

# HOSPICARE

## NEWS

JUNE 2003

### In Celebration of Hospicare's Twentieth Anniversary of Service

NINA MILLER



As we considered what might be of interest in a newsletter recognizing our twentieth anniversary, we thought about offering a history of the agency: how we began, who got us launched, how we grew. Although local institution building always has some interest, the real story of Hospicare is the people—both those who have used our service and those who make it work.

As a result, we began to think about asking people in the community what Hospicare has meant to them. The voices you hear in these pages are a sampling of your friends and neighbors as they share their experiences and their ideas. If all of this seems a little self-congratulatory, allow us a moment for review since that's what anniversaries are for.

We have grown from a tiny office in the Presbyterian Church, to the Biggs Building, to our beautiful home on South Hill. Our unique Hospicare Residence, the first in New York State, is a model for many currently being developed. We also have expanded from services delivered by volunteers to a comprehensive interdisciplinary professional team able to deliver sophisticated pain management, symptom control, and emotional and spiritual counseling. We have moved from offering services only in patients' homes to caring for patients at their bedside in nursing homes and adult care facilities. And we have grown from offering a small bereavement program that addressed the needs of survivors to providing an expanded set of services for the entire community, including group and individual counseling as well as our "Good Grief" camp for children.

*continued on page 2*

# *20th Anniversary Celebration*

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## A Message from the Director *(continued from page 1)*



Children in the Intergenerational Nature Program bringing cheer and flowers to residents.

When it comes to our business—the end of life—we don't delude ourselves into thinking that we have all the answers. Yet we are out there, day after day, trying to do our best to ease the final journey of people in our community and care for their survivors as well.

There are many challenges before us. We need to help the community understand our newest direction, the provision of palliative care for those who may be getting treatments with a goal of cure but who still need help with the physical and emotional impact of life-threatening disease. We must carefully monitor the use of our hospice residence and determine if and when to expand the number of beds. We look forward to working in a harmonious partnership with more of the people who live in skilled nursing and adult care facilities. We are committed to keeping up in learning the latest technologies and strategies to treat and prevent pain. And we must attract and retain a well-trained staff who meet the highest standards of medical practice.

As we celebrate this twentieth year, we celebrate you. You have taken this program into your hearts and have opened your checkbooks to assure its continuity and its ability to provide whatever is needed by people whose lives have been changed by serious illness. We thank you for your faith in our mission and hope we will be able to share many more celebrations with you.

*Nina Miller*

*Hospicare News* is published three times a year by Hospicare and Palliative Care Services of Tompkins County, Inc.

### Editors

Joan Jacobs Brumberg  
Nina Miller  
Judy Stewart

### Designer

Dennis F. Kulis

### Printing

A New Beginning Press

Hospicare and Palliative Care  
Services of Tompkins County, Inc.

172 E. King Road  
Ithaca, New York 14850

Tel: 607/272-0212

Fax: 607/272-0237

e-mail: [hospicar@twcny.rr.com](mailto:hospicar@twcny.rr.com)

Web site: [www.hospicare.org](http://www.hospicare.org)

### Office Hours:

8:30 a.m. to 4:30 p.m.

Monday through Friday

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# The Real Story of Hospicare—From Those Who Know It Best

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Rev. Pete Hood, chaplain, Cayuga Medical Center at Ithaca

I first became acquainted with the hospice concept in the early 1980s when one of my parishioners became a patient with hospice services in her home in Trumansburg. I will never forget the fine physical, emotional, and spiritual care and attention she received. Later, after I moved away and received my credentials as a chaplain, my first chaplaincy job was with Hospicare of Dayton. For about seven years I had the privilege of visiting folks in their homes and providing spiritual care. In Dayton I was part of a care team—nursing, social work, health aides, and volunteers—which I called “the multi-symptom stress reliever.” The team provided time for the patient and the family to take care of unfinished business and to stay in a home environment of love and concern. (As our reputation became very favorable, we expanded to provide our services to folks in nursing homes.) Direct patient care with love and attention was at the center of all we did together. It was a wonderful ministry.

When I returned to the Ithaca area, I was privileged to serve on the Board of Directors of Hospicare for several years. Under the direction of Nina Miller, I saw a small service with a big heart and idea begin to grow. I know many of the staff personally, and I am impressed with their dedication and desire to provide meaningful end-of-life care to all who desire it. Yet despite efforts to publicize the work of Hospicare, many people still do not fully understand what a unique service we have here. My prayer is that this valuable service will be much better utilized. The hospice concept knows no creed, race, or economic boundaries. It is a service of ministry to all people. I congratulate Hospicare for the fine work it has done in these past twenty years and look forward to more of the same in the future.

Charles Garbo, M.D., and Irene Kohlberg, N.P.,  
Ithaca Medical Group

Despite rapid advances in technology and medications, a reality in an oncology practice is that many patients will eventually die from their cancer. Hospicare and Palliative Care Services has made the reality of incurable disease manageable for about 2,000 patients and their families over the past twenty years.

For two decades, we have watched Hospicare continuously assess the needs of our community and respond to them. From the tiny, stark offices in the Biggs Building to the graceful, peaceful residence on East King Road, Hospicare has met the need for end-of-life care in a manner that few communities can match. For those who choose care at home, a team of skilled professionals and volunteers provide superb, highly individualized care in the patient’s own, familiar environment. But not everyone can die at home, so the residence was a perfect response. More recently, Hospicare has recognized yet another reality: many patients who are actively treating their disease have side effects from those treatments; they and their families have emotional struggles; and pain and fatigue can make everyday activities seem overwhelming. And so the Palliative Care Program was born, making a highly specialized team available to meet the unique medical and emotional needs of patients still undergoing treatments such as chemotherapy and radiation.



Ray Oglesby, volunteer  
Hospicare means partnership, working together with wonderful staff and other volunteers to give those nearing the end of life, and their loved ones, a little extra touch of comfort and humanity. Sometimes it’s just a smile or, in my case, serving pancakes every week and a few fresh flowers in a bud vase. Sometimes my participation evolves into friendship, a friendship made poignant—but more meaningful—by our awareness of its inevitable briefness.

On a personal level, serving with Hospicare and Palliative Care Services has given me new insights into who I am and what I can still become even in retirement. In short, the concept and practice of “hospice” has imparted some of its inherent wisdom to me.

## *20th Anniversary Celebration*



David Banfield, president,  
The Hospicare Foundation

As someone who has benefited a lot from life, it only seems fair to give something back. While financial contributions are greatly needed, helpful, and most appreciated, getting involved in a hands-on way was my choice.

I have participated in many boards and organizations in Ithaca, but none so meaningful as Hospicare. When I was asked to join the Hospicare Foundation to help raise funds to build the residence, I couldn't have been more honored. All the meetings, phone calls, and visits to spread the news of our wonderful residence soon bore fruit. Suddenly, it grew from bare ground into a wonderful, welcoming facility to become a benchmark in Ithaca and New York State.

Today, twenty years later, we can look with pride at what we as a community have done. Our residence is blessed with many wonderful, caring staff and volunteers. Our gardens are tended by young and old, giving great comfort to those who spend their last precious moments with us. I was honored to have been a part of Hospicare's birth, and I am proud to be a part of its future—and so should everyone in the larger Ithaca community.

The issues facing cancer patients today are huge: the advent of new therapies to treat disease has allowed patients with cancer to live longer, productive lives. Although there may be an expectation of unending treatment options, those options can become exhausted. Fortunately, at this point, we never have to say, "There is nothing more we can do for you." We are privileged to be able to offer Hospicare as the logical next step in treatment.

As medical professionals, we are confident that the skilled professionals at Hospicare will meet the needs of our patients when they are unable to come into the office. We know that all interventions will be communicated to us, and that if a plan of care has to be changed, the team at Hospicare will make sound recommendations. We also know that if a patient needs a nurse, social worker, spiritual leader, or volunteer on short notice, Hospicare will deliver. We have come to expect that when our patients are facing the end of their lives, they will die with dignity and comfort. And we also know that those who love them will be cared for through the agency's bereavement services.

On this twentieth anniversary, we thank Hospicare for providing a standard of excellence in end-of-life care that keeps pace with modern medicine, and for being so attuned and responsive to the needs of our community.

Marty Luster, former member, New York State Assembly

My father died on July 5, 1975, following a one-year battle with cancer. After months of chemotherapy and experimental treatment, repeated hospital stays, and occasional temporary rallies, it became clear to him and to the family that the end was approaching. The thought of him languishing in a hospital bed, sometimes alone, receiving the impersonal attention that is often the hallmark of busy, big-city hospitals was something our family shuddered to imagine. More importantly, my father, a man of quiet dignity, made clear his wishes to die at home.

At home, Dad was provided with the assistance of a sensitive and caring physician who made frequent visits to the house, nursing services, and the company of family, including his young grandchildren, and friends. He was as comfortable as he could be, and we were comfortable knowing we had made the right decision. By being together we gave each other courage and were able to express our grief, share our stories, and express our love for him and for each other. Although my father and I had always had a good and loving relationship, the conversations we had with each other during those final weeks were the deepest and most significant of our lives.

I don't think I was aware of the word "hospice" in 1975, and I'm quite sure that professional hospice services were not easily available, even in New York City. However, it is clear to me now that what we instinctively put together during those difficult days was exactly the kind of end-of-life services rendered by Hospicare to our region, a service that allows the ill, their families, and their loved ones to face death in an atmosphere of mutual comfort and grace.



During my career as a member of the State Assembly, I was privileged to work with Hospicare on several occasions. I was happy to have sponsored the legislation that permitted the creation of Hospicare's unique residence, the first in the state, as well as the law that allows that facility to receive partial Medicaid funding for qualified residents. At other times I have worked with recipients of hospice home care services, residents at the East King Road facility, and the staff of Hospicare to deal with urgent requests for transportation assistance for a family, frustrating difficulties with one state agency or another, and once, to arrange for an expedited marriage ceremony.

I offer my most sincere congratulations to Hospicare of Tompkins County upon its twentieth anniversary. There are few in our community who have not, at some time in the past twenty years, known someone or some family that has received the kind, loving, and attentive care for which Hospicare is known. Hospicare has brought to those it serves that sense of peace that only those who have experienced it can fully understand.

Helen Daniel, volunteer

I became a Hospicare volunteer in the fall of 1998. I had taught elementary school in Ithaca for the previous twenty years and had worked with children all my adult life. I decided to retire at the end of the school year and looked forward to having free time to read, knit, cook and bake, garden, travel, and perhaps, learn some new skills. I also knew that I wanted to have some structure in my life, something I thought volunteer work might provide. Yet I knew it might take some time to find a specific volunteer opportunity that could provide a level of satisfaction and fulfillment comparable to teaching.

That fall I decided to learn something about what was expected of Hospicare volunteers and commit to the organization for one year, even though I was still teaching full-time. Sometimes I was tired and somewhat depleted as I drove to the Hospicare Residence for my Thursday dinnertime shift. But I invariably perked up as I began to prepare dinner or visit with one of the residents. By the time my shift ended, I left with a feeling of well-being and peace. I still do.

When I reflect on what I have gained personally from my association with Hospicare, I am overwhelmed. Where else could I have met so many interesting people? Because of this experience, I am part of the Hospicare family that does amazing work. What I do makes a difference, whether it is preparing a special food request for one of the residents, or working with a group of volunteers and staff to plan a special event such as the annual Memorial Service, or pushing the wheelchair of a resident through the exquisite gardens, pausing so she can reach out to cup a wildflower in her hand. My favorite carrot soup recipe at home was the soup I made for a resident; every time I make it, I still think of her. And I have sat quietly at the bedside of someone who will die within a few hours, holding her hand so that she will know that she is not alone.

Marcia J. Fort, director,  
GIAC

I am on the Hospicare Board of Directors and chairperson of the personnel committee. I became involved with Hospicare while trying to make the last days of life for my friend and co-worker Gale "Trim" Trimble comfortable and dignified. At Hospicare, we found warm, caring, and professional staff plus a residence that was beautiful and peaceful and allowed for personalized room decor. We found the support and assistance we needed to let Trim, our friend and family member, leave this life surrounded by people who loved her, pain free and at peace.

Through that difficult experience five and a half years ago, I gained an appreciation and deep respect for all the work that the wonderful and dedicated staff at Hospicare performs. I can never say thank you enough for the help we received. I decided to show my thanks by volunteering with an organization that does so much for so many people. Gale "Trim" Trimble died December 4, 1997. She is now our guardian angel and a bright shining star. Thank you to Hospicare for helping her to rise above with grace, spirit, love, and peace. Thank you Hospicare for enhancing the quality of both life and death in our community.

# *20th Anniversary Celebration*



Irene Stein, executive director, Tompkins County Office for the Aging

Most people want to die at home. Over twenty years ago, before the establishment of Hospicare, it was very difficult to accomplish this if dying was a long, drawn-out process. The hospice movement allowed the combination of resources to support both the patient and the care giver along the road to death by providing help, practical factual information, and, if desired, spiritual counseling.

And Hospicare did more. Although most people want to end their lives at home, some have to move to a nursing home. Today, when someone is dying, Hospicare comes into nursing homes as well. And most lately, Hospicare can help—through its palliative care services—when someone is fighting a life-threatening condition.

For these reasons, the Office for the Aging commends Hospicare for the wonderful assistance it has provided to over 2,100 Tompkins County residents during the past twenty years. Hospicare has distinctly enriched the array of social services in Tompkins County, and we thank all of you who have participated in this important work.

Every Hospicare volunteer has heard someone say, “I really admire you for what you do, but I couldn’t do it. I’d find it too depressing.” But it isn’t. We all feel sad when a resident we have come to know and care about dies, but we also feel privileged and honored to have been a small part of the life of that person, and of their loved ones, at this transcendent time of life. There is actually a lot of laughter and fun in the residence, in large measure because of the staff and volunteers, who are smart, dedicated, thoughtful, and compassionate and understand that humor serves people well in their final days, as it does throughout life. I recall a sweet and sassy little woman whom I assisted with eating when her hands could no longer hold the utensils. One day I spilled her beverage on my trousers, leaving a big stain. “It looks like I’ve peed my pants,” I said, and she immediately quipped, “Don’t worry about it, that’s permitted here, too.”

My mind is crowded with memories of so many residents who enriched my life by sharing recollections. Some led extraordinary lives filled with outstanding honors and accomplishments; some came to Hospicare without friends or family, after lives filled with severe deprivation. For them, the Hospicare Residence is a haven where they are pampered, fussed over, and treated with respect, perhaps for the first time. You can imagine what pleasure a volunteer can derive from helping to make the final days of these folks as special as possible.

All of Hospicare’s clients have in common the right to live their last days, weeks, months pain free and with dignity. Two stand out in my mind: one was a tiny, very old lady whose beautiful face radiated goodness, or so it seemed to me. Although she



Residents enjoy an outing near the pond.



spoke little English, her expressive eyes communicated perfectly, and I frequently found myself stroking her lovely face. It seemed clear that she enjoyed this touch as much as I did. I'll also always remember Bob, a World War II veteran who so valued his rights and duties as a citizen that he was not content to vote by absentee ballot even though he was extremely frail. When election time came, I took him to his polling place and helped him out of the car. Once inside, he had to sit down to rest and catch his breath before summoning the strength to fill out his ballot. When we returned to the residence, Bob spent the rest of the day recuperating from the strain of this important civic act. I felt honored, even humbled, to have witnessed such an act of courage and determination. Little did I know when I first decided to try out the Hospicare volunteer experience that I had found the perfect match for me. Five and a half years later, I still treasure my connection to this wonderful organization.

James Geuder, chaplain and associate director of Hospicare  
What does Hospicare mean to me? "There Is a Balm in Gilead" comes to mind. As a clergyman, it's not surprising that I find its meaning in a religious song, a well-known spiritual that captures hospice in general but also in a way that is personal and particular for me. The notion of hospice as an agent of physical, emotional, or spiritual comfort is certainly not surprising; most people would quickly associate the word with "comfort."

But Hospicare means something a good deal more personal to me. When I was told my fifteen-year-old son was dying from complications of a rare illness almost twenty years ago in another part of the country, hospice was never mentioned. I had no idea then of what a hospice could do that might have been helpful for him in the intensive care unit where he was a patient. Deron had excellent medical care, and his physician told me that he could have whatever comfort medications he might need. In spite of this, the last words that he weakly wrote on his communication pad over several hours before his death were "morphine pain terrible pain morphine." On one hand, the memories of how my son died are made more difficult for me because of my perspective today. I now know that his experience could have been different. On the other hand, I am made easier by knowing that today there is a "balm" in the form of hospice care for others in similar situations in this community.

Professionally, it is a wonderful, if not bittersweet, gift that I am now the chaplain at Hospicare and a member of our agency's committed and talented multidisciplinary team. Hospicare was born out of a community need for better end-of-life care. Our new, expanded mission to offer palliative care services on a wider basis comes from a demand that we offer our expertise in symptom management to more people who need and deserve comfort care. The eight years I have spent in Hospicare's "army of comfort warriors" have been healing for me. I hope that I have been helpful in channeling my energy into the effort to ensure comfort for persons in private homes,

Mikki McGivern, R.N.,  
director of patient care  
services

To me, Hospicare is such a gift. Every day I am invited into someone's life. It may be to discuss a critical issue or to be present at an intimate time. It may be to speak to community members about palliative care, to insert an infusion line for pain management, to counsel a staff person who is having difficulty, or to know when a hug is what someone really needs. In my position I am fortunate to have the opportunity to work with patients and families as well as our staff and community.

Hospice work has given me a clearer perspective and greater tolerance and guided me toward more patience. End-of-life care pushes me to recognize my own biases in any given situation and to keep me humble about my place in the big picture.

It is so important for our community to know the total dedication of the incredibly diverse individuals who make up this agency. Our staff and volunteers are our greatest asset, the heart and soul of this agency. We strive every day to work together on the common ground of carrying out Hospicare's mission.

# 20th Anniversary Celebration



Anonymous family member  
and major donor

Hospicare has meant a great deal to my family and me for quite some time. Our experience with Hospicare helped us all realize and better understand the important values of life. In the 1990s, my family and I found ourselves facing the reality of the approaching death of my husband and their father. We were given a prognosis of about six months. Then came the question of what to do. Some in the medical field felt an operation and hospital stay were the answer for extending his life. My husband did not want an operation. He wanted to stay in his own home. We decided not to force the issue of going to the hospital, as the end results were going to be the same. Every family member decided to do their best to help and follow his wishes.

All this took place at a time when Hospicare was becoming known and established in the Ithaca area. A friend suggested we visit Hospicare. This we did and learned how it would be possible to fulfill my husband's needs and wishes.

We found a doctor who would be willing to work with the Hospicare nurses and with our family.

As my husband's life grew shorter, the nurses and staff helped prepare us for what to expect and make the necessary arrangements. Death came soon after. He died as he wished with his family near and in his own home. We felt he was able to die with dignity and in peace. The Hospicare nurses were with us through this time.

We all feel indebted to Hospicare for the various services provided and the greater meaning we learned about the value of life.

hospital beds, older adult and skilled nursing facilities, and our Hospicare Residence. Walking both with and among our patients and their loved ones has been a great privilege for me. In this twentieth anniversary year, my wish is that everyone in our community would know that there is comfort care available to them, and that they have a right to that care.

Mary Opperman, vice president for human resources,  
Cornell University

In my role at Cornell University I have seen many families struggle through the issues that surround the end of life. So many faculty and staff have lost loved ones, or have themselves endured illness or injury that has resulted in a slow, sometimes painful death. I have watched, and sometimes shared, the process with these families and have seen the difference Hospicare has made for the family and for the dying person. Our society struggles with the issue of death and dying, and we do not always know how to go through the process in a way that is best for the dying person and for the family.

The staff members of Hospicare have a way of guiding and supporting the person and his or her family and friends through this journey that is unobtrusive yet comforting. When a good friend of mine died recently, I found that it was easier to be at Hospicare than almost anywhere else, because it was okay for me to be scared, sad, or nervous when I was there. My friend felt at home and comfortable in the residence. Her family was also supported in important emotional ways. Hospicare is a warm, inviting, safe place to be during a time when safety, warmth, and comfort are desperately needed.

Personally, and on behalf of those I know who have benefited from the services of Hospicare, thank you. Our community is better because Hospicare is here. Happy twentieth anniversary.

Denise and David Kooperman, Kooperman Counseling Services  
*David:* Back in 1985, when I became director of social work at what was then called Tompkins Community Hospital, I became acquainted with Fran Ahern Smith, the first director of Hospicare, and her small group of hospice care providers who were operating out of the back end of the Biggs Building. Trained as a social worker, I discovered that many local physicians at that time did not include Hospicare as part of discharge planning, perhaps because they considered the dying patient a "treatment failure." It became a unique challenge for me to help introduce a new and dynamic service to patients, families, and health care providers in Tompkins County. Around that same time, I taught a course at Ithaca College in the health care sequence, where I met two professors—Tom DiMatteo in Allied Health Services and

Slawomir Grunberg in the film department. Slawomir had just produced a documentary film on end-of-life decision making called *Right to Die*. We put together a program for hospital staff and the medical community with a showing of that film and a discussion of end-of-life concerns of physicians, clergy, attorneys, and family members.

*Denise:* As Hospicare grew in community acceptance and size, so also did the need for on-call nursing services. After participating in a hospice program in London (a two-week TC3-affiliated course led by nursing professor Kate Milnor in 1987), I, an R.N. and nurse practitioner, began doing on-call nursing work for Hospicare. This usually meant being called out in the middle of the night to confirm a death and support the family. Because I was not part of the regular staff, I did not have relationships with these families beforehand, and yet I found the experiences to be incredibly rewarding. In the midst of crises and life-changing events, people were very receptive to me as a care giver, and I considered it a privilege to have been there at those times.

What goes around, comes around. In the fall of 1992, David's mother was diagnosed with rapidly growing and untreatable ovarian cancer. She moved here from Florida to spend her last months with us, and once again, we and Hospicare crossed paths—only this time we were clients. The service of the nurses, a loving home health aide, and bereavement counseling allowed David's mother to remain in our home until her death and for the experience to be as positive as it could be for our family.

*David:* Our relationship with Hospicare continued. In the late 1990s, I was invited to participate as a consultant to the Hospicare staff, and I found that to be a gratifying experience. In addition, our work as psychotherapists has us frequently confronting end-of-life issues with our own clients. We feel incredibly blessed to have such a caring and comprehensive provider of hospice and palliative care in this community. It has been amazing to watch the agency grow from its infancy in the Biggs Building to the beautiful, comfortable residence. It has been our privilege to participate in this liaison, both personally and professionally.



The great room at the Hospicare Center.

# 20th Anniversary Celebration

Charles Guttman, attorney

I was asked to join the Board of Directors of Hospicare about fifteen years ago by friends who were then on the board. I was advised that the board needed an attorney and that it was a good organization. I agreed, thinking I would be fulfilling my community and professional responsibility and my desire to work with friends. Only later, after service as a board member, president of the board, and a member of many committees, would I realize how much more I would receive from Hospicare than I could give to it.



Illuminations: an evening of candlelight, music, and memory in the gardens.

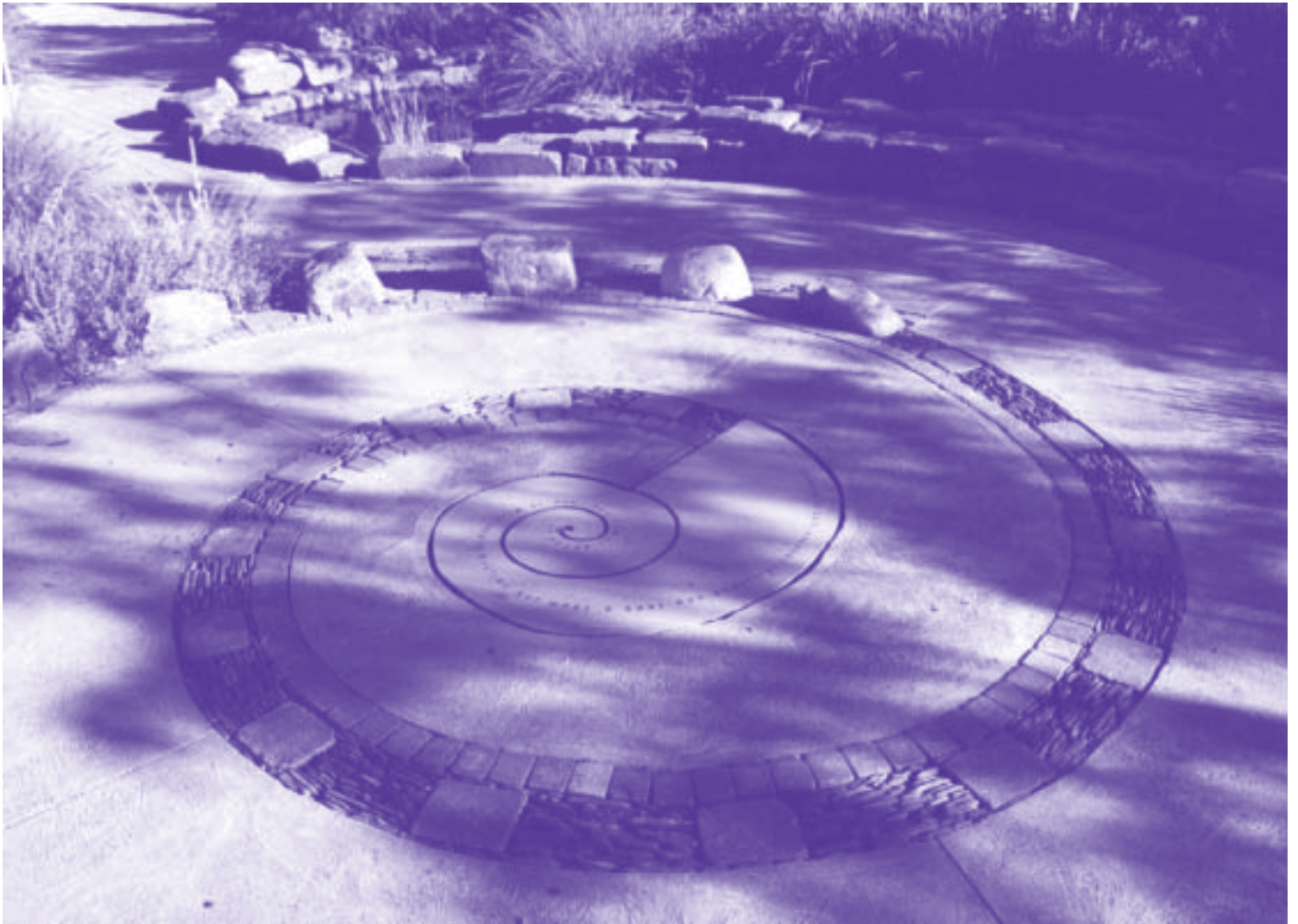
Before my association with Hospicare, “death” was a very uncomfortable subject for me. I had never seen anyone die and had rarely spent time with anyone who was approaching death. I did not know the “right” things to do or say. I attempted to avoid issues of death by either not discussing them at all or by making jokes.

Through my involvement with Hospicare, I have learned that death is one of the key stages of life and that the period before death can be a time for growth. It is not a time for the individual to be left alone in pain, but rather a time for comfort and companionship, a time to strengthen bonds with loved ones and to create moments of profound meaning. I have learned that people, with support from organizations like Hospicare, often “die as they lived” and that in their last days, if comfortable and supported, they can experience a “good death.”

Working with the exceptional staff and volunteers of Hospicare, I have met a wide range of individuals, all united by their desire to provide support at this crucial stage of life. Hospicare has an amazing cast of characters. The mood of the Hospicare staff and volunteers is not despair and depression, but rather the appreciation of life and love for the people they work with and for. Working with the staff and patients, and getting to know them, has been very important in my personal growth.

After several years of seeing the organization from the viewpoint of an attorney and board member, I had the privilege of seeing it function from the viewpoint of a family member. A dear, long-time friend of mine was admitted as a patient to the residence with brain cancer. This man had acted as a surrogate father to my wife, so she chose to act as a surrogate daughter to him while he was at the Hospicare Residence. We spent his final days with him. We watched as he gradually left this world in peace—free of pain—surrounded by love from the Hospicare staff and volunteers, many friends, and later a daughter who drove back to Ithaca to be with him before he died. I was there to give support in his final days, but I received so much more than I gave. This time was one of the most spiritually significant periods in my life: it brought me closer to my wife, and it gave me a much greater understanding of the meaning of life. When an individual dies, free of pain, in a supportive, loving environment, it is an incredibly spiritual, even beautiful, event, in some ways like a birth.

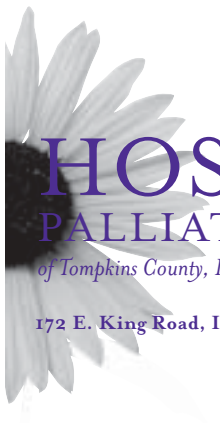
Hospicare provides our community with the arena and the vocabulary for understanding death and talking about the process of dying. It helps families come together and be closer to their loved ones as they die. It affirms that all people have a right to die comfortably and with dignity; it provides a conducive setting for end-of-life emotional connections and personal growth even during the final stage of life. I take great pride in being associated with this organization.



The Spiral Garden with Diane Ackerman's words:

*"It began in mystery and it will end in mystery, but oh, what a rare and beautiful country lies in between."*

# *20th Anniversary Celebration*



# HOSPICARE AND PALLIATIVE CARE SERVICES

*of Tompkins County, Inc.*

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