Filling in the gaps in Palliative Care

By Nancy Lofholm

How One Colorado Hospice Pioneered a Comprehensive Palliative Care Program

Nearly 40 years ago, when Christy Whitney was organizing an all-volunteer hospice in the small Colorado mountain town of Durango, she was struggling with a word, and with a void. The term “palliative care” hadn’t yet entered the lexicon as the designation for what would eventually be a range of services encircling hospice care. And ill people were falling through cracks in the fledgling hospice system: There was a gap between those who qualified for hospice because they were close to dying, and those with serious illness who needed care at a lesser level.

Those issues were still conundrums in 1993 when Whitney moved on to Grand Junction, CO and became the founding CEO of HopeWest. The non-profit hospice she organized would grow and expand services to become a respected model for creative and effective palliative care. Through trial and error and leaps of faith – with a cadre of committed volunteers and inventive financing – HopeWest was able to create a continuum of care that operates successfully beyond the confines of the healthcare and insurance industries.
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“We wanted to do whatever we could so we would not become one more cog in the business of healthcare,” explained Whitney. “We learned early on to use philanthropy and volunteerism to create what we wanted.”

HopeWest was able to be creative in stepping outside the standard hospice lines because there was no template at the time for seamless care. The effort began with a minuscule hospice staff – so small the staff directory fit on an index card. They gathered around a table in a rented office, brainstorming ideas. The nurses, nursing assistants and social workers in that room shared Whitney’s passion for improving a flawed system. They recognized how expensive and fragmented care could be if patients were forced into emergency rooms and had to be hospitalized while they were in hospice-care “gaps.”
Their ideas – dozens of them – went on the whiteboard. It was an egalitarian process: Everyone’s ideas had equal weight. Those that were unworkable were erased. Others were checked off as they were put into practice.

“It boggles my mind to think about where we started with all that,” said Beth Brown, who was on the nursing staff then and is now the HopeWest Clinical Manager of Transition and Living with Cancer programs. “Still, we are always coming up with new and improved versions of what we do.”

Louise

In the beginning, one patient in particular helped to set the tone for HopeWest’s continuity of care. Louise was a woman in her 80s with breast cancer. Her physician had recommended hospice care when he estimated she had three months to live. That prediction proved far too short. Louise thrived on the care and attention she received as a hospice patient. She lived for three more years.

Finding creative ways to continue her care all that time helped to truly shift paradigms at HopeWest. Ideas about continuity of care were put into practice. HopeWest broke out of the healthcare realm and took on the added role of social service agency. Louise’s case inspired the HopeWest staff to view the end of life as a human experience rather than a medical condition.

“Louise really set our course,” Whitney recalled. “We realized that to discharge a person who needs our help is horrible.”
The Bucket

At HopeWest, that course eventually led to the creation of four channels for palliative care, or what Whitney calls “the bucket” of services. These channels, with continued tweaking, and with team work on complex case management, ensure all patients are cared for in as seamless a fashion as possible:

- **Transitions:** RNs provide palliative care case management with the support of an interdisciplinary team that includes social workers, occupational therapists, chaplains and volunteers. The majority of patients in this program are admitted with a prognosis greater than six months with chronic disease and advanced illness. More than 95 percent of them are not eligible for hospice and don’t qualify for a home health benefit through their health-care provider. HopeWest served 171 patients in this program last year.

- **Journeys:** This program serves patients who initially are enrolled in hospice but, after receiving care, no longer have a terminal prognosis of six months or less. So, they no longer qualify for hospice care under Medicare guidelines. They do still need specialized care to address medical symptoms as well as emotional and spiritual needs. To give these patients continuity of care, they are followed by the same hospice interdisciplinary care team they had as hospice patients. The continuity of care helps to reduce emergency room visits and hospitalizations and makes it easy to re-enroll in hospice once a patient becomes eligible again. Last year, 72 patients were served in this program.

- **Living with Cancer:** This program focuses on survivorship. The format is similar to Transitions, but it has a unique planning and evaluation partnership with three cancer centers. More than half the patients in this program could be eligible for hospice if they were not pursuing aggressive curative therapies. Living with Cancer patients receive services at home, such as hydration, blood draws and dressing changes, when they are too sick to travel to their medical providers. This lessens the burden on caregivers and families and addresses the concerns beyond treatment, to how a cancer diagnosis is impacting someone on a day to day basis. Social workers from the cancer centers and from the Living with Cancer program work together to connect families to resources that cover everything from medical expenses to everyday needs. A hospice nurse attends oncology team sessions. This program helped 129 patients last year.

- **Palliative Care Consults:** All palliative care patients qualify for consultations. So do ill community members who are experiencing uncontrolled symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. When a referral for consultation is made – usually by a HopeWest team member or a primary care physician – HopeWest medical directors make visits to patients to assess their needs and come up with suggestions for symptom management. They work in
conjunction with the patient's primary care physician to make changes that help to control symptoms.

“With these layers of programs, we can tell physicians to call us and we will figure it out. We will find where a patient fits,” said Brown.

**Speed Bumps and Education**

Those channels all flow together now, but there were missteps along the way. What Whitney refers to as “speed bumps” included not training hospice nurses in palliative care in the early days. It took HopeWest time to zero in on the concept of educating employees to the job. Caregivers needed to be taught to look at the whole person – to make sure patients' toenails were trimmed and they had food in the refrigerator, as well as ensuring they had their pain under control and their dressings changed. As HopeWest's total patient census grew from 30 to the current 635, another growth-related problem surfaced: there was a lack of coordinated care between different caregivers in the palliative and hospice channels. Coordination is still a work in progress. HopeWest continues to fine tune that system so that patients aren't handed off to different caregivers as they move through the channels of palliative care and hospice.

HopeWest’s learning experience with building a palliative care program has evolved into an educational effort. HopeWest holds annual training conferences that have educated more than 300 providers each year. The conferences are headlined by nationally recognized visionaries in hospice and palliative care, Dr. Frank Ferris and Dr. Charles F. von Gunten of OhioHealth Hospice. The two hospice and palliative care physicians share Whitney’s mission to make palliative care a standard part of the healthcare system.

HopeWest has incorporated the concept of telemedicine to open this training to a wider audience. Internet training is bringing palliative care concepts to an expanding network of partners that include emergency department physicians, pharmacists, ICU staff, and employees of assisted living centers and nursing homes. Online training also is being used to build satellite HopeWest programs and to instruct volunteers in rural areas, including the ski town of Telluride and the ranching community of Meeker.

**Funding**

It goes without saying that all-encompassing care brings costs that don't fit in the parameters of insurance coverage. HopeWest relies on a dossier of funding sources. Holly Howell, a social worker who serves as Director of Palliative Care at HopeWest, said one of her biggest chores is “getting really creative” about funding. The palliative care programs at HopeWest create a deficit of about $255,000 annually. Medicare and Medicaid don’t pay for those services. Even Medicare supplements rarely cover palliative care. Most private insurances don’t pay. To cover the cost of the palliative care programs, HopeWest charges patients a sliding fee for monthly care that ranges from $10 to $150. Total annual palliative care expenses of about $410,000 are covered by these fees, by Veterans Administration benefits, by a small amount of private insurance, and by United Way donations. A very active HopeWest Foundation annually adds another $100,000 to the palliative care program.

“Don’t get caught in the paradigm of not doing anything that isn’t being paid for,” Whitney advised. “Use philanthropy and volunteerism to do what people need.”

The uncertain finances of palliative care are balanced by the fact that more patients choose HopeWest covered hospice care after they have experienced the palliative-care benefits. These patients tend to enter hospice care earlier rather than waiting until their final few days. The length of stay at HopeWest has doubled over the years, from 45 days to 90 days.
Volunteers have made these emotional and practical support services possible.

Community support and financial buy-in is essential for a non-profit palliative care program to work. So is a volunteer-intensive focus. HopeWest has 1,400 volunteers. Those volunteers have made for sky’s-the-limit care to become the norm at HopeWest. Whitney’s philosophy about volunteers is to recognize their unique talents and put them to work where they fit. At HopeWest volunteers offer aromatherapy and hair cutting. They notarize documents and knit blankets. Volunteers record patients’ life stories. They help patients decorate pillows with handprints for loved ones to have for keepsakes. They make iPads available, and instruct in their use, for communication with distant family members.

If a patient has always dreamed about violin lessons, a volunteer with musical talent arranges lessons. If a patient is having trouble reading on a computer, a tech-savvy volunteer puts larger font on the screen. If a patient’s caregiver can’t buy milk at the grocery store because it is too heavy to lift from the cooler, a volunteer steps in as a shopping companion.

When a couple in hospice care longs to make one last visit back to their Louisiana hometown, but are too ill for the trip, HopeWest staff and volunteers cook southern fare and hold a Mardi Gras event at their home. When a woman who has loved horses all her life wishes for one more ride, it is arranged at a HopeWest board member’s stable. For a former smoke jumper in WWII pining for one final jump from an airplane before he dies, a volunteer with pilot connections coordinates a skydiving adventure.

Volunteers have made these emotional and practical support services possible. They have also helped give the HopeWest medical staff the flexibility to treat patients more broadly on the healthcare side. There are success stories in this realm, too:

- Gary entered the Living with Cancer program with a pre-leukemia syndrome that was causing a succession of devastating infections and requiring debilitating treatments. After the 58-year-old began receiving palliative care in the form of weekly home visits for blood draws and coordinated symptom control, his chain of hospital admissions stopped. His infections were brought under control.

- Laurie had stopped seeing a doctor for her emphysema because of the cost before she was referred to the Transitions program. The uninsured 54-year-old was suffering worsening symptoms before HopeWest became involved and helped treat her lung problems. A nurse and social worker also helped her apply for Medicaid and disability benefits. She began regular visits with a pulmonologist and a primary care physician. For the first time in years, she has been able to leave the house and is participating in pulmonary rehabilitation.

Horse Rides and Mardi Gras

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“This program saves lives,” a grateful Laurie said. “It’s not just medical care.”

Good Ratings

Kudos from patients like Laurie are common in the five western Colorado counties now served by HopeWest. Their praise is underscored by the results of telephone surveys begun in 2012. The surveys show the HopeWest palliative care teams have helped reduce patients’ pain 95 to 98 percent of the time. One hundred percent of respondents credit their HopeWest teams with assistance in managing symptoms. More than 90 percent say the palliative care program had increased knowledge about a patient’s diagnosis. Respondents also give high praise to the efforts of palliative care teams related to emotional support, family involvement, and to generally increasing quality of life for patients.

HopeWest has also earned national recognition. Whitney has been tapped to lend her expertise and bring her vision to the Health and Human Services National Rural Advisory Committee and the National Hospice and Palliative Care Organization. She wrote the first American Hospice Nursing Standards of Practice. She currently serves on the board of the National Partnership for Hospice Innovations and the Caring for Colorado Foundation.

HopeWest recently was named one of 141 hospice organizations in the United States to be a demo site for Medicare’s Care Choices Model. This demonstration program is attempting to quantify a benefit for patients who receive hospice-like support services while also receiving curative treatments. This program aligns with what HopeWest has already been doing successfully.

Proof it Works

National studies have already begun to chart the benefits of palliative care. A recent study published in the *Journal of Palliative Medicine* shows that home-based palliative care for individuals with advanced illnesses is linked to a $12,000 reduction in the mean total cost of care per person. It is also associated with

Patients have a range of options to choose from and have the freedom to develop a customized plan of care to suit their needs.
fewer hospital admissions and emergency room visits and a greater use of hospice in the last three months of life.

A University of California cancer study finds patients who received palliative care for 90 days or more saved thousands of dollars in medical costs per patient based on reduced emergency room visits and hospital stays. The New England Journal of Medicine reports that patients with an aggressive form of lung cancer had less depression and less pain and discomfort if they received palliative care in addition to oncology treatments. Those receiving palliative care lived 2.7 months longer than those receiving only oncology services.

Whitney said she sees all that as validation that palliative care is a valuable safety net for the healthcare system. It is an impetus for establishing a more seamless system of delivering palliative care nationwide.

She hopes more hospice organizations will take the same philanthropic view HopeWest has embraced – a mission that it carries out and refines every day. It hasn’t been easy. It hasn’t been without stumbles. But it has proven that gaps can be filled. It has shown a way forward for delivering the expanded care that didn’t even have a name when Whitney entered the hospice field.

Whitney’s overarching advice for other hospices who want to join this mission is daringly simple: “Decide what you want to do. And jump off that cliff.”

HopeWest Advice About Adding or Expanding Palliative Care

- Have a leader with the right philosophy about palliative care.
- Draw ideas from every level – from nursing assistants to physicians.
- Create a continuum of care.
- Become an integral part of the community, churches and neighborhoods.
- Look beyond the obvious for partnerships.
- Broaden your view of volunteers.
- Integrate palliative care into hospitals.
- Seek buy-in from physicians.
- Keep a focus on the non-medical parts of end of life care.

About HopeWest

HopeWest is a non-profit hospice, palliative care and grief support organization dedicated to profoundly change the way the community experiences serious illness, aging and grief – one family at a time. Founded in 1993 through a community-wide vision, HopeWest now serves more than 2,500 patients and well-over 1,500 individuals coping with grief each year across 7,000 square miles of western Colorado in Mesa, Delta, Montrose, Ouray and Rio Blanco Counties. For more information visit HopeWestCO.org.