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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

Providing Expertise at the End of Life

SINCE THE MEDICARE HOSPICE BENEFIT was introduced in the 1980s, hospice has been viewed as a special type of care—both comprehensive and multidisciplinary. Lawmakers took note of the expertise that hospice providers like Hospicare needed to offer patients and their families, if they were going to respond effectively to the requirements of those at the end of life. Hence, hospice was designed as a team of expert

care providers—physicians, nurses, aides, social workers, spiritual counselors, bereavement counselors and others. The teamwork of our professionals is the bedrock of all we do. Each specialist brings a particular strength, and together, they provide far more benefit for each patient and family than could either a generalist or a single professional from any one discipline.

Over time Hospicare has added more expertise, and therefore more teammates. We now offer massage therapy, acupuncture and therapeutic music. These complementary therapies add further richness to the patient's hospice experience. In this issue you can read about the impact of one of these, therapeutic music, as Certified Therapeutic Harp Practitioner Jayne Demakos shares her experiences playing at the bedsides of dying patients (page 3).

Sometimes the synergy of hospice experts extends beyond our own staff and agency. This issue's trio of center spread articles (pages 4-5) highlight the many ways that an effective partnership between Hospicare and local senior facilities can generate benefits, not only for patients and their families, but also for each organization.

We are proud of our collaboration with area senior facilities. By joining with them, we ensure that patients have the best of both worlds—specialized hospice care combined with the familiarity of the setting that has become home. As Michael Kilmer, executive director of Brewster House, makes clear, once residents have settled in at his facility, they want to remain there during their last days. (See “Keeping Patients in Familiar Space” on page 5.) That is what Hospicare helps make happen. And the potential need for our services in facilities is enormous. An estimated one out of every ten nursing home patients is eligible for hospice services.

It's important to recognize that hospice is an entitlement for anyone who is enrolled in Medicare and meets the medical criteria. The arrangements vary a bit depending on the type of facility where a patient lives. For residents of assisted living facilities or senior apartments, the coordination of care is fairly straightforward. For those who live in skilled nursing facilities, it's only necessary that Hospicare have a contract with their facility, and fortunately those contracts are in effect for nearly all of the skilled nursing facilities in our two-county region.

Hospicare's connections with our local senior facilities are growing deeper and richer as we work to more closely integrate our end-of-life expertise with the dedicated care provided by facility staff. If you or someone you love lives in a facility in Tompkins or Cortland Counties and is in need of our help, give us a call to discuss the services we provide. We can help determine eligibility for hospice and also work out the logistics of providing care.

Dale Johnson



On the cover: Our Hospicare gardens are blooming! Benches tucked in quiet spots await visitors, patients and families, encouraging them to rest and relax in these beautiful surroundings. All are welcome to stroll along our garden paths.

COVER PHOTO BY CLAIR T. PENNELS

A Poignant Journey and a Sacred Experience

Music for the Dying

BY JAYNE DEMAKOS, CTHP, HOSPICARE MUSIC SPECIALIST

When people learn that I play therapeutic harp for Hospicare's patients, they are often surprised. Usually they imagine the music is a performance or entertainment. The truth is that the music I play at patients' bedsides uses the latest understanding about how sound affects human physiology. Its purpose is to help patients cope with end-of-life physical and emotional distress. There are often no recognizable tunes. As I play, I tailor my playing to uniquely support each patient.

I am a certified harp therapist and a candidate for certification in music thanatology (music for the dying) with the Music Thanatology Association International. That means I have professional training in the special needs of the dying. I also follow a long tradition that has been implicitly understood by mothers the world over: music offered with love is a kind of human medicine.

Usually I visit patients in their houses, but I will also play in hospitals and skilled nursing facilities—and, of course, at the Hospicare Residence. Research has shown that the sound of the harp acts upon the human parasympathetic nervous systems. It can lower our heart rate, breathing rate, blood pressure and the level of a stress hormone called cortisol. When this happens for a dying patient, they become calmer and more restful. Often their physical symptoms, such as pain, restlessness, agitation, sleeplessness and labored breathing, improve.

When I'm playing, I use the elements of music to address certain symptoms. For instance, by working with tempo and rhythm I might ease distress of a patient who is having problems breathing. I determine what will help a patient from moment to moment as I play.

The sound of the harp can also help patients suffering from emotional or spiritual distress. That's what happened with a patient named Debbie. Debbie had a lot



DEDE HATCH

Helping ease the distress of patients and their family members is why I do this work.

of spiritual conflict that was causing her anxiety and fear. I played for her many times over the course of weeks, and each time she would become calm and contemplative as I played. Then Debbie's health declined sharply, and her family called me in to play for her in her last hours. She had been unresponsive, yet as I entered the room, she smiled when they told her I was there.

I played while Debbie took her last breaths, then continued to play for her family members who were gathered. Her passing was calm, and her family members later told me they felt the music gave her permission to die. I don't know what she really felt, but her family was sure the music helped her with the death process and eased her spiritual fears, and that helped them feel at peace, too.

Helping ease the distress of patients like Debbie and her family members is why I do this work. Playing for the dying is an amazing and often poignant journey. It is a very intimate, sacred experience, especially in the final hours. There's a sense of time stopping at those moments. You're not in the world's time—you're not where time is measured by appointments and all the other daily minutiae. Something mysterious is happening that's not graspable, and we are following it, perhaps like a midwife might follow the delivery of a baby.

As a musician, working with the dying is some of the most profound work I do.

Music offered with love is a kind of human medicine.

Working with Facilities

Collaboration Brings Comfort

BY JACKIE SWIFT

In this article, we bring you three perspectives on the work we do in senior living facilities throughout Tompkins and Cortland Counties. Hospicare partners with these facilities to provide hospice services to the residents there, as well as support to the family and staff who care for them. The teamwork between our staff, the facility's staff and the patient's primary doctor results in the best care possible, tailored to each patient's unique situation.

Responding Quickly to Patients' Needs

"When a resident at Bridges chooses hospice services, that begins a collaborative process," says Christina Slattery, RN, director of nursing at Bridges Cornell Heights. "My staff and I work closely with Hospicare's team and with the resident's primary physician. We want to make sure that resident is as comfortable as possible."

Christina was once a primary nurse with Hospicare. In that role, she visited patients at many adult care facilities, including Bridges, and worked with facility staff and primary care physicians to create the best end-of-life care plan possible for each patient. Now, as a staff member at Bridges, she is on the other side of the equation, but the teamwork is as important as ever.

"When a patient is on hospice, their health is constantly changing, often quickly," Christina says. "Depending on the patient's situation, the Hospicare primary nurse will usually check in with us daily, and we'll discuss the situation. It's a wonderful support for a facility like ours."

Bridges is an assisted living residence made up of three separate houses with a total of 37 residents, situated in Cayuga Heights just outside Ithaca, NY. The facility's philosophy is that each resident is a member of the Bridges extended family. That philosophy blends well with Hospicare's, which puts the patient and their family members at the center of the care plan and provides a team of healthcare professionals to support them.



JEFF COLLINS

Christina Slattery, RN, Director of Nursing at Bridges Cornell Heights.

"The Hospicare team of trained professionals is extremely helpful to facilities," Christina says. "You get the support of social workers, spiritual care counselors, massage therapists, bereavement counselors and many others. They supplement what is available at the facility."

Another aspect of Hospicare's service that is especially important to Bridges is the on-call nurse who is available for consultation at night and on weekends. "That support for our LPNs who are on duty at those times is very valuable," says Christina. "If the LPN sees a change in the patient's situation, they can call the hospice nurse, and the nurse will come in and assess. If medications need to be changed or a new regimen started, the on-call nurse can confer with the patient's physician and have new medications or regimens put in place."

Quick response to a patient's needs is what Bridges values, and Hospicare helps make that possible at the end of life. "I appreciate the relationship we have with Hospicare," says Christina. "It's good for our residents and their families, and for our staff."

Providing Extra Support

"I didn't realize Hospicare came to facilities," says Sue Willcox. "But when my father was hospitalized with cancer, I was glad to learn that he could be cared for by hospice no matter where he was living."

Sue's father, Bill Hiney, was diagnosed with end-stage cancer. In the hospital, he began receiving palliative care to deal with his pain and symptoms. Then he signed up for hospice services with Hospicare, but the question of where he would spend his last days once he was discharged from Cayuga Medical Center remained unanswered. He could not go home. "He had a brain tumor, which affected his behavior," says Sue. "So he was not appropriate to stay in the Hospicare Residence, either."

Sue searched the county for an appropriate facility and found Bridges Cornell Heights. Bridges was extremely accommodating, Sue says, and her father was settled in quickly. That was where Hospicare Primary Nurse Amanda McLaughlin, RN, first visited him. "Amanda was wonderful," says Sue. "She had a real rapport with my father."

The care and expertise provided by Amanda and the other Hospicare team members were immensely helpful to Bill, Sue says. "Bridges is a very special place, but



Sue Willcox with her father, Bill Hiney.

the job of the staff at a facility like Bridges is to make residents comfortable, to keep them safe. Hospice goes a level beyond that. They are the experts on the end of life.”

Hospicare also put Bill’s mind at ease about his last days. “People are afraid of hospice because it coincides with the word ‘death,’” Sue says. “You’re scared to die; you’re scared to leave what’s here. Towards the end, my dad was comfortable with passing. Hospicare, especially Amanda, brought that extra comfort, that feeling that, ‘everything is going to be fine.’ It was really special the way Amanda sat him down and just talked to him.”

The job of staff at a facility is to make residents comfortable, to keep them safe. Hospice goes a level beyond that. They are the experts on the end of life.

Hospicare helped Sue and her family, as well. Each dealt with Bill’s situation in different capacities; Sue had brothers who lived far away and a step-mother in another facility. “We needed the extra support Hospicare gave us to get through it all,” Sue says. “If we didn’t have the help of people like Amanda and Christina Slattery (Bridges director of nursing), we wouldn’t have known what to expect.”

Keeping Patients in Familiar Space

“It’s been a huge benefit for our residents and their families to be able to have Hospicare’s services when they need them,” says Michael Kilmer, executive director of Elizabeth Brewster House in Homer, NY.

Brewster House is an adult care facility with room for 45 residents located in the heart of Homer, across from the Village Green. One- and two-bedroom apartments and private suites make up the accommodations. Cozy lounges for quiet conversation are scattered throughout the building. A dining room, exercise room, beauty salon/barber shop, and a game room for larger gatherings make Brewster House a true “senior community” where seniors can age in place.

Over the last year, a few Brewster House residents have needed hospice, Michael says, and the Cortland-based Hospicare team has provided end-of-life services for them in their own apartments at the facility. This is important because state regulations require that when a resident becomes too frail or sick for the Brewster House staff to provide safe care, then the resident can no longer live at the facility. If that resident becomes a hospice patient, however, Hospicare becomes the primary caregiver and hospice regulations supersede the facility’s state regulations. That means the resident spends their last days in the place they call home.

“We’re grateful as an agency that we have our relationship with Hospicare,” Michael says. “It’s important for our residents to be able to stay at Brewster in their last days. They’ve already experienced the transition from living independently to moving into our facility. Once they’ve settled into Brewster and call it home, it’s very traumatic to have to move yet again and die somewhere unfamiliar.”

Once a Brewster resident has chosen to have hospice services, Michael and his



JEFF COLLINS

Michael Kilmer, Executive Director of the Elizabeth Brewster House.

staff will sit down with the resident and their family members, and with Hospicare’s admissions nurse to discuss the situation and plan the care process. “We talk through what Brewster’s limitations are and what hospice can and can’t do,” Michael says, “so that everyone’s on the same page.” Then the Hospicare team begins managing the patient’s care.

While any of a number of Hospicare nurses might be assigned as primary nurse to a Brewster patient, Michael is particularly familiar with Corey Stevens, RN, who has cared for several patients at Brewster in the past year. “Corey is amazing,” he says. “She’s very respectful, very knowledgeable. She’s educated myself and my staff about end-of-life care. The better we understand the process, the easier it will be for us and for residents and their families the next time someone needs hospice.”

Establishing Rapport, Smoothing Transitions

Staff Member Profile: Carrie Szewczyk, RN

BY MELISSA TRAVIS DUNHAM



JEFF COLLINS

Residence: I own a home in Freeville.

Pastimes: I love hiking, walking the dog and cooking amazing, creative things. I also recently started sharing a horse, Piper, with another Hospicare staff member.

Years on Hospicare Staff: 9 years

If there's one constant in Carrie Szewczyk's work it's that nothing is ever the same. "I don't know what I'm doing until I get to the office each day," she says, "and I like that." As Hospicare's admissions nurse, Carrie (whose last name is pronounced "shef chek") spends her work week traveling throughout Tompkins and Cortland counties, meeting with potential patients and their families, explaining what hospice is and what services Hospicare can provide, and assessing potential patients' eligibility for hospice services. "Every situation is really different from every other. Every patient is an individual," she says.

Individual relationships are central to Carrie's work. As one of the first Hospicare team members patients and their families meet, she works to establish rapport so they feel comfortable with the situation. She collaborates with Hospicare medical directors and other interdisciplinary teammates to ensure a smooth transition for the patient and family.

While she says she enjoys her time driving alone between appointments, connections to people are important to Carrie. She smiles when she speaks of her family members and close friends. Her "framily," as she puts it, includes those who "are kindred spirits in their appreciation of food, gardening and the outdoors. They are more important than anything else to me."

Carrie came to Hospicare in 2007 as a primary nurse case manager. Previously she had been a charge nurse at Taughannock House at Kendal at Ithaca (Kendal's skilled nursing unit), but was ready for a new challenge. Carrie credits her experience working at a long-term care facility for her ability to build rapport with staff at facilities. "I understand what they need and where they're coming from," she says. "The people who live at the facility are like family to the nursing home staff."

Her depth of knowledge about senior care and end-of-life issues, and her ability to recognize what

As hospice nurses, we're in people's lives at an important time, and we know what they need.

others need are crucial to her job. "I adjust to what the patient needs me to be," she explains. "It helps to develop the relationship so they feel they can call Hospicare when they need something."

When she is with a new patient, Carrie spends much of the time assessing the medical and care situation. That requires her to make some informed decisions—deciding what medications and equipment the patient needs, for instance, or which aide or LPN would be the best fit for the patient's personality. But she's also ready, she says, "to put on my therapeutic hat and focus on the person's emotional or spiritual needs."

There are times, too, when Carrie has to tell someone they unfortunately don't meet the specific hospice eligibility guidelines set by Medicare for their particular diagnosis. "It's really hard," she says, "but usually when I go over the guidelines, they understand." She'll do whatever she can for the person that day. "I'll give them a list of recommendations they can discuss with their doctor. And I'll give them my card, so they can call me if they need advice."

Carrie is passionate about her hospice work. "It's one of the best things I've ever done," she says, but she is quick to dismiss the idea that she's an "angel" as a hospice nurse. "As hospice nurses, we're in people's lives at an important time, and we know what they need. We're good at what we do, and for that people are grateful."

Carrie remembers one grateful family member who became tearful by the end of her visit—a man who was caring for his ill loved one with the help of his daughter. They had no other support systems or extended family to help, and both caregivers worked full-time. "He was just so grateful to have someone to call so he didn't have to keep figuring things out on his own," she says.



WWW.JONREIS.COM/DEIDRE MOLLURA

Women Swimmin' Set for August 13

Women Swimmin' for Hospicare is only four months away! Our 13th Annual Swim will take place on Saturday, August 13. Early that morning, more than 300 women will swim across Cayuga Lake in Ithaca to raise money to support Hospicare's services. They will be escorted by more than 150 kayaks and other boats in a fundraising event that has come to be one of the premier summer experiences in the Finger Lakes.

Registration to swim across the lake begins online at 6:00 AM on Monday, May 2, at womenswimmin.org. But plan to get up early: last year all available spots were filled in less than two hours! Registration for boaters opens a week later, on Monday, May 9.

Women Swimmin' Laps Is Back

Last year we introduced Women Swimmin' Laps for Hospicare—a chance for women who weren't able to swim across the lake to swim in pools instead (with a certified lifeguard) to raise money for Hospicare. Nineteen swimmers took part in the first Women Swimmin' Laps. This year we're hoping to double that number. Please join us!

If you would like to participate in Women Swimmin' Laps, you can 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 13. Registration for Women Swimmin' Laps began March 1 and continues until August 12.

To learn more about Women Swimmin' (either the lake or the lap version) visit womenswimmin.org

Kitchen Renovation Underway

Thanks to your generosity, the Nina K. Miller Hospicare Residence will have a new kitchen! Last fall we told you about a fundraiser to renovate our Hospicare Residence kitchen, and you responded in spades. We raised a total of \$20,000 and eagerly turned to planning our new kitchen. Throughout the winter we've worked with Andy Foster and Mindy VanderVen of Foster Custom Kitchens, as well as numerous other professionals, to determine the best design and features to maximize space and function. Work on the new kitchen will start in the spring.



Farewell to Jane Schantz

In January Hospicare said farewell to Jane Schantz, MS, FNP-BC, ACHPN, who has taken a position as clinical instructor at Binghamton University's nurse practitioner program. Jane began working at Hospicare as a nurse in 2004 and later became our palliative care nurse practitioner. In that role she was our expert in palliative care, as well as a

pivotal member of the Palliative Care Team at Cayuga Medical Center. She was often the first Hospicare staff member patients met at the hospital. Her ability to clearly explain care options and answer questions helped ease their transition from the hospital to hospice care.

Jane was an integral member of our Hospicare team, and we will all miss her calm, compassionate demeanor and wise counsel. While she is no longer part of our staff, she continues to be a friend and hospice partner. We have no doubt Jane's guidance and instruction to future nurse practitioners will benefit us all.



GRANGER MACY

Join Us for Illuminations

On Thursday evening, June 9, we will be holding Illuminations, our annual memorial event, in the gardens at the Nina K. Miller Hospicare Center in Ithaca. The pathways around our building will glow with luminaria, 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 and is open to the public.

To learn more, or to purchase a luminaria in memory of a loved one, visit hospicare.org/events/ or call 607-272-0212.

Did You Know?

Medicare now reimburses physicians and other healthcare providers for time they spend with patients discussing end-of-life wishes.

Our newsletter is mailed twice a year to patients and family members, donors, community supporters and other friends of Hospicare. If you'd like to share thoughts about our newsletter, email communications@hospicare.org. This newsletter is also available online at hospicare.org/newsletters



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/donate/

- **Matching, extra-long, jersey, twin sheet sets (new only):** Hospital beds require extra-long, twin-size sheets of jersey fabric. When patients remain in their own homes, Hospicare arranges to have hospital beds delivered to them so the patients can rest more comfortably and safely. However, many families do not have the special-size sheets to fit this type of bed. Please note: we can only accept *new* sheets.

- **Baby monitors (new only):** It may not be obvious why a hospice needs baby monitors, but they can be helpful tools for family caregivers, allowing them to listen in from another room. This gives family members peace of mind that they will be able to go about their daily activities and still be available if their loved one needs something.

- **Reusable, microwavable heating pads (new only):** Microwavable heating pads filled with grain (such as rice, buckwheat or flax seeds) work well to ease pain in patients' backs, necks or legs. We prefer heating pads sized 20-48 inches long by 10-12 inches wide.



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