Hospice professionals today owe a debt of gratitude to Dame Cicely Saunders for the model of healthcare she developed in the 1960s. As a nurse, turned social worker, turned physician, she established St. Christopher’s Hospice in London in 1967. St. Christopher’s, still thriving today, credits her for revolutionizing the way society cares for the ill, the dying, and bereaved.

The cornerstone of Dame Cicely’s philosophy of care is the total pain model, which illustrates that the pain experienced by a seriously ill person is a complex combination of physical, emotional, social and spiritual factors.

The total pain model is central to hospice care; it reminds us that the pain experienced by a seriously ill and dying person cannot be alleviated with medication alone. Hospice care is provided by a team of caring professionals, each with unique skills and training to address one aspect of the total pain. A key component is its acknowledgement that the pain experienced by the patient and caregiver are interrelated. Therefore, hospice care focuses equally on the patient and caregiver.

Dame Cicely’s work - and modern-day hospice - are influenced by the experiences and wisdom of the early hospices in medieval Europe. Their care for the sick and dying was deeply holistic, focusing in large part on the spiritual aspect of pain and suffering. They realized that pain is primarily a physical and emotional experience centered in our physical body.

Suffering, however, develops when we apply meaning or “tell ourselves a story” about the pain. For example, a patient with severe cancer-related pain may have intractable suffering if he or she believes the “cancer is punishment” for prior misdeeds. Suffering, as a result, does not often improve with medication. The medieval approach to addressing suffering - based on Celtic tradition - was to “lean into it.” They believed it was possible to have a more peaceful death if the spiritual pain of a dying person was dealt with directly, and with compassionate support. Celtic wisdom also understood that having a realistic acceptance of death throughout life allowed for a more joyous life and a more peaceful death.

see “Visionary,” on page 2
Dear Colleagues:

In this issue, we take a look at the deeper work of hospice and why appropriately timed referrals are so essential in achieving a “good death.” These articles represent a small sample of the work we do every day to enhance our patients’ quality of life. We know you have choice in where to send your patients. We want to be your choice and to partner with you to meet your needs and those of your patients and families. Please don’t hesitate to contact me with any questions, concerns or suggestions on how we might improve our services to you and your patients at 216.383.2222 or bmessinger-rapport@hospicewr.org.

Dr. Kevin Dieter is one of our inpatient and home-based hospice physicians. This spring, he and a team of colleagues presented at the Annual Assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) in Chicago. He shares his insights in this issue.

We’ll also take a closer look at caring for caregivers in this issue. Most family caregivers are not medical professionals, so as they are thrust into the role of caring for a dying relative or friend, they can be overwhelmed by the challenges. Social worker and team leader Gwen Rifici writes about the crucial role social workers play in mitigating family dynamics to support caregivers and help patients achieve a peaceful death.

Who better to relate the value of hospice support than a family caregiver? On page 5, Jackie Pfadt, daughter of the late Michele Tripi, one of our patients who had ALS, shares her personal story.

Finally, to celebrate the 20th anniversary of our Hospice Institute, we will be hosting an extraordinary Annual Conference this year. You won’t want to miss it. National speaker Dr. JoAnn Paladino, MD, from Harvard University, will share with us the tools developed by Dr. Atul Gawande in Boston’s Ariadne Labs. You may have seen the award-winning PBS documentary based on his book, Being Mortal. Our focus will be on evidence-based practices that help you initiate difficult conversations with your patients. Hope to see you there!

Kind regards,

Dr. Barbara Messinger-Rapport
Chief Medical Officer
bmessinger-rapport@hospicewr.org

Sadly, in today’s world, we often deny the existence of death until we are facing it. Studies have confirmed that we are the most death-denying culture in all of history. We also tend to ignore, repress, and self-medicate the spiritual pain accumulated during life. The result is that serious illness often becomes a time of suffering and “total pain.” Caregivers become victims of the transmitted suffering of their loved ones.

The hospice philosophy of care understands this reality. Hospice team members are uniquely trained and compassionately motivated to guide patients and their caregivers through this final part of life’s journey. Their holistic approach recognizes that pain and suffering respond best to a combination of medication and interventions provided over time, often beginning early in the terminal illness. Hospice professionals understand the end of life can be a time of healing, forgiveness, transformation and hope.

 ABOUT THE AUTHOR

Dr. Kevin Dieter (MD, FAAHPM) is Medical Director at David Simpson Hospice House and supervises the agency’s Lakeshore East home care clinical teams. He is a nationally known speaker on the “total pain” model of care, a holistic approach to addressing pain and suffering. Dr. Dieter earned his medical degree at Northeastern Ohio Universities College of Medicine (NEOMED) in Rootstown, Ohio, in 1985. He is Board Certified in Hospice and Palliative Medicine as well as Family Medicine and is a Fellow of the American Academy of Hospice and Palliative Medicine.
The Total Pain Model: 9 Key Points

THE “CAREGIVER” DESIGNATION at the diagram’s base illustrates the crucial role caregivers play in addressing total pain. Celts believed total pain and suffering were transmitted and transferred between patient and caregiver. By adopting their ancient wisdom and “working through” rather than “around” all contributing aspects of pain and suffering, transformation and healing are possible.

1 | The hospice model of care is based upon the concept of “total pain,” which acknowledges that patients with serious and life-limiting illness suffer because of physical, emotional, social and spiritual sources of pain and suffering.

2 | Pain and suffering are related, but not necessarily the same. Pain, whether physical or emotional, has a physiologic basis. Suffering, on the other hand, arises when we apply meaning to or tell ourselves stories about the pain we are experiencing.

3 | Pain can often be alleviated or improved with medication, whereas suffering often is resistant to medication. Failing to recognize the difference can lead to over-medication and over-sedation of patients who have serious and life-limiting illness.

4 | Seriously ill patients and their families often resist the recommendation for a hospice referral due to concern about over-sedation and over-medication. Understanding the role of the hospice team in addressing total pain can enable the referring physician to alleviate these concerns.

5 | Suffering can be successfully evaluated and treated by using a spiritual pain model that addresses the following four aspects: forgiveness, meaning, relatedness, and hope. To access a spiritual health evaluation clinical tool offered by the Sacred Art of Living Center, visit hospicewr.org/assessment.

6 | Pain and suffering, particularly in the setting of terminal illness, often involves and affects the caregivers in addition to the patient. The hospice team can be a valuable resource in terms of time and expertise in helping the referring physician address and manage the complex impact of pain and suffering on family relationships.

7 | The hospice transdisciplinary team is comprised of compassionately skilled professionals from many disciplines who work as a cohesive and integrated unit. This allows the patient and family to receive focused care that addresses the complexity of terminal illness.

8 | The appropriate management of suffering, especially spiritual pain, requires time, and is best delivered by hospice involvement early in the course of a terminal illness.

9 | Appropriately timed referrals that allow sufficient time for hospice to do this important work are fundamental to maximizing quality of life and achieving peace for both the patient and caregiver.

Patterns of Spiritual Pain

Based on self-evaluation of patients during pastoral care visit

- Relatedness
- Hope
- Meaning
- Forgiveness

THE SACRED ART OF LIVING CENTER (SALC) IDENTIFIES FOUR CONSISTENT QUALITIES impacting spiritual pain at the end of life: Meaning, Hope, Relatedness and Forgiveness. “Forgiveness pain” is considered the “common cold” of spiritual pain. SALC is a not-for-profit institute in Oregon established in 1997 by Richard and Mary Groves. It is committed to end-of-life spiritual care and the issues of aging, loss and bereavement. A key focus is bridging the gap between science and spirituality. For more information, visit sacredartofliving.org.
As a hospice social worker, commitment to a patient’s goals of care entails being a good listener, honoring each person’s need to follow his or her own path without judgment and collaborating closely with other members of the transdisciplinary team to achieve the best possible outcome.

When a loved one is dying, the swirl of intense emotions frequently creates complex dynamics that can lead to family discord and disagreement. I have witnessed family rifts that have deeply affected a patient’s peace and well-being. While social workers certainly cannot change family history, they can provide options for creating a peaceful and harmonious journey.

A hospice social worker’s many skills include knowing how to read and defuse a stressful and potentially volatile situation.

A 37-year old man dying of prostate cancer was newly married. His ex-wife and children from his first marriage were also involved in his goals of care, as were his parents. Conflicts, jealousy and tension arose between these parties, causing the patient spiritual distress and suffering.

I spoke privately with this patient, allowing him to express feelings for his ex-wife, his new wife and his parents. He expressed his desire for peace, but acknowledged several family members were unlikely to get along or feel comfortable in each other’s presence. He provided me with permission to speak with each of them individually to present options on how they could assist him. The private conversations the patient and I had with each individual allowed him to express his desires and feelings with each of them.

After the meetings, we devised a care plan that included each of them. A calendar was created denoting each person’s role and coordinating visits to minimize friction. I provided one-on-one weekly support to the patient’s new bride, identifying her unique role as the patient’s wife, and assisted her in coping with the family’s involvement.

The outcome was a peaceful patient and family members who were able to show their individual love for him. The patient died as he had wished, with his wife and children at his side. The family members attended the funeral without conflict or malice toward each other. They thanked the whole hospice team for giving each of them purpose, and for validating their love for the patient.

My career as a hospice social worker is deeply rewarding, and one that I cherish. I believe each person deserves dignity and validation at the end of life. I am honored to be a hospice social worker and team leader, interacting with people every day who teach me about living life to the fullest with strength, grace and hope.

“While social workers certainly cannot change family history, they can provide options for creating a peaceful and harmonious journey.”

- Gwen Rifici

Gwen Rifici (LSW, CHP-SW) has 25 years of experience as a social worker, including specialized training in geriatrics and caring for HIV patients. Currently, she is Clinical Team Leader for the Medina Home Care and Alternative Home Care Teams.
A Family Caregiver’s Story

Michele Tripi is a former Hospice of the Western Reserve home care patient who had ALS. Her daughter, Jackie Pfadt, played an integral role in her care, along with her father, Joe Tripi, and other family members and friends. Pfadt shares the family’s experiences with hospice in this interview with Clinical Connections.

Q: Why was it so important to your mom to have a voice in her care?
A: Mom was scared. Her disease was causing her to lose her autonomy. When you can no longer feed yourself, go to the bathroom alone or even raise a tissue to wipe tears from your eyes, having a say in your care matters. While she became trapped within her own body, she could still decide who she invited into her home. She welcomed the hospice team into our family.

Q: How valuable was the time you had as a family?
A: We needed that time. I was so afraid I would sink without her. We all agree that she was waiting for us to be ready. As she continually lost more of her physical abilities, she would have little “funerals” to mourn each of the losses. We grieved these losses together, yet we all grew in our faith and became better people.

Obviously, living with a terminal illness is extremely stressful and heartbreaking. But we as a family went “all-in” together. Hospice of the Western Reserve created a strategy to care for Mom and enabled us to make many memories.

Q: What were some of the challenges you faced?
A: I fell apart. I went into an extremely hard period of my life that required a lot of therapy and treatment to get healthy. In our time together taking care of Mom, I learned to trust and rely on her hospice team. In the last few months, the expert clinical care they provided allowed me to be a daughter. They enabled me to get the emotional, social, and spiritual support I needed to endure the unimaginable heartbreak of saying “goodbye.” Mom and I found forgiveness and peace through our work together during this time.

Q: Your mother’s faith guided her life. How did hospice help her draw upon that?
A: We were able to share our faith and help each other grow. Hospice of the Western Reserve created a space for us to do this. Mom had a spiritual care coordinator she could talk to. She became totally reliant on other people for her basic needs and survival. She could have become bitter. Instead, she filtered this energy into her faith and became her most beautiful self.

Q: How did hospice help in the final hours?
A: Mom’s nurse practitioner as well as the ALS Association service coordinator came over to discuss Mom’s concerns regarding her increased difficulty with breathing. Her BiPAP machine no longer made her comfortable. When they laid out the various options, Mom decided on palliative sedation, a medically induced coma, where they would get her to sleep and then remove her life-sustaining BiPAP device. Arriving at this decision gave Mom peace knowing that her struggles would soon be over and that we all supported her.

Mom’s doctor, nurse practitioner, nurse, nurse’s aide, music therapist, and her spiritual care coordinator were all with us when she passed. Her art therapist came over earlier in the day to spend time with her grandchildren to make sure they were doing okay. As the drugs were being administered, the hospice spiritual care coordinator led us in prayer and the music therapist sang our favorite songs. She was surrounded by 17 of us made up of family and her hospice care team.

As her time of death approached, Mom was completely cognitive and able to speak. She was so brave and at peace. She was ready to go and her hospice team supported her and our entire family during and after.

We opened ourselves up to the opportunity, which was absolutely necessary for this to be possible. Hospice of the Western Reserve came into our home and helped transform a life-shattering situation into a life-giving blessing.

ONLINE EXTRAS

Art and music therapy played a crucial role in improving quality of life for Michele and Jackie. Listen to Michele’s story, in her own words, and read more of Jackie’s reflections at hospicewr.org/resources.
Telling the Stories
THE DEEPER VOICE OF HOSPICE

“Having the Conversation”
Friday, September 16, 2016 • 7:30 a.m. – 4:30 p.m.
Corporate College East 4400 Richmond Road, Warrensville Hts.

FEATURING:
Joanna Paladino, MD is an instructor of medicine in the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute. She also serves as an assistant director of implementation of the Serious Illness Care Program at Ariadne Labs. As a member of the team working with Dr. Atul Gawande, MD, MPH, author of the bestseller, Being Mortal, Dr. Paladino will share valuable insights for improving the end-of-life experience.

CONFERENCE OBJECTIVES:
• Discuss the importance of having serious illness conversations from the healthcare community.
• Demonstrate how spiritual distress, mental illness and grief can affect these conversations.
• Identify how to assist patients in addressing Goals of Care and how to overcome barriers.

PLENARY SESSIONS:
• Joanna Paladino, MD
  “How to Improve Serious Illness Care for All Patients: The Role of Training and Systems Change”
• Kevin Dieter, MD, FAAHPM
  Medical Director, Hospice of the Western Reserve
  “Starting from the End: “How to Introduce Conversations About Death into Advance Care Planning”
• Karen Komondor, RN, BSN, CCRN
  Director, Organizational Development and the Health Literacy Institute, St. Vincent Charity Medical Center
  “Health Literacy: A Foundation for Clear Health Communication”

REGISTER TODAY AT HOSPICEWR.ORG/CONFERENCE

Hospice of the Western Reserve, OUN-001-P, is approved as a provider unit of continuing education by the Ohio Board of Nursing through the approver unit at the Ohio League for Nursing (OBN-006-92) and provider unit status is valid through October, 2017. 6.0 contact hours. Hospice of the Western Reserve is approved by the State of Ohio’s Counselor, Social Work and Marriage and Family Therapist Board to provide professional continuing education for social workers (RSX079403). 6.0 contact hours. Counselor hours have been applied for and are pending. Hospice of the Western Reserve is accredited by the Ohio State Medical Association for Continuing Education to provide continuing medical education credit for physicians. Hospice of the Western Reserve designates this education activity for a maximum of 6 AMA PRA Category 1 credits(s) TM. Physicians should claim credit commensurate with the extent of their participation in the activity.