A HOLISTIC APPROACH

Expanding Care To the Sick and Dying

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Portraits line the walls of Providence TrinityCare Hospice in Torrance, California — photos that resonate because the message is both sobering and uplifting. These are the faces of hospice patients as they approached the end of life with the comfort and care of loved ones.

One portrait is of an elderly man, flanked by three freckled grandsons. It illustrates Providence St. Joseph Health's model of palliative and hospice care that encourages patients and their families to treasure moments, even as they make difficult decisions in the face of impending death.

Providence TrinityCare and its pediatric hospice program, TrinityKids Care, are ministries within Providence Health & Services, Los Angeles Region. The hospice programs serve Los Angeles and Orange counties, living the organization's mission of compassionate care to the poor and vulnerable by providing palliative and hospice care to the chronically ill and the dying. The goal is to address symptoms — physical, emotional and spiritual.

Over time, the philosophy is being integrated throughout the seven-state Providence St. Joseph Health Catholic health care system, which was formed in 2016 when Renton, Washington-based Providence Health and St. Joseph Health System, based in Irvine, California, joined to create a new organization.

The emphasis is on healing people, not curing them.

"Curing is when you have an illness or injury, and you want to get back to normal," said Glen Komatsu, MD, chief medical officer for TrinityCare. "Healing is a very different process, an internal process within the patient and the family, a process whereby the individual comes to a new understanding of themselves. Hopefully in that process, we can help them come to terms with their health challenges. When we are successful, that's when we see people who are dying come to terms."

Thus the photos of men and women of varying ages, who have since died, reflect the Providence commitment to integrating palliative care throughout the health care continuum, treating patients and their families with respect and dignity while honoring their traditions, their cultures and their values.

Palliative care helps open paths of communication among physicians, caregivers, patients and their families to discuss care based on personal values and beliefs. It begins with personalized attention from a team of physicians, nurses, chaplains and social workers, and it may eventually lead to hospice. It encourages patients and their families to discuss and formulate care plans, including end-of-life care, with their providers.

Providence believes patients and families want and respond to this personal style of health care.

Their physical well-being is essential, but so is their emotional, interpersonal, social and spiritual well-being.

"Health care at its best is highly personal," said Ira Byock, MD, a pioneer in patient-centered care that addresses and honors the values and priorities of patients and their families. "Personalized medicine is not just about your genome, it's about who you are as a person, what matters most to you as a person. The best health care is never a one-size-fits-all model."

In 2014, Byock founded the Providence Institute for Human Caring, in partnership with Providence Health & Services, to develop a program that advances the level of whole person care from birth through the end of life. His approach to integrated palliative care is unique. It is an aggressive approach, one that begins by educating primary care physicians as well as specialists to talk with their patients in order to complete advanced directives, spelling out the type of care they want and whom they designate to make their health care decisions, if ever necessary.

The documents live in patients' health care records. In fact, an Institute for Human Caring physician has developed software for electronic health records that alerts emergency department teams to these directives and any other documents detailing patient wishes.

"It's a big deal if someone says they don't want CPR performed, and the provider orders a full code," said Matthew Gonzales, MD, an associate medical director at the Institute for Human Caring, who helped implement the system. "As clinicians, we should be consistent with what a person's wishes are when admitted to the hospital."

PILOT PROGRAM

The concepts are being tested in a pilot program that began this year at Providence Little Company of Mary Medical Center Torrance, a 442-bed hospital within a mile of TrinityCare's main offices in Southern California. Lessons learned will be applied as the practice eventually expands to Providence St. Joseph Health's 50-hospital, 825-clinic system. There is no timeline for this expansion, but each hospital is being assessed for readiness, and a phased schedule will be drafted in 2018.

The pilot program weaves palliative care into care for the chronically ill. Unit by unit, specialty by specialty, clinicians learned about whole person care and the continuum for palliative and hospice care. The hospital's chief medical and nursing officers, in collaboration with the Institute for Human Caring leadership, led the teams of physicians, nurses and chaplains. Social workers soon came on board. The program slowly expanded throughout the hospital as care teams in new units and disciplines were educated about the concepts and applications of palliative care.

Physicians, nurses and volunteers train to care for the ill and dying by treating "standardized patients," people who have been taught how to play the role of a patient with a specific condition. The team learns how to initiate serious conversations with patients about their conditions and the care they prefer. These conversations, recorded in the patient's electronic medical record, are designed to continue over time as situations evolve.

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"We wanted to develop a comfortable level around whole person care, and using these discussions (stored in the medical record) can guide the conversation so there's standardization in documentation while capturing conversations as they evolve over time," said Mary Kingston, the hospital's chief executive. "The goal was to hardwire how the conversations are conducted and document patient preferences or goals of care."

The timing of the conversation can be critical.

"Sometimes patients and families are ready to have the conversation, and it's the chaplain, not the physician, who is in the room," Kingston said. "It's important to engage at that moment. These conversations bring clarity, and that clarity is valuable for the care team when patients share how they want to manage their illness. It gives a patient the power to direct their care with consideration to who they are and how they want to be treated during an illness that might feel out of control."

One of the first lessons the group learned, however, was that although chaplains are comfortable with such conversations, physicians and nurses sometimes are not.

"One of the things that was a bit of a surprise to us was that this education and practice is not something offered in nursing school or medical school," Kingston said. "But the receptivity of the clinicians to learning to engage in serious conversations was exceptional."

Komatsu at TrinityCare credits Terri Warren, executive director of Providence Senior and Community Services, for her vision in recognizing more than a decade ago that the future of hospice was in palliative care.

Warren said the Sisters of Providence and the Sisters of the Little Company of Mary, founders of Providence ministries in the coastal communities of southern Los Angeles County, built the foundation of the continuum. They recognized the value of seamless care, especially for vulnerable patients, she said.

"What is unique to our care is that palliative services is a partnership between the hospitals and hospice, the whole continuum of how it's delivered is a partnership," Warren said. "In most hospitals, they'll have their own program — it's very small, and there's no backup. By building partnerships and nourishing them, we have made changes in the entire approach."

The work can be daunting, Warren said, stressing the importance of supporting the caregivers who provide palliative and hospice care.

"We're taking the principles of the care we provide to the next level by looking at how we care not only for the person living with illness, but for our caregivers," Warren said. "How do we build resilience and compassion for our own caregivers who are caring for patients from infancy all the way through the very elderly? Our goal is to support our caregivers, understanding the very difficult work they do and the toll it can take if they don't receive the support they need."

Komatsu talks of the "wounded healer" and the relationships between caregivers and patients that are created by whole person care.

"This work, it's a two-way relationship," he said. "The patient is wounded, we are wounded. We are walking alongside with our patients as fellow wounded healers. We're helping them to heal; they are helping us to heal."

LOOKING TO SYSTEMWIDE PALLIATIVE CARE

Providence's goal is to provide whole person care to every patient, embedding the principles of palliative care throughout its system. Komatsu advocates for extending the values of the holistic approach to care, saying, "All patients deserve the palliative care approach."

Komatsu trained as a neonatologist. His vocation shifted over decades to palliative care and hospice as he sought more compassionate care for tiny patients and their parents in the neonatal intensive care unit.

"I came to understand there wasn't the concern or the recognition of the suffering of babies and their families," he said. "I started giving small amounts of pain medication to babies. That led to the feeling that there had to be better ways."

The approach for the pilot program is based on a model designed by Balfour Mount, a Canadian physician considered to be the father of palliative care, and his colleagues at McGill University in Montreal. As modified by Komatsu and Byock, the model relies on materials developed by the Institute for Human Caring that include videos, instruction manuals and advance directive tool kits, all emphasizing whole person care and available to the Providence hospitals. The techniques help clinicians better cope with their work and also become better listeners for their patients and families.

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The institute provides various patient and physician education materials to help people make conscious choices about how they interact with the health care system. For patients and families, these materials include videos that illustrate certain medical conditions and treatments, and "Advanced Care Planning Decisions" videos

that are straightforward explanations of advance directives, cardiogenic pulmonary edema, hospice care and include details about what some treatments entail.

MEANINGFUL INTERACTION

With the Institute for Human Caring, Providence made a major commitment to person-centered care to help people — particularly those with serious illness — interact in more meaningful ways with their health care providers.

"Illness is not just medical, but personal," Byock said. "You start to shift the clinical encounter from being transactional to being relational."

Palliative care team members at Providence Little Company of Mary Medical Center Torrance are the champions of the approach, but they have significant allies among the hospitalists, critical-care specialists, surgeons, cardiologists, oncologists and others working together to add an element of the personal to all aspects of care, including clinical workflows, processes and metrics.

"We start with the premise that every person we touch has inherent value, worth and dignity," Byock said.

That translates to making it routine for an advance directive to be on the chart before a patient goes to surgery, even for a relatively minor procedure. Hospital employees insured by Providence can earn health savings account incentives to do their own advance care planning. "This helps change the culture so it becomes normal," Byock said.

The whole-person care approach is aligned with the organization's existing and comprehensive hospice and palliative care programs. TrinityCare maintains two adult hospice teams along with a dedicated pediatric hospice team that cares for 158 young patients on average.

"I tell my pediatrics team all the time, there are no words we can say that will ease the pain of a parent of a dying child," Komatsu said. "But we can keep showing up, we can show them we are not afraid to accompany them on this journey and bear witness to their suffering and grief, and point out the small slices of joy still possible."

OUTREACH THROUGH PARTNERSHIPS

TrinityCare has built a number of partnerships to enhance and expand its care of the sick and dying among particularly vulnerable populations.

Recently, an agreement was inked with a not-for-profit organization called Keiro — a Japanese term that means "respect for the elderly." Keiro supports aging Japanese-Americans and Japanese living in the region, enhancing their quality of life and advocating for them through the end of life. For many of the oldest members of the Japanese communities in Southern California, there is a gap in medical and support services that meet their unique needs, particularly in terms of a language barrier. TrinityCare will bring palliative care services to those whom Keiro serves.

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The partnership establishes a three-year joint program to address issues regarding pain and symptom management, advance care planning, caregiving planning, safety assessments, psychosocial and spiritual support, medication, health care systems and alternative treatments, transportation and Japanese cultural questions that affect health care decision-making.

The Keiro-Providence program is the first of its kind in the U.S. to focus on delivering palliative care services to Japanese-American and Japanese-speaking older adults, taking into account the cultural preferences, needs and philosophies of life for each individual. The goal is to improve their quality of life by enabling these clients to remain in their homes if that is their choice and to decrease emergency department visits and inpatient hospital admissions.

Other partnerships involve volunteer outreach. At Providence Little Company of Mary, volunteers participate in No One Dies Alone, a program founded in 2001 in Oregon. Volunteers train with the "standardized patients," learning to provide very basic care and comfort to the dying and to be companions to those who have few or no visitors in their final days.

And there's the local songwriter who meets with young TrinityKids Care patients to help them write songs, often sharing their feelings and perspectives in the lyrics they compose. Later, grieving parents treasure the recordings of their children singing the songs they wrote.

A teenager debilitated by cystic fibrosis has been captivated by the virtual reality program a volunteer team set up, allowing him to "experience" space through an Emmy-nominated film about the International Space Station. He is being featured in a short documentary that the producers hope to use to encourage donations of virtual reality equipment so more terminally ill youths can experience such adventures at home.

"The focus isn't on death — we recognize death may be near — but the focus is on living now, in the present," said Barbara Roberts, administrator with Providence Senior & Community Services. "What can we do to make our patients as comfortable as possible now? And our community partners are with us to bring value-added programs into the homes of our patients and families to ease their way."

ERIK G. WEXLER is chief executive of Providence St. Joseph Health — Southern California Region.

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Mt. 25:31–46
The Last Judgment

2018

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5th Sunday Ordinary Time
Mark 1:29–39
Healing of Peter's Mother-in-Law

FEBRUARY 11
World Day of the Sick
6th Sunday Ordinary Time
Mark 1:40–45
Healing the Leper

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