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The mission of Hospicare & Palliative Care Services is to bring medical expertise and compassionate, respectful care to people and their loved ones at any stage of a life-threatening illness and to provide information and education about advanced illness, dying and bereavement to the entire community.

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Message from the Director

Hospicare's Residence: A Worthy and Worthwhile **Community Venture**

THIS ISSUE OF THE NEWSLETTER features articles about the Nina K. Miller Hospicare Residence and Women Swimmin'. Each is remarkable and noteworthy in its own right, and the first relies very heavily on the second. It's hard to imagine how we could maintain the Residence without the philanthropic



donations generated by Women Swimmin'. The Residence requires support on the order of a quarter million dollars a year over and above the fees that we receive from patients and insurers. That's a lot of money, but thanks to the generosity of all our swimmers, boaters, volunteers and donors, we have been able to fulfill our pledge that no one will be denied the services of the Residence because of an inability to pay. All of us who have a part in that success can be proud of our community achievement.

It's fair to ask why such an expensive service is worth that level of involvement. Why should our community devote such substantial resources to that single service? Aren't there other places or services that are just as good but cost a lot less?

We've done some serious thinking about that issue over the last year or so. The answer is pretty clear: the Hospicare Residence is unique. It was built 20 years ago to serve a specific purpose—the care of the dying—and history has shown that our community views it as a valuable resource for fulfilling that purpose.

End-of-life care is not simply a medical issue; it's not even mostly a medical issue. Dealing with a specific person's confrontation with mortality is primarily an ethical pursuit. The ethical challenge is in optimizing the values and interests of the patient and family through the judicious use of medical tools within the constraints of terminal illness. Our Residence is one of the most powerful of those tools. Like all tools, the Residence is asked to perform work, in this case to maximize the best available possibilities for the patient's life.

Recently Hospicare collaborated with Paul Eshelman and Rana Zadeh, Cornell University professors of design and environmental analysis, and their students, to help tease out and define the ways that a Residence like ours can help complete the special work of dying patients and those who care for them. Their resulting publication, Designing End-of-Life Care Settings to Enhance Quality of Life, compiles a long list of practical recommendations and best practices that, indirectly at least, help describe the reasons that a hospice residence is truly different from other health care settings. It also highlights why it is such a worthwhile community venture: a hospice residence is a platform for the highest form of applied ethics.

Eshelman and Zadeh entered into this research because 20 years after our Residence was built, there still are not many extensive guidelines for how to design for end-of-life care. That makes it even more impressive that, for two decades now, leaders like Nina Miller have given life to the Hospicare Residence project. Even without a basis in academic research, their gift to our community is both real and profound, and we, the beneficiaries of their foresight, owe them our continuing thanks.



Dale Johnson

On the cover: The Tompkins Trust Team gets ready to jump into Cayuga Lake for Women Swimmin'. This year's event featured 299 swimmers escorted by 170 boaters. New this year, 19 swimmers independently swam their own distances in pools as part of Women Swimmin' Laps for Hospicare.

COVER PHOTO BY WWW.JONREIS.COM/JON REIS



WWW.JONREIS.COM/DIANE DUTHIE/ DEIDRE MOLLURA /JON REIS

Our annual Women Swimmin' for Hospicare event took place on the beautiful, slightly chilly morning of August 8. For the twelfth year, swimmers, boaters, volunteers, and friends and family gathered in the early morning hours at the Ithaca Yacht Club. This was the sixth year I've stood on shore and watched Women Swimmin' unfolding. After all these swims I am still amazed and inspired to see the enthusiasm and courage of the swimmers, the loving support of the boaters and volunteers, and the generosity of the thousands of donors and well-wishers across our community and around the world.

Hospicare truly could not do all we do without Women Swimmin'. All funds raised through the event are used to provide physical, emotional, psychological, social and spiritual support to patients and families facing the hard issues of mortality and loss. No one is ever turned away from Hospicare because of inability to pay—and Women Swimmin' is one of the main reasons why!

Women Swimmin' is usually a 1.2 mile swim across Cayuga Lake, but this year we had to modify the swim course when we learned that our transport boat, the MV Columbia, had suffered an accident and was irreparably damaged. Without this large boat to ferry the majority of swimmers across to the eastern shore of Cayuga Lake, we had to regroup. Our friends at the Ithaca Yacht Club and our planning committee worked out many details and came up with an alternate plan. Our 299 swimmers jumped from the swim dock of the Yacht Club (many of them holding hands as they leapt into the water) and swam into the lake for a half mile, accompanied by boaters. Then they turned north for 0.2 miles and returned to the Yacht Club.

This year we also instituted an alternative swimming opportunity: Women Swimmin' Laps for Hospicare! Women Swimmin' Laps allowed swimmers who couldn't swim in the lake on August 8 the chance to participate in Women Swimmin', to raise funds for Hospicare and to be part of the "sisterhood of swimmers" by swimming in pools, for whatever distance they wished. Nineteen swimmers took part in Women Swimmin' Laps. Collectively, their swim goals equaled 189.34 miles! They swam in pools in and around Ithaca and as far away as Hawaii.

Thanks to the generous support of our corporate sponsors, 100 percent of the money raised by swimmers goes toward patient care. Special thanks to our host, Ithaca Yacht Club; Ithaca Bakery and Collegetown Bagels for donating a nourishing breakfast; Maguire Family of Dealerships; our media sponsors Cayuga Radio Group and *Tompkins Weekly*; and our corporate sponsors: 15 STEPS; Asthma & Allergy Associates P.C.; Cayuga Medical Center; Ciaschi, Dietershagen, Little, Mickelson & Company, CPAs; CSP Management; Family Medicine Associates of Ithaca, LLP; Ithaca Cayuga Optical Services; Miller Mayer, LLP; Morgan Stanley; OB–GYN Associates of Ithaca; Satori Day Spa and Salon; The Computing Center; Tompkins Insurance Agencies, Inc. and Tompkins Trust Company; Visiting Nurse Service; and Warren Real Estate. Thanks also to Puddledockers for donating—for the sixth straight year—a fabulous kayak, plus accessories, for our raffle.

The 13th Annual Women Swimmin' event will be held in August 2016. We hope you will join us in the lake, in a pool, or just in spirit.

Hospicare Residence A Home Away From Home

BY JACKIE SWIFT



MELISSA TRAVIS DUNHAM

When the Nina K. Miller Hospicare Residence was built, it was envisioned as a place of tranquility and peace—a home-away-from-home for those at the end of life. In the 20 years since it opened in 1995, the Residence has met those expectations for more than a thousand patients and their families. On any given day in the Residence you will find family members sitting in the breakfast nook with their loved one, or sipping coffee together in the welcoming Great Room. Those who are musically inclined sometimes play the piano or bring their own instruments to play for whomever wants to listen. And then there are the family meals

sometimes eaten at the dining table or more informally in the sitting area before the TV, as well as in a loved one's room.

"We've gotten to know so many people here," said Penny Eddy last May, reflecting on her mother's stay at the Residence. "We stop to talk to each other sometimes in the kitchen when we're getting coffee or when we pass in the hall."

Diagnosed with congestive heart failure, Penny's mother, Peggy Houghtling, chose to have Hospicare's services in March 2014. At first she stayed in her own home with her son, Steven, as caretaker, and Hospicare staff visited her there. But then came the day in

A Place of Peace, Respect and Comfort for 20 Years

BY NINA MILLER

Each time I walk into the Hospicare Residence I am flooded with memories. Most of all I remember the final week of my husband's life in Room 5, but also I think of the people whose lives came to a peaceful close in the tranquil rooms overlooking the pond and beautiful gardens.

Images flash through my mind: the young women from a cancer support group camped in the Great Room to be close to their friend who was dying in Room 3; the "Mayor of Hospicare," who outlived everyone's expectations and was adored by all of the Residence staff; the first baby who was cared for in the Residence; my dear friend Henry, lying in his bed in Room 6, balancing not one but two ice cream sundaes and grinning broadly for the photographer.

There are more memories: patients in wheelchairs listening to choral music in the Great Room; volunteers preparing meals in the Residence kitchen; nurses and aides bringing ice chips, checking for any signs of pain, plumping pillows, whatever might make a patient more comfortable; bereavement counselors and social workers holding weeping family members.

When Hospicare decided to build a free-standing residence, we were ahead of our time. Nothing like it had been built in New York State. There were no regulations, no construction requirements, nothing. Yet we knew there was a need, that some dying patients lived alone without caregivers, that others lived with frail partners unable to manage their care. It took numerous trips to Albany to lobby our legislators and enormous fundraising efforts in the community and beyond. But we persisted, driven by the vision of a safe and beautiful home for people as they moved toward the end of their lives.

It took a sometimes frustrating year to find the perfect place for the new facility. And indeed, the land on East King Road, overlooking a quiet pond and woods, has been perfect, and has had the consistent support of friendly and helpful neighbors. Architect Peter Newell and



LISA MILLER

landscape architect Paula Horrigan understood at the deepest level the needs of our patients and their families, and they designed a setting that communicated peace and respect and comfort, both inside and out.

The Hospicare Residence is now 20 years old. During those years, it has served as a model for other programs throughout the state and beyond. It has provided a place for our friends and neighbors at the end of their lives. No one has ever been turned away because they were unable to pay. The cost of care in the Residence has been subsidized thanks to the generosity of the community and, more recently, the success of Women Swimmin'. The Residence continues to provide tender and skilled care in a place of quiet beauty for people whose lives are coming to a close and comfort for the families and friends who love them.



ELISSA TRAVIS DUNHAM





September 2014 when she was hospitalized with sepsis and pneumonia. Her needs were too great for Steven to deal with at home, so Peggy moved to the Residence. It was one of the best decisions they could possibly make, said Penny and Steven emphatically.

"Mom had a prognosis of two weeks when she arrived at the Residence," said Penny. "She's been here eight months now. She's done great. She's been here for so long, this has become like a home for us."

The Residence staff helped Peggy keep active and involved in life, Penny said. She mentioned the aides, in particular, who lavished Peggy with care and attention: Mishi Turner, an accomplished knitter who helped Peggy continue knitting even though Peggy's eyesight was failing, and Dave Sochia, who set up a "Breakfast Club" for Peggy and two other patients. Every day, as long as they were able, Dave helped the patients get out of bed, get dressed and meet for breakfast in the breakfast nook.

"They did that for two months," Penny said. "It really gave them a reason to get up and get going."

"When they built the Residence, they got it right," said Frank Carollo, whose wife, Mary Ellen, came to the Residence in September 2014, one week after Peggy. The two women were next-door neighbors for the next eight months, and Frank came to know the Residence building and staff extremely

well. "It's so homey here," he said in an interview last May. "We really feel like we can come and go as we want. And we've gotten to know other patients and their families. We had sing-alongs in the Great Room, and we even had a Super Bowl party with another patient in the sitting room."

"We spent the holidays here too," Mary Ellen's sister, Sue Schuldeis, added. "Mary Ellen and I have a huge family—nine siblings and all our families. We had Thanksgiving, Christmas and Easter dinners here." She smiled as she recounted prepping for the dinners, taking over the staff kitchen and conference room in the downstairs of the Hospicare building, leaving the Residence kitchen and Great Room for other patients' families. "Our family had 18 people here for Thanksgiving and 13 for Easter," she said.

"But we ate Christmas dinner with the other patients and their families in the Great Room," Frank added, "because there were only six of us for that!"

Mary Ellen was diagnosed with a brain tumor, and Frank and Sue were adamant that the Residence helped her live much longer than her prognosis. "We were fortunate that there was a vacancy for her to come here right when we needed it," said Frank.

Frank had been caring for Mary Ellen in their own home with the help of a family friend, who looked after Mary Ellen during the day while he was at work. The strain Opposite page: volunteer Sally McMillin arranges flowers; top photo: the Hospicare Residence from across our pond; small photos left to right: patients Jayne and Lola work on a puzzle in the sitting room; Peggy waves from her recliner; Mary Ellen listens to her brother, Joe McMahon, play the banjo.

became too much for him, especially when Mary Ellen took a turn for the worse. That's when the Residence provided the answer they needed.

"I tell people, if you are in Mary Ellen's situation, the Residence is the best place to be," said Frank.

"You see spouses like Frank fading as they try to care for their sick wife or husband," Sue added. "Frank and Mary Ellen have both survived and thrived all these months since she came to the Residence because Mary Ellen is cared for so well here, and Frank can go home and rest when he has to."

After the May interviews, Peggy and Mary Ellen passed away, within a few weeks of each other. The Residence staff members carry memories of both women in their hearts as they comfort and care for new patients and their families. The mission of the Residence continues as well: bringing dignity and the warmth of home to those at the end of life.

This is Noble Work

Staff Member Profile: David Sochia, CHHA, CHPNA

BY MELISSA TRAVIS DUNHAM



Residence: on the West Hill in Ithaca

Family: Daughter Eileen, age 20, in third year of college in California; currently looking for a dog "that will be a good fit"

Pastimes: Meditating, yoga, hiking, sailing on Cayuga Lake, dinner with friends, and movies, especially ones based on real life or documentaries

Years on Staff: 11 years

Mottos: Treat everyone like a brother or sister.

If you think you can or you think you can't, either way you're right.

It doesn't take long when speaking with Dave Sochia to realize he loves working in the Nina K. Miller Hospicare Residence. Being a hospice aide is far more than just helping patients with activities of daily living, he says. To him there is a spiritual aspect that goes beyond providing personal care to patients (bathing, toileting), preparing meals, transferring patients from bed to chair or repositioning a bedbound patient. He sees

the connections between staff and patients and family members as the heart of the work, bringing great meaning to what he does. "Our job is to minimize their suffering," he says. "The connections help with alleviating that suffering."

Dave started working as an aide more than 20 years ago at a facility for people with traumatic brain injuries. Being an aide is "noble work," he says, but it was not what he anticipated doing in his early life. Growing up, he thought about studying medicine or psychiatry. Clearly he imagined a lifetime of helping people. "I have a knack for connecting with people," he says.

Dave started working in the Hospicare Residence in 2004. He moved quickly from being a per diem aide to working part-time to filling a fulltime position. Through those years, he has valued most the relationships he has forged with patients.

Dave especially remembers Joe. Joe was "a tough guy," Dave says, who experienced paranoia toward the end of his life and was resistant to some of the care he needed. "I remember he looked at me with these puppy-dog eyes and said, 'Et tu, Brute?""

Joe and Dave developed a rapport over their shared childhood experience of working as

"We clicked like two peas in a pod. She would always pick on me, but that meant she liked me!"

shoeshine boys in the respective cities in which they grew up. As Joe was dying, Dave held his hand. He knew this physical connection to another man was certainly not something Joe would have sought earlier in his life. "Every once in a while Joe would turn his head and look at me and say, 'Dave, am I going to be all right?" Dave recalls. "And I'd say, 'Yeah, Joe, you're gonna be all right."

More recently, Dave felt an instant rapport with Peggy Houghtling (featured in this issue's story about the Hospicare Residence, pp. 4–5). Dave's eyes twinkle when he speaks of her. "We clicked like two peas in a pod," he says. "She would always pick on me, but that meant she liked me!" Dave and Peggy watched *Family Feud* together every afternoon. Peggy loved animals, and the two would often talk about the wildlife that inhabit the Hospicare grounds; Peggy enjoyed watching Dave put out seed and suet for the birds.

Dave admits that sometimes his job can be hard, both physically and psychologically, but his perspective on death puts things in focus. "It's a consciousness change," he says of death. "You go from one realm into another."

In the long term, Dave plans eventually to get a master's degree in social work and focus on other areas where he can help people, perhaps substance abuse, family violence or the prison system. And it's always possible that he could return to hospice work. "I've really enjoyed working in the Residence," he says. "I derive meaning from this work."

"Every once in a while Joe would turn his head and look at me and say, 'Dave, am I going to be all right?' And I'd say, 'Yeah, Joe, you're gonna be all right."

Join Us for Holiday **Memorial Events**

Memories of those who are gone can be especially poignant during the holiday season. To bring light into days that may be dark for some, Hospicare and the Hospice Foundation of Cortland County each hold a special memorial event at the end of the year for the entire community.

Light of My Life

The Hospice Foundation of Cortland County will hold their annual memorial fundraising event in conjunction with the Village of Homer's holiday celebration, Christmas on the Green, on Friday, December 4 at 6:30 p.m. The Light of My Life memorial tree will be lit, and the names of loved ones will be displayed on the memorial boards.



GRANGER MACY

Light the Landscape

Hospicare's annual winter memorial event and fundraiser will take place on Sunday, December 6, at 3:30 p.m. This afternoon of music, refreshments and lights will be held in the Great Room of the Nina K. Miller Hospicare Center and will include a special display of the names of those who are being remembered.

For more information about either of these events, call Hospicare at 607-272-0212, or visit www.hospicare.org/events/

You Can Help Renovate Hospicare's Aging Kitchen

Twenty years ago our Residence was created as a home-away-from-home for our patients, their family members and their friends, and like any home, the kitchen is its heart. This is where volunteers, nurses, aides and family members prepare three meals a day for our patients. It's where staff and visitors come for a comforting cup of coffee or a small snack.

After so many years of use, the kitchen is in great need of a facelift. Drawers and cabinet doors are rickety and worn, countertops are scratched, and the sink and stove are functionally outdated.

We are raising funds for a new kitchen through the Kitchen Renovation Project.

The project will include new flooring, efficient and easy-to-access cabinetry, a new under-mount deep sink, a new stove with a separate toaster oven, and all new countertops, as well as a new window to brighten the room. The goal of the renovation is to increase the functionality of the current space, keeping in mind ease of use, organizing and cleaning. The estimated cost is \$15,000.

We anticipate the new kitchen will serve us well for another 20 years, meaning it's a one-time project not covered by our operating budget. For that reason we are asking for



Hospicare Volunteer Virginia Spiers is leading a campaign to renovate the Residence kitchen for improved efficiency and functionality.

donations specifically for this project. Our other fundraisers such as Women Swimmin' support Hospicare's general operations, direct patient care, and programs and services not covered by Medicare or insurance.

In addition to donating to the project, you can help us raise funds by signing up to become a "Kitchen Champion," and help us spread our message about the Kitchen Renovation Project through email and social media. To learn more about becoming a Kitchen Champion or to make a donation, please visit our secure Kitchen Renovation Project website at www.hospicare.kintera.org/kitchen, or contact Melissa Dunham at 607-272-0212.

Surprise Bequests Benefit Hospicare

This year, Hospicare has been the beneficiary of estate gifts from five generous supporters. We are honored that these friends have remembered us in this way. The gifts range from \$2,000 to \$90,000 and will be invested with the Hospicare Foundation to provide for the continued health and success of Hospicare.

Leaving a bequest to a charity is increasingly popular and, as these gifts indicate, not just for those with larger estates. Many of our supporters are choosing to include Hospicare in their wills as a way to help make compassionate end-of-life care available for generations to come. If you are thinking of including Hospicare in your will or estate plan, please call Mike Katz, 607-272-0212, for more information.

Welcome to **Our New Volunteers**

The following volunteers completed training this year.

In April 2015: Kathleen Ballard, Karen Borst, Mary Dexter, Brandon Douglas, Lisa Eisenberg, Shura Gat, Ryan Goble, Mary-Carol Lindbloom, Kathleen Patton, Eric Pritz, Annamarie Root, Angela Rudert, Lisa Ryan, Karen Smith, Kathy Troy and SooYoung VanDeMark.

In September 2015: Holly Cestero, Shelley Cooper, Joan D'Antonio, Simeon Darwick, Jarrod Newcomb, Abby Ricklin, Patricia Schaffer and Rebecca Weger.



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Did You Know?

Studies show people live longer the earlier they sign onto hospice.

Wish List

Your support of Hospicare enables our bereavement services team to connect with grieving adults, teens and children in our community individually and in groups. If you would like to help with this work in a tangible way, please consider donating an item from our wish list. A complete list of items can be found on our website, www.hospicare.org/our-wish-list/

In particular, we have need of these specific tools to aid children through their grief:

Guatemalan "worry dolls"

These dolls give grieving children a specific place to focus their fears and worries. Children who would like to donate to help other children dealing with loss may find these dolls to be an especially appealing donation item.



After a Death: An Activity Book for Children

by Amy Barrett Lindholm and the children at The Dougy Center for Grieving Children

This activity book is especially useful when our bereavement counselors go to schools to meet one-on-one with grieving children.

When Dinosaurs Die: A Guide to Understanding Death

by Laurie Brown and Marc Brown

Lifetimes: The Beautiful Way to Explain Death to Children

by Bryan Mellonie and Robert Ingpen
Both these books explain death and
normalize it as a natural part of the life
cycle. Our counselors may read one of
these books together with a grieving child
or may send a book home with a parent
to read. Our social workers sometimes
counsel families and young children before
a patient dies, and they may use these
books to help children understand death.



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