

It's about how you LIVE!

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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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SHERYL D. SINKOW

## Message from the Director

### Each of Us Adds Something to the Hospicare Story

AS I WRITE THIS, I'M LOOKING OUT OVER THE POND at the Nina K. Miller Hospicare Center on Ithaca's South Hill. The March wind is gusting and seems to hint at the possibility of spring. All the ice and snow have melted, the geese are returning to their nesting grounds, and the days are getting noticeably longer. Change is in the air.

This newsletter documents, figuratively at least, a similar change of season. Sue Merrill, the subject of the article "A Circle of Giving and Care" (see pages 4-5), is a longtime friend of Hospicare. For nearly 20 years Sue has been indispensable to Hospicare. She has been a valued volunteer and enthusiastic supporter, carrying out all sorts of important tasks that make the agency go. Without supporters like her, the core mission of our agency could not be fulfilled. But as time has marched on, Sue has reached the point at which the roles have reversed. She is now on the receiving end of Hospicare's services, after having spent years helping make those services available to others.

There is something very special about that. Hospicare is well over 30 years old—old enough that we now see a second generation of our neighbors as patients. As a resource that is both owned by, and responsible to, a generous and caring community, we have been honored to be the beneficiary of the great gifts hundreds of supporters like Sue have given us. And we embrace our responsibility to take care of those same supporters at the end of their lives.

This circle of giving and care represents the continuity of the *idea* of Hospicare. Each of us takes a portion of our time for a portion of our lives to add something to the Hospicare story. The contributions take many forms and perform different functions, but all of them add to the advancement of the larger and continuing idea. We believe that Hospicare is essential to how we live our lives, how our community functions and how we care for those who are facing life-limiting illness. Each of us adds something because the idea of Hospicare creates a community of meaning that exists separately beyond any single one of us.

Decades ago, when the early hospice movement was just gathering momentum, the idea of Hospicare took root. Since then, like the tree that is part of our logo, Hospicare has grown strong and spread its shelter over all of us. We are aware that, barring a sudden accident, the need for hospice will one day arrive for each of us. We all continue to grow older, and the seasons will inevitably change. Over Hospicare's 30-odd years the wind has continued to blow, the snows have come and gone, and the geese have flown away and returned to the pond. How pleasant it is to be able to say to good friends like Sue Merrill, "Thank you for what you've done for us, and now we're here for you."

Dale Johnson



On the cover: The Hospicare gardens are blooming all spring and summer, brightening the day for patients, volunteers and staff. All are welcome to visit us on East King Road in Ithaca and stroll the grounds.

# Offering Emotional Support and Help with Problem Solving

BY SUZANNE CARREIRO, LMSW



As a Hospicare social worker, I play an essential role on the care team. I am committed to a non-judgmental, loving and supportive approach to patients and families. I work closely with the primary nurse/case manager assigned to each patient. While the primary nurse helps the patient and family understand and cope with the medical aspects of a terminal illness, I can assist with the emotional and practical aspects. My goal is to help families understand that they will not have to go through this process alone. We have expertise and knowledge in facing the end of life, and we will be there to support and help them.

When I first meet with a new patient and their family, I let them know I am there to offer emotional support and to help with problem solving, decision making, care planning, advanced directives, and financial and legal matters at the end of life. I identify any immediate needs they may have. I will also make referrals for additional services offered through Hospicare and through other agencies within the community, which may supplement the patient's care or help with other issues the family faces. Throughout the patient's time with Hospicare, I will continue to visit them at home. The frequency of these visits is driven by patient and family needs and preferences.

Recently I worked with a large family whose members had different ideas about how to approach the end-of-life decisions for their mother, who was no longer able to communicate her wishes to them directly. I arranged a meeting with the whole family. Each person had the opportunity to talk about their fears and concerns and what was important to them. I answered their questions about their mother's illness and what to expect under different scenarios. I also helped them consider what her quality of life would look like in her final weeks of life. These are issues many of us have never had to consider before, and the support of a hospice social worker when making decisions like these can be a big relief to family members. This family was able to recognize that, while they may have differed on certain ideas, they all loved their mother and wanted the very best for her. In the end they realized that fear of losing her was contributing to unclear communication between them. The meeting ultimately brought them closer together as they were able to accept the different ways they each experienced and communicated their grief.

While one family's needs centered on communication between the members, another family I worked with had more of a need for logistical help with their

**“Our goal at Hospicare is to provide the assistance each individual needs.”**

father's care. The patient's daughter, who was the caregiver, had cared for her mother at home with hospice services and now she was caring for her father, who had moved into the Nina K. Miller Hospicare Residence in the final weeks of his life. The relief that the daughter felt at being able to let go of some of the hands-on care, to know that her father was in capable and loving hands, made it possible for her to reconnect more fully with him. She was also able to experience the grief of her mother's loss, which she had been too busy to really address prior to getting Hospicare's help.

As these two families' experiences show, the journey that is undertaken by patients and their family members at the end of life is unique for each of them. Whatever comes, our goal at Hospicare is to provide the assistance each individual needs. We will walk each step together with the patient and their family members, respond rapidly and be there in an emergency. Most importantly, we strive to accept and respect all family members for who they are—loving caregivers on the verge of great loss.



## From Volunteer to Patient

# A Circle of Giving and Care



MICHELLE TUREK



Hospicare's motto, "It's about how you live," articulates the core of our presence in the community. Life is meant to be lived to the fullest, even in the last months. Hospicare exists not only to provide compassionate care to those with a life-limiting illness, but to celebrate life itself with patients and their families, volunteers, donors and other community members.

"Hospicare is of the community and for the community," says Dale Johnson, Hospicare executive director. "We can't do what we do without the support of those who believe in our mission. At the same time, we are there for everyone in the community if they should need us. It's this circle of giving and care that makes Hospicare one of the leaders of the hospice movement."

One community member who has participated in and experienced our mission from both sides is Sue Merrill. For almost 20 years, Sue volunteered with Hospicare. She started out as a general office volunteer at the end of the 1990s, answering phones, folding brochures for mailings and doing other office tasks. In those early days, she was especially attracted to Illuminations, Hospicare's summer memorial event. She first attended Illuminations right after her son Steven died from cancer. "That was one of the things that made me want to get involved with Hospicare," she says. "The event was something I could take part in as a remembrance of Steven."

Illuminations was only a year or two old at that point, and staff and volunteers were still working out the kinks. Sue joined in, helping to figure out how to make the luminarias—votive candles inside paper bags lining the garden walkways that are a key part of the Illuminations experience.

"In the first years, they used sand to weigh down the bags," Sue remembers. "But when we picked up the bags the next day, the sand had gotten damp and it just tore the bottom right out of the bags and fell onto the ground. One of us said, 'What if we use stones instead of sand, and then we can dry out the stones each year and reuse them?'" She laughs. "I'd like to say it was me who said that, but I'm not sure after all this time."

Like so many Hospicare volunteers, Sue broadened her involvement with us as time went on, giving of her time and abilities in ways that increased the comfort and the depth of care our agency could offer to her fellow community members. She eventually ended up focusing her volunteer work on the kitchen in the Nina K. Miller Hospicare Residence. Every week, for years, she



GRANGER MACY

**Top photo: Sue Merrill receives the 2015 Hospicare Volunteer Honor from Dale Johnson, while Wendy Yettru congratulates Sue with a kiss and Melissa Travis Dunham, manager of community relations, joins the audience in applause.**

**Bottom photo: Sue quietly takes part in the Illuminations event after helping set things up earlier in the day.**

## “The best part was doing something I enjoyed for people who needed my help.”

shopped for Hospicare at Wegmans and cooked Monday breakfast for patients in the Residence. “It kept me busy,” she says with a quiet smile. “The best part was doing something I enjoyed for people who needed my help. I really liked the physical side of doing things.”

As Sue became older, she moved into an independent cottage at Kendal at Ithaca, but she continued to volunteer at Hospicare. Rain or shine, Monday morning would find her in the kitchen, cooking up patients’ favorite breakfasts. Then, last fall, she discovered she had multiple myeloma and amyloidosis, an overgrowth of normal tissue that had invaded her cardiac area. Now Sue has a room in the skilled nursing section of Kendal, and she is experiencing our mission from a different perspective—as a patient. “I went on hospice because they thought Hospicare might make it easier for me,” she says. “Not that Kendal can’t care for me, but they felt that the Hospicare team might have some thoughts about additional things they could do to help keep things under control.”

Sue’s Hospicare team right now consists of her primary nurse, Kat Lynch, RN, who visits her once a week—or more, if needed—and her Hospicare aide, Sue Iglthaler, LPN, who helps her start her day five mornings a week. Another regular visitor who spends time with Sue is Wendy Yettru, Hospicare manager of volunteer services. After so many years of working closely with Sue, Wendy found her professional respect for Sue deepening into a friendship when Sue first became sick.

“It’s an honor to be taking care of Sue at this point,” says Wendy. “It feels good to know that I can give to her after all she’s done for Hospicare. For me, that giving is just simply being there with her. She appreciates every time I visit. And she gave me a gift when we became friends: being with her as a patient has taught me that I can bridge that distance between knowing someone as a volunteer and knowing them as both a volunteer and a friend.”

When it came time for Sue to decide whether to utilize our services as a patient, her years as a Hospicare volunteer gave her an understanding of hospice that many people don’t have. She knew that the focus of hospice is on easing a patient’s physical, mental and spiritual pain—just what she needed at that point. “For many people, their perspective about going on hospice is that they only have six more months to live,” she says, referring to Medicare guidelines that mean hospice coverage kicks in when a doctor says a patient



Sue and Wendy spend time together in Sue’s room at Kendal at Ithaca.

has a life expectancy of six months or less. “Somehow you have to get past that stage emotionally, and you have to get to the point of saying, ‘Yes, I do need to talk to the people at Hospicare because they might have something they could suggest or do that would be helpful to me.’ For instance, if you have pain problems, Hospicare can give you pain medication and make you comfortable. They can’t guarantee you’ll live longer than six months, but they can make you as comfortable as possible.”

For now Sue is doing extremely well on hospice. “It’s turned out that things have improved a lot,” she says. “How long that will last, I don’t know. I don’t think Hospicare knows either, but I think I’ve surprised them with how well I’m doing.”

Sue’s rich experience with Hospicare mirrors what community members say time and again they expect for themselves and their loved ones. “When I interview prospective volunteers, many of them say flat out that’s why they’re here,” says Wendy. “They know one day Hospicare will be there for them, and they want to be there for Hospicare while they can.”

# “I Feel Good When I Help Someone Pass Away Peacefully”

## Staff Profile: Danielle Parker, LPN, CHPLN

BY MELISSA TRAVIS DUNHAM



JEFF COLLINS

“I love my job!” says Danielle Parker, Hospicare licensed practical nurse (LPN), with a smile. Danielle provides personal care and nursing support to Hospicare patients in their own homes or in skilled nursing facilities. She spends an hour at a time with each patient, sometimes as often as five days a week, depending on the patient’s needs. She helps them with bathing, dressing and eating. As an LPN, she can also manage or administer medications, take care of wounds or address other medical needs for patients living in their own homes.

But Danielle is quick to point out that her help isn’t just for the patient: she also provides respite for family caregivers who can take a break while she stays with their loved one. “A lot

of people enjoy that time to step away and run an errand or take a nap,” she says. Many times family members don’t realize Hospicare will help them as well as their loved one, she explains. “I tell them, ‘We’re going to help you and the rest of your family, too.’ It’s more than just me coming in as a nurse.”

Danielle began her career in healthcare working as a certified nursing assistant in a skilled nursing facility. After the birth of her second child she decided it was time for something different. “The work I enjoyed, but the long hours weren’t fun,” she says. She became an LPN, then joined the Hospicare team when the agency expanded its service area to include Cortland County in 2014.

Working with hospice patients is not right for everyone, Danielle acknowledges, but it’s a good fit for her. As she explains, “One of the main things that attracted me to working with end-of-life care is that so many people become nurses because they want to save lives, but not all lives can be saved. I enjoy being able to help people live the rest of their lives the best they can. With dignity.”

Taking care of a patient at the end of their life is a special privilege and can result in a close relationship, Danielle says. She remembers one patient, Henry, whom she visited five days a week for several months. When Henry died, Hospicare primary nurse Corey Stevens, RN, personally called Danielle to let her know. “Henry and I really connected,” Danielle says. “I enjoyed visiting him. Corey knew how close I had grown. That was the first time I cried at the death of a patient.”

For some patients, the benefits of the attentive, personalized care they receive from Danielle and the rest of the Hospicare team leads to an improvement in their health—so much so that they are no longer medically appropriate to be on hospice services. When this happens, it’s a bitter-sweet circumstance for Danielle and her patient. “I’ve had patients be sad that they won’t be seeing me or the rest of the team anymore,” she says. “I’ve been there five days a week for months, and that’s a relationship we’ve built.”

One patient in these circumstances was Jack. When Danielle first started visiting him, “he could barely get out of his chair to walk. I went to a physical therapy consultation with him and helped him continue the exercises. When we began, he could do five simple leg lifts. By the time we finished, he was doing sixty leg lifts. He could walk all the way upstairs to the second floor! I feel good about that because I helped him regain strength and get better.”

Most patients Danielle takes care of stay on hospice, and she is with them all the way until the end; that’s why she loves her job. “I feel good when I help someone pass away peacefully,” she says simply.

Residence: Cortland (grew up in Truxton, NY)

Family: Husband Derrick, her childhood sweetheart; daughter Haylee (10) and son Hayden (8); two cats and a newly adopted dog.

Pastimes: Spending time outside with family, having BBQs; listening to music. (Driving between patients’ homes, she unwinds by listening to music in her car, including Hospicare’s CD *Beauty Crowds Me*.)

Years on Staff: 2.5 years



# Women Swimmin' Set for August 12



MICHELLE TUREK



WOLFGANG SACHSE



MICHELLE TUREK

Women Swimmin' for Hospicare is only four months away! Our 14th annual swim will take place on Saturday, August 12. Early that morning more than 300 women will swim across Cayuga Lake in Ithaca to raise money to support Hospicare services. They will be escorted by more than 150 kayaks, stand-up paddleboards and other boats in a fund-raising event that has come to be one of the premier summer experiences in the Finger Lakes.

Registration for women who will swim across the lake begins online at 6:00 a.m. on Monday, May 1, at [womenswimmin.org](http://womenswimmin.org). But plan to get up early that day: last year all available spots filled in just a few hours! Registration for boaters this year begins on April 15 and is ongoing. Training opportunities will be available all summer for boaters who have registered to take part in the event.

Can't make it on August 12? Women Swimmin' Laps for Hospicare may be for you. Women who are not able to swim across the lake but would still like to raise money for Hospicare can join us by swimming in pools (with a certified lifeguard). Just register online for Women Swimmin' Laps. Then find an appropriate pool, set your own distance goal and let your friends and family know you are swimmin' for Hospicare. Swim at your own pace anytime and for as many days as you want between now and August 12. Registration for Women Swimmin' Laps began March 1 and continues until August 11.

Visit [womenswimmin.org](http://womenswimmin.org) to learn more about Women Swimmin' or to register for the event either as a lake swimmer, a pool swimmer, a boater or a land-based volunteer.

## Farewell to Mike Katz

In November 2016, Hospicare said farewell to Mike Katz, director of development and community relations. During his time at Hospicare, Mike led our development and outreach team with warmth and humor. Among notable accomplishments, he secured multiple grants to help fund Hospicare's transition as hospice provider in Cortland County, as well as to implement a new electronic medical record system and to renovate the shower room of the Nina K. Miller Hospicare Residence. Mike also smoothed the way for some very necessary updates to our online fundraising software, Hospicare's website and the Residence kitchen.

After a few decades working for local non-profits, Mike has embarked on a new adventure—as the owner of the Ithaca area's first Edible Arrangements franchise. In that capacity, he's already donated to Hospicare a few lovely arrangements of fruit, which were greatly appreciated by staff and volunteers. We wish Mike all the best on his new venture.



SHERYL SINKOW

## Wish List

Your support helps bring physical, emotional and spiritual comfort to our patients and their families. If you'd like to contribute to our work in a tangible way, please consider donating items from our wish list.

A complete list of items can be found on our website: [hospicare.org/our-wish-list](http://hospicare.org/our-wish-list)

### Did You Know?

More than 80 percent of Americans say they want to die at home. Hospice can help those with life-limiting illness stay in their own homes until the very end.

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Our newsletter is mailed twice a year to patients and family members, donors, community supporters and other friends of Hospicare. If you have received multiple copies of this newsletter, please let us know so we can correct the mailing error. In addition, we welcome your thoughts or feedback about the contents. Contact us at [communications@hospicare.org](mailto:communications@hospicare.org). This newsletter is also available online at [hospicare.org/newsletters](http://hospicare.org/newsletters).

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### Join Us for Illuminations

On Thursday evening, June 8, we will be holding Illuminations, our annual memorial event, in the Hospicare gardens. The pathways around our building will glow with luminarias, each dedicated to the memory of someone who has died. The service includes live music, spoken words and refreshments. The event will begin at 7:30 p.m. and is open to the public.

To learn more, or to purchase a luminaria in memory of a loved one, call 607-272-0212 or visit [hospicare.org/illuminations](http://hospicare.org/illuminations).



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