sky. The heron, who until late fall browsed the shallow waters of the pond on his spindly legs, is no longer visiting. I hope he is somewhere warm. Even the ducks

spend more time pressed close to the walls of the building, pecking at spillage from our dozens of bird feeders.

True, there are moments when I can almost find pleasure in the winter landscape, especially those hushed nights when Trotsky, our terrier, and I walk out into newly fallen snow that has powdered each twig on the trees along our path. But mostly I grouse, as I pull on layers of clothing and boots and view going out to get the newspaper as a challenge akin to the conquest of Everest.

Perhaps the most difficult part of winter for me is the gray. When we first arrived with our young family, Seasonal Affective Disorder had not yet been identified. But we knew of some people who left the community after a year or two, finding themselves inexplicably depressed by the lack of sunlight. Rumor has it that Ithaca is one of the least sunny places in the United States because of lake effects. That seems to me a marvelous irony, and an invitation to succumb to metaphor. The lake—that wonder of nature that is the source of so much pleasure and beauty—is also the major cause of our cloudy days, our blowing, drifting snow.

I won't say that the metaphor makes the winter any easier to bear, but it does make me think about the value of contrasts: bright/dark; well/ill; life/death. I wonder if we need to experience one to value the other. I never cared so much about the coming of spring or experienced the beautiful melancholy of autumn when we lived in a place where winter was less dramatic. We take for granted—in fact we don't even think about—not having a headache until we have one, and when it eases we are filled with the pleasure of its absence.

It can be tempting in good times to avoid thinking about the mutability of our lives. While it may provide some comfort to stash in our "to be considered later" file thoughts of what may be difficult or challenging, there is a cost to be paid. Many people flee from the certainty of death, living as if their days were infinite. And in so doing, they may neglect opportunities to protect themselves and those they love by completing advance directives—the appointment of a health care proxy and completion of a living will, writing a will, expressing one's wishes about funeral arrangements. These are the practical matters that, in the midst of life's rich vitality, are a reminder of its eventual absence.

If in the fullness of our days we truly accepted the reality that they are finite, would we use them differently? Would we communicate more openly with those we love, do more to leave our mark on our community, turn off the television and read some of those books we've promised ourselves we would get to one day? Would we attend to our relationship to our spiritual selves?

I've wandered far afield in this little musing. Perhaps that's a hazard of too much time indoors in front of a computer screen. Maybe I'll pull on my boots and take Trotsky out for a walk. There's a hint of brightness behind the low-lying clouds. It's the end of January—only two months until spring.



*Nina Miller*  
Nina Miller

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# Profile

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

## Alice Moore



The friends and neighbors who connect with Hospicare every year are an eclectic group, as are the men and women who serve on the agency's board. The directors come from various disciplines, though they share much in common, including a strong work ethic and a marked compassion. Alice Moore is a good fit in the mix.

Everybody comes to the Hospicare board with a story about why they're there. In Alice's case: "Five years ago my mother-in-law became critically ill in California. No one was there to take care of her, and we were faced with the challenge of making arrangements for her should she be able to leave the hospital. I had read and heard of all the wonderful things Hospicare did, and had seen it in action during Judith Aronson's death, so I suggested to my husband that he call Nina Miller.

"It was no surprise that she was simply wonderful and gave us good advice and counsel," says Alice. "As it turned out, my mother-in-law died and the services of Hospicare were not needed. But as a result of this experience, and my admiration of Nina Miller's many contributions to many agencies in the community, I could not say no when asked to serve."

Perceptive and goal-oriented, Alice brings the human touch and years of practical, professional experience to the board. For her, it's all about community and the next set of goals, starting with the basics.

"I have several friends who are volunteers at Hospicare. They are so committed and devoted to their volunteer efforts and to the work Hospicare does. In December I attended for the first time the Light the Landscape program and was struck by the sentiments expressed by the people participating. It is a wonderful venue for families and friends to remember and honor loved ones. It makes me proud to be a part of this important community resource."

Alice is determined to help keep that resource successful and accessible. Like any viable nonprofit agency, Hospicare remains a fluid work in progress. Its myriad supporters, including board members, have to look ahead to the next series of challenges and opportunities, and decisions aren't always easy.

"Having adequate resources and facilities to meet the demands will always be a challenge," says Alice. "The demographics of the local population most likely will dictate an increased demand for hospice services over time, as well as for palliative care. Increasing the awareness of our palliative care services is a very important goal for us. Working with the issues that confront us as a result of the politics of death will always be a challenge.

"Still," says Alice, ever positive, "the leadership and participation of the community members involved in Hospicare and Palliative Care Services of Tompkins County, and the commitment and support of those using the services, will carry the day. They will most assuredly guarantee that those services will be available to those who need and want them."

In more ways than one, leadership and participation represent Alice Moore, mother, wife, business person, and Hospicare Board member. She's a valued player on a very good team.



### Residence:

Ithaca, N.Y.

### Family:

Husband Robert Smith, a professor of labor economics and associate dean in Cornell's School of Industrial and Labor Relations, and five children: Theo, Becca, Libby, Alicia, and Gabrielle; the youngest is a senior at Cornell.

### Occupation:

An associate broker with Audrey Edelman and Associates and a realtor since 1986, after 22 years of employment at Cornell, primarily in human resources.

### Pastimes:

Family, traveling, and cooking; long-time member of the Planned Parenthood of Tompkins County Board of Directors.

### Years on the Hospicare Board:

Since 2001; member of the Personnel Committee.

### Favorite quote:

"They that can give up essential liberty to obtain a little temporary safety deserve neither liberty nor safety."

—Benjamin Franklin

## Staff News

We are delighted to welcome new faces to our staff. **Linda Hubert**, administrative assistant, is the first voice you are most likely to hear when you call HPCS. Beverly Hubbard has joined us as assistant to the director of finance. **Regina O'Donnell** is our new primary and Residence nurse. Regina, a nurse practitioner, worked as a midwife and decided that there were striking parallels between helping people who were coming into the world and those who were leaving it.

**Patricia Butler and Susan Iglthaler** are both talented licensed practical nurses who are working in the field to provide personal care to our patients. And we are delighted to welcome back **Amy Farrell**, who is a certified hospice and palliative care nurse. Amy is overseeing our Quality Improvement Program.

## A Successful Year

Thanks to the generosity of this wonderful community, Hospicare and Palliative Care Services met and even exceeded its fund-raising goal for the year. Our deepest gratitude to all the donors who responded to our Friends' Campaign, or gave memorial and other gifts, and to all the volunteers who raised funds through special events.

## Cancer Support Group

As part of our Palliative Care Services, we are offering a drop-in support group for people with cancer. The group will meet on the first and third Wednesday of the month from noon to 1:30 p.m. at the Hospicare Center, 172 East King Road. Suzanne Merryfield, C.S.W., who has many years of experience working with people with serious illness, will be the group leader. There is no charge for attendance, and people with any kind or in any stage of cancer are welcome. For more information, call Suzanne at 272-0212.

## Congratulations

To **Mikki Megivern, Pauline Cameron, Lisa Skeval, and Cathy Knauff** for passing the examination for certification as hospice and palliative care nurses. The exam recertified Mikki and Pauline for another four years. We're very proud of all of them!

## Upcoming Events

- April 24** Elegant Yard Sale, 9:00 a.m.–1:00 p.m., at Hospicare (now accepting donations)
- April 15** "Providing Culturally Competent Care: Diversity and Life-Threatening Illness," 7:00 p.m. in the Borg Warner Room of the Tompkins County Library
- May 1** Team Hospicare Bowls! at Ide's Lanes, 5:00–8:00 p.m.
- May 3** Volunteer training begins
- May 28** Illuminations, Hospicare's annual Memorial Day observance


## Littlest Caregiver *continued from page 1*

One of Nancy's very special friends was Pat Dougherty's grandson, the little boy in the photograph at her side with his arm around her. Over the years, Nancy had visited Pat Dougherty's home many times, and that's where she met Jacob, who lived next door. When they first met, Jacob was just seven years old. He was a good student at Newfield Elementary School and fond of baseball and basketball. He and Nancy became friends, his grandmother says, primarily because they both liked to talk about England. Nancy had been there, and Jacob was learning about England in school. Over the next two years, the two saw each other at picnics and cookouts, and they talked about many things, including the New York Yankees; but they never talked about Nancy's illness, even though she was obviously getting sicker and weaker. When Nancy began to wear a head scarf to cover the baldness that resulted from her chemotherapy, Jacob donned one himself. When he was nine, he volunteered to walk on Nancy's behalf in the American Cancer Society's local Relay for Life. He told his grandmother, "I want to walk for Nancy. I'm sort of a caregiver to her."

Jacob understood that Nancy was seriously ill, but he was never frightened by her deteriorating condition. Nancy always delighted in his conversation and in his acceptance. In June when he and his grandmother came to visit Nancy at the Hospicare Residence, they found that she had experienced a small stroke. Jacob waited patiently in the living room until the ambulance came. He kissed her arm as she was placed in it, and Nancy managed to blow him a kiss as well.

Pat Dougherty speaks with love and pride about how Jacob handled Nancy's death in the Residence just a few months later. When she tried to prepare him for the fact that their friend's death was imminent, Jacob told her candidly, "I want to know, but I don't want to know." Grandmother and grandson agreed then to a secret code: when Nancy did die, Grandma would tell him that there was a new light in the sky.

In August Pat Dougherty returned home from the bedside vigil at the Residence to tell her grandson that there was a new star in the sky. Jacob said very little and went to his room and cried. But soon afterwards, he came to sit with his grandmother to say that he was ready to hear what had happened. With one leg thrown casually over his grandmother's, he listened carefully as she told him how the "five sisters" had gathered to be at Nancy's bedside, about the candles they lit, how they held her hands, and how she slipped away peacefully. A few days later, Jacob told Pat wisely, "I realized she wouldn't die before you got there, Grandma."

Jacob really was the littlest caregiver in Nancy's surrogate family. As a group, the "five sisters" provided young Jacob with a model of compassionate behavior in the face of human illness. What might have been a lonely and frightening experience for Nancy Cannata became for everyone concerned—patient as well as caregivers—a time of meaningful connection, this time across the generational divide 

# The Winding Road from Surgery to Hospicare

BY JOE WILENSKY

**R**oy Coats, who was a practicing surgeon in Tompkins County for three decades before he became Hospicare's medical director, has often explained that hospice medicine is as different from surgery as pediatrics is from dentistry.

Coats served as medical director of Hospicare for six years, first becoming involved with Hospicare when he was still a full-time surgeon. He retired from Hospicare in October 2002, although he remains in a consultant position and fills in when the current medical director, Eric Lessinger, is unavailable.

"The philosophy I brought into the position was a philosophy of the patient as number one," Coats explains. "We tried to do all we could to make patients comfortable and as free of pain as we possibly could—and we always tried to be creative in our thinking. Creativity is a very strong part of being a hospice professional, because there are a lot of things that go on toward the end of life that you're not prepared for, medically speaking."

When patient comfort is paramount, medical staff have to be prepared to look for different, often innovative, solutions that may not be common knowledge, he says.

Another issue Coats dealt with often was fear of addiction—something doctors and medical personnel have had to overcome when taking care of patients who are in a lot of pain. "Addiction really does not occur on the basis of pain," Coats describes. "It occurs on a basis of psychological need. So when there is pain, and a person is battling that pain, the use of opiates, even in high doses, may cause dependence, but not necessarily addiction." He describes dependence as something you need to have, but also something that can be tapered off. Addiction, in contrast, is a psychological need to have a particular drug. "And that becomes a much more difficult thing to defeat, to take care of," he says. "We almost never had any problems with that."

Medicare places restrictions on coverage for hospice care for terminally ill patients, requiring a life expectancy of six



months or less, if the disease runs its normal course. It's a prognosis that doctors often hesitate to issue and one with which many patients and their families have difficulty. Coats is enthusiastic about the new emphasis on palliative care, which means that Hospicare can now offer services to people with life-threatening illnesses long before a six-month prognosis comes into view.

Through palliative care, Hospicare is able to manage patients' symptoms even while they are still receiving active treatment—another major distinction from traditional hospice care. "By definition, hospice can be rendered only when there are no active treatments being used to 'cure the disease,'" Coats says. "So if a person is on big-league chemotherapy or big-league curative radiation therapy, they can't really be in hospice care. But this is not true with palliative care. They can be on treatment, they can be expected to have some recovery, and possibly even a miraculous cure, and still receive the physical, emotional, and spiritual support provided by palliative care."

Coats fondly remembers working closely with Hospicare staff and nurses and the wonderful rapport they had. The entire Hospicare team is very savvy in negotiating and publicizing the myriad services available in the community and connects people with what they need, he says, "Ithaca is a very blessed community as far as available services are concerned. We have visiting nurse services, we have Gada-bout, we have everything from A to Z."

One of Coats's proudest accomplishments is *The "Roy" Book*, which is essentially a printed version of what could be described as the Hospicare medical manual. During his six years as director, Coats streamlined processes, established protocols, codified procedures, and detailed regimens, which are now assembled in a reference form. Hospicare staff members compiled the booklet, had it printed for Hospicare's use, and presented a copy to Coats when he retired. It's made to be easily updated and features a photograph of Coats on the cover, which is appropriate because this gentle surgeon has been identified with Hospicare for the better part of the past decade.



# The Doctor Is In . . . New York: An Interview with Eric Lessinger

BY JOAN JACOBS BRUMBERG



**Eric Lessinger**, Hospicare and Palliative Care Service's medical director, recently spent a month at Mt. Sinai Hospital in Manhattan

for special training in palliative care, our organization's newest initiative. His responses to questions posed by newsletter editor Joan Jacobs Brumberg are instructive for what they tell us about the nature and importance of palliative care and its future in Ithaca.

**Brumberg:** Tell me about your experience at Mt. Sinai.

**Lessinger:** I spent four weeks working as part of the palliative care team. No program exists for training people at my level of experience, so this was arranged at my initiative as a special program, a kind of hybrid, although the team is interested in the possibility of making it into a program for practicing physicians who want to go back for more training as I did. Palliative care as a medical specialty is relatively young—about 10 years—but growing rapidly.

Mt. Sinai is a prominent tertiary care institution at the forefront of high-tech medicine, and the culture there is to treat everything possible. This has led to seeing death as a failure rather than an inevitable end to life. Therefore, many physicians in that setting will treat people's diseases until they die. For example, you will see long-term cancer patients still in the hospital and getting chemotherapy on the day they die, never having the opportunity to step back, acknowledge, and deal with the fact that death is coming. As a result, the palliative care team at Mt. Sinai is in the belly of the beast, and it has to be careful to tread lightly as it tries to educate providers, patients, and families.

**Brumberg:** How was your time organized?

**Lessinger:** We met every morning, Monday through Friday, at 8:00 a.m. for one-half to one hour as a team, which included the main attending physician for the month, the nurse who administers the program, the social worker who does bereavement counseling, and two subteams, each headed by a nurse and having one or two trainees (fourth year medical students, residents, or fellows and me). Residents are ranked by their postgraduate year, normally one, two, or three, so I jokingly introduced myself as a PGY-31. We would go over the list of inpatients that we were seeing (usually 15 to 30), follow up on previous consultations, and note what needed to be done—such as arranging a family meeting, checking on the adequacy of a new pain control regimen, trying to get a health care proxy designated, etc. Then we would divide up the new consultations and run around all day, catching a little lunch on the fly, until we were finished, usually between 5:30 and 7:00 p.m. We did a lot of pain control and a lot of clarification of goals of care and plans of care, and arranging appropriate discharge placements to a home hospice program, various nursing homes, Calvary Hospital and Hospice, etc. We also had a lot of family meetings to provide information, both medical and prognostic, to concerned families and to give them a chance to come to grips with difficult realities. The role of consultant was hard for me in several ways—making recommendations but not being in charge, getting emotionally involved and then having to sign off and move on when our job was done.

**Brumberg:** Was the definition of palliative care familiar to you, or in any way different from what you have experienced here in Ithaca?

**Lessinger:** What was different was the setting and the culture. The overwhelming majority of the Mt. Sinai patients were receiving very active treatment for their diseases. However, I haven't had much experience yet in Ithaca with providing palliative care to people getting active treatment for their disease, so this was new, if not different.

One thing I learned and very much appreciated was that it makes sense for the palliative care team to have no agenda for the patient and family. We were not trying to convince them to stop treating the disease and just go for comfort care—although we certainly did help many patients finally make the transition from active treatment of their disease to active treatment of the symptoms only and to hospice. A palliative care team works to make sure that patients and their families have the medical information to make good decisions and the emotional space to begin to deal with the extreme stress involved with a life-threatening illness. We can't and shouldn't prejudge the correct course of action for patients and families. In fact, modern medical treatment can be pretty amazing sometimes—not to mention the occasional miracle, for which no one can take credit. This makes palliative care more difficult for me emotionally than hospice—there is the anxiety about making the right decision about how aggressively to treat the disease, rather than relaxing with the thought that death is coming inevitably and we just have to treat the suffering and let nature take its course. In this regard I think my 30-plus years as a physician come in handy: I have some confidence when I say, "In my experience, this is what is likely to happen."

**Brumberg:** Did this recent "training" experience in any way change your perspective on our program in Ithaca, and if so, how?

Lessinger: To date, palliative care is an emerging program in Ithaca. I will try to bring the relevant parts of my experience in New York City to Ithaca, and especially to the Cayuga Medical Center. Once I obtain consulting privileges, I plan to lead a palliative care team that I hope will function in a way similar to that of the one at Mt. Sinai, with appropriate modifications for our size and our local medical culture. I want to persuade providers of health care that we should not try to push any philosophy on patients or families. We need to help people deal with their suffering whether or not they continue to pursue whatever treatment is recommended. We have to be more comfortable with medical treatment, including high-tech treatment, even though we are not directing that part of the treatment. But I also am determined to help our medical community recognize the value of looking squarely at extreme suffering, acknowledging death, and providing good palliative care.

Brumberg: How did the program you attended assure continuity of care once a patient left the hospital?

Lessinger: It didn't. We've got nothing to learn from the chaos of the New York City health care scene. Not that they didn't try, it's just that they didn't have much success, as far as I can tell. We should have a much better shot at continuity here, because Hospicare and Palliative Care Services will be the main agency coordinating palliative care. It may be a little tricky here too though, since we may often be consultants and not involved as intensely as we are with patients who opt for hospice. I expect that there will be many patients and families with whom we will establish an ongoing relationship for outpatient palliative care, and many of these may ultimately sign on for hospice as well. We will consult on patients in hospital, make suggestions to their primary care

provider, and sign off the case until we are called back. Part of ratcheting up the level of palliative care in the community involves working with and educating physicians and other care providers, so that we don't take over from them but help them to do it themselves.

Brumberg: What did this experience mean to you personally? Has it affected your view of yourself as a physician?

Lessinger: I worked hard and enjoyed the experience overall. I made some contacts with people I liked who are important in the palliative care field, and I hope to nourish those relationships—maybe get some of them to come to Ithaca to look over our program, or to co-teach with me an Education for Palliation and End-of-Life Care (EPEC) course to medical and nursing staff here. I felt good about myself in the context of my medical competence and my caring competence.

Brumberg: What do you consider to be the most common misunderstandings about palliative care?

Lessinger: The big misunderstanding is that the palliative care team has an agenda for the patient or family, that we are trying to get them to give up on medical treatment and just go for comfort care.

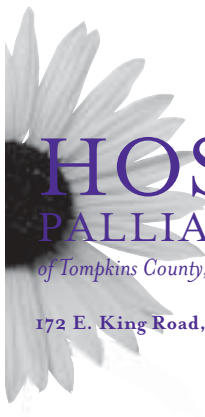
Not having an agenda can be very freeing for doctors and nurses; it was for me. For example, we went into the Neurosurgical ICU and met with the family of an elderly Greek man who had not recovered from a severe stroke and was dependent on a mechanical ventilator for survival. The palliative care team did not try to convince the family that it was the right thing to do to take him off the ventilator and allow him to die. We spent time finding out about the man and who he was, and what he might have wanted for himself in this situation, and about the family and what their relationships were like. Needless to say,

these are always complicated—a daughter who had been somewhat mistreated by him felt guilty about making a decision to let him die and “abstained” from the decision.

In effect, the palliative care team listened to this family try to sort out what might be “God’s plan” and whether the mechanical ventilator was God’s will, human folly, or something else. After our first 90-minute meeting, it was decided to continue the ventilator while the family continued to process the information and their feelings. It was decided to delay, at least for a day or two, a decision on tracheotomy and gastrostomy tubes, which would be needed soon if the patient were to be kept alive as long as possible. The possibility of a miracle was not totally discounted either—he might continue to breathe and recover after removal of the ventilator, although that was not what we expected. After a few more days and a few more meetings and phone calls, the family decided, without any pressure from us, on a “terminal wean.” This was scheduled when the family could be present, and the patient lived for about a day after coming off the ventilator, his dying process eased by medication. It was all very sad, but satisfying that we all did our best in the situation.

This kind of cooperative, humane decision making represents the best in palliative care.





# HOSPICARE AND PALLIATIVE CARE SERVICES

*of Tompkins County, Inc.*

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## Hospicare Wish List

Once again, we were awed by the response to our last wish list. We received every item on it, including a check to purchase a piece of medical equipment that will make drawing blood simpler, more comfortable, and more efficient. So we thank all of you who responded and humbly submit below our wish list for this season.

Black pens

Baby monitors

Head phones for televisions in patient rooms

Good knives—especially bread knife, carving knife

An ink-jet computer printer

Four pumps for alternating pressure pads (to prevent or relieve bedsores), \$83.86 each

Beds—the Residence has now been open for almost nine years, and our electric beds have been in constant use. We are starting to have significant problems with motors and other wear and tear. We hope to replace these beds with a very fine model that will last considerably longer and provide greater patient comfort and ease of operation. In addition, the operation of the bed facilitates patient care and ease of cleaning. Each costs approximately \$3,000.

Visit us at [www.hospicare.org](http://www.hospicare.org)

## Do You Make Purchases Online?

Of course our priority is to support our local businesses. But if you can't find what you're looking for at a locally owned store and need to turn to the Internet, you can help Hospicare by going first to [www.iGive.com](http://www.iGive.com) and registering Hospicare to receive a percentage of your purchase. There are about 500 online stores in the iGive mall. It's a painless way to make a contribution. Thank you!

