

# heartnotes™

(A JOURNAL OF HOSPICE & PALLIATIVE CARE)



## Exercise and Grief: Finding Peace in Movement

**Run  
to  
Remember**

(See page 16)

Hospice Facts  
and Figures

Culturally sensitive  
end-of-life care

## editor's note

Perhaps more than any other field of medicine, hospice and palliative care are steeped in an absolute commitment to customized, compassionate care. There's no generalizing about what's good for "patients" and for "families" — hospice services are based on the individual needs of each person, including the physical, emotional, social and spiritual components of life.

This commitment is also demonstrated through planning documents like *Five Wishes*, an innovative way for people at all phases of life to tackle end-of-life topics and open a dialogue among family members, friends and doctors. *Five Wishes* helps people voice their preferences and expectations and addresses them in simple, straightforward language, without clinical terms or legal jargon.

*Five Wishes* provides a format to speak honestly about all the elements of care and community that are important to you as an individual. Specifically, *Five Wishes* helps you explain:

1. Which person you want to make health care decisions for you, if you can't make them yourself.
2. The kind of medical treatment you want or don't want.
3. How comfortable you want to be.
4. How you want people to treat you.
5. What you want your loved ones to know.

Ultimately, *Five Wishes* is about being prepared, so that no matter when these issues come up, you can take comfort in knowing that your wishes will be clearly communicated and respected, with a written record that preserves your rights and your dignity.

That focus on individual values, practices and needs is a recurring theme in this issue of *Heartnotes*. This quarter, you'll learn about how ethnic and cultural considerations impact the acceptance and use of end-of-life services. You'll see how non-profit organizations are fulfilling personal dreams for patients at the end of life, and supporting families as they move through their unique bereavement process. You'll read the latest facts and figures about hospice use, expansion and outcomes, as reported by the National Hospice and Palliative Care Organization. And, you'll hear from top researchers who have found that people who leave hospice often experience a decline in the personalization of their health care.

I hope *Heartnotes* provides you a place to think about what you would want and need at the end of life, and I invite you to send your thoughts, comments and questions to me at [jenn\\_gatti@uhc.com](mailto:jenn_gatti@uhc.com). ❖

Sincerely yours,

Jennifer Gatti



### ABOUT HOSPICE

Hospice is a patient-centered, interdisciplinary approach to end-of-life care that respects the needs of terminally ill patients and helps them remain as comfortable as possible, with loved ones nearby. At the center of hospice care is the belief that every person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow patients to do so.

### ABOUT PALLIATIVE CARE

Palliative care is for those who have advanced illness but are continuing curative therapies. Care includes physician consultation and support services for the patient and family. This can be a time to learn about how an illness is likely to progress and plan for end-of-life care.

*Heartnotes* is published by Evercare<sup>™</sup> Hospice and Palliative Care, 9701 Data Park Drive, Minnetonka, MN 55343. We provide compassionate care for those facing end-of-life issues and personal support to their families. We are proud to offer resources, education and advocacy on issues relating to long-term care, hospice and palliative care, and the needs of patients and caregivers. This information is not intended as medical advice. If you are concerned about your health or any symptoms you may be experiencing, please contact your primary care provider.

To learn more about Evercare<sup>™</sup> Hospice and Palliative Care and the services we provide, please call **1-877-765-3917** or visit us online at **EvercareHospice.com**.

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*Kay, an Evercare  
Hospice patient*

# FULFILLING DREAMS:

## MAKING HOLIDAYS HAPPIER FOR HOSPICE PATIENTS

**T**HE DREAM FOUNDATION IS THE first and largest national wish granting organization for people age 18 and older who suffer from life-limiting illness. Their mission is to enhance the quality of life for patients and their families, helping adults realize a final dream.

Dream Foundation has granted thousands of dreams to adults who are emotionally, financially and physically devastated by terminal illness. They work with volunteers, hospices and healthcare organizations nationwide to identify prospective recipients. All dream recipients have been diagnosed with a terminal illness and have a life expectancy of one year or less.

"We believe that adults at the end of life should receive managed physical care and comfort, and that every adult deserves the peace of mind that comes from knowing he or she has achieved a final wish, a goal or a dream," says Dream Foundation Founder and President Thomas Rollerson. "The emotional care Dream Foundation is able to provide is a natural accompaniment to end-of-life care provided by hospices. Working together, we are able to ease the passage and provide peace and resolution."

Dream Foundation has been designated as one of the recipient organizations of donations received by Evercare Hospice & Palliative Care, and several Evercare patients have been granted their wishes. "Hospice is a heart-driven component of health care, where compassion, respect and dignity are paramount in serving a patient's needs," says

Patricia Ford, Vice President of Evercare Hospice and Palliative Care. "It's important to support the individual wishes of patients and help them create the closure they need."

Some wishes funded by Evercare Hospice donations include: a GED study guide, tutor and application fees; a home wheelchair ramp, gift cards, sports memorabilia and a laptop computer. Here are the stories of four more patients who had personal wishes fulfilled through the Dream Foundation.

### ROBERT: ADDING ACCESSIBILITY

After suffering a stroke, Robert had trouble leaving his home because of the steps he had to navigate. With the help of a local contractor, the Dream Foundation was able to build a wheelchair ramp and empower Robert to move in and out of his home more easily. The ramp was a major element of improving Robert's quality of life and helping his family.



*Robert and his wife*

*It's important  
to support the  
individual needs of  
patients and  
create closure.*



Jimmy

### JIMMY: ROOTING FOR THE BULLS

Jimmy had also experienced a stroke that significantly limited his mobility. His dream was to see the NBA's Chicago Bulls play the Atlanta Hawks, but he was not well enough to travel to the game. The Dream Foundation interpreted his Dream and sent him a Chicago Bulls jersey signed by all the members of the team. They also provided a financial gift to help Jimmy and his wife buy Christmas presents for their children.

### KAY: HELP IN THE HOME

Kay's advanced ovarian cancer made it impossible for her to go upstairs in her own home. Thanks to the Dream Foundation, a local carpenter built Kay a custom railing to assist her and allow her to live comfortably in her entire home.

*It's just as important for adults to achieve a final dream.*

### UNCHARINE: BRINGING FAMILY TOGETHER

Uncharine lives in Atlanta and wanted very badly to see her mother and stepfather, who live outside of Binghamton, New York. Through the Dream Foundation, Evercare Hospice arranged a Christmas visit for them all in Atlanta. The Dream Foundation provided airline tickets, hotel accommodations, holiday gifts and covered their travel expenses. ❄️



Uncharine and her mother

## \* Supporting Holiday Traditions with Charitable Giving

During a regular care planning session, the Evercare Hospice & Palliative Care team in Massachusetts was reviewing their patients' needs and discussing how the added financial burden and stress of the holiday season impacts patients and families.

"Our patients have so many struggles, and when they are faced with additional financial burden and caregiver burden it presents a challenge for us all," explains Executive Director Sue Mullaney. "I'm so grateful to all our colleagues who rallied for donations to help support our families."

A significant amount of money was raised by employees and distributed to three different families who needed help

with a cornerstone of the season: groceries to create those special meals and dishes that are such an important part of holiday traditions and family history.

"One young woman with ALS was given a gift card to a grocery store to help with holiday meals for her young family," says Mullaney. "An elderly man and his wife who are struggling financially received a holiday food basket, including a turkey and all the fixings. Our third recipient was an older woman who is being cared for by her granddaughter. They received a gift card to the local grocery store and were very thankful."

# HONOR, FAMILY AND RESPECT:

## UNDERSTANDING CULTURAL NEEDS AND DIFFERENCES AT THE END OF LIFE

**T**HE HOSPICE CARE MODEL HAS made a significant impact on the lives of patients and families, giving them highly individualized care and personal attention during the last phases of life. Through this process of understanding, decoding and translating a patient's needs, hospice clinicians and researchers<sup>1</sup> have identified three elements of end-of-life care that can vary culturally, and with significant differences: openly discussing a terminal illness or end-of-life issues, (b) decision making within the family unit and (c) attitudes about life support and advance directives.

### WHEN TALKING DOESN'T HELP: DYNAMICS IN COMMUNICATION

In their article "Cultural Differences With End-of-Life Care in the Critical Care Unit," Jessica Doolen, MSN, APRN-C and Nancy L. York, PhD, RN examined how these issues emerge in critical areas of communication. "While Americans typically believe that patients should be informed about their disease process and prognosis," they wrote, "and patient control and autonomy are core values in western bioethics, people from other cultures often see the western healthcare system as hurtful in its direct and truthful approach to death and dying."

For example, in the Korean cultures that discussion of death is shunned because talking openly about death and the dying process is believed to bring sadness and may even accelerate dying. Some Asian cultures protect family members from being told that they are terminally ill or are dying, feeling that the truth is too emotionally painful and will further weaken their loved one — even when death is imminent.

The Filipino culture believes that individual fate is decided by God, and that if the terms "death," "dying" or "terminal illness" are used, it will interfere with God's will and may actually cause death to occur. These families shield their loved ones from any discussion of

death and dying in an effort to support and protect them.

Healthcare providers in other non-western cultures may hide serious illnesses from their patients because it is considered rude, disrespectful or harmful to discuss it. Physicians may allude to problems or conditions with vague terminology instead of using the term "terminal illness." Physicians in some European countries typically avoid telling a patient of a cancer diagnosis, instead consulting with the family first. This is not seen as deceiving or inappropriate, but as being sensitive to the patient and acting humane.

### ADVANCE DIRECTIVES: THE ROLE OF FAMILIES

Typically, western healthcare's core values are tied to patient autonomy, self-determination and individual decision making. There is a strong endorsement of a patient's participation in all healthcare decisions. Patients are encouraged to exercise their own advance care planning, including advanced directives that indicate their wishes and values and their instructions for end-of-life care.

At the same time, some cultures and ethnicities within the United States do not recognize the concept of advance directives. Often, African Americans and Hispanics believe that the family's voice is more important than a written document. While families understand the need for patients to participate in end-of-life planning, the need to sign a legal document is not recognized. Some African American communities prefer that a trusted family member, clergy person or friend make end-of-life decisions, rather than sign a document.

Patients of Chinese descent are also not likely to sign an advance directive or agree to a do-not-resuscitate order because of their cultural values of respecting their elders and the practice of beneficence. Directly approaching an ill or dying patient with legal forms, such as an advance directive, is viewed as not only inappropriate, but also inhumane.

*Family participation  
in end-of-life  
decisions is often  
paramount.*

## WHEN CULTURE COLLIDES: THE HISPANIC COMMUNITY AND HOSPICE

As part of a study conducted in Austin, Texas, and Las Cruces, New Mexico, researchers saw many of these cultural issues emerge up close and in highly personal ways within the community.<sup>2</sup> As study authors J. Carole Taxis, PhD, RN, CNE; Teresa Keller, PhD, RN and Victoria Cruz, MSN, RN wrote, "Hispanic/Latinos are the fastest growing ethnic minority group in the U.S. and the most unlikely of any racial or ethnic group to use hospice services for end-of-life care. Hispanics, a heterogeneous group that includes persons of Mexican origin, is the largest minority group in the U.S. but is underrepresented in hospice and palliative care programs."

There are fundamental philosophical differences in the dominant white and Hispanic/Latino constructions around end-of-life values. Hispanics emphasize living and prolonging life as compared to the focus by whites on helping people cope and prepare for their eventual death. Thus, Hispanics/Latinos tend to request life-sustaining treatments more often than whites and are less likely to use advance directives. Hispanics

in their study agreed that once started, life-sustaining measures should never be stopped because the participants believed the doctors would not suggest or implement life support if there was no hope for survival.

Families may be reluctant to discuss a poor prognosis and often request that healthcare providers refrain from such discussions with the patient because of a fear that it may eradicate hope of recovery. This stance is problematic for operating within the ethical bounds of informed consent and autonomous decision making regarding care. This care communication is of particular concern between Hispanic elders and their adult children, with children afraid of "tempting fate."

Hispanics value family involvement in healthcare decisions and believe it is the responsibility of the family to be involved in caring at the end of life. Hispanics frequently construct their dying experiences as they construct experiences of life: as a family affair. When discussing the needs of a dying person, the role and responsibility of family members are paramount. Outside care assistance may be perceived as negative, diminishing the role of the family. 🌟

*In some cultures, families may discourage communications because of their fear of "tempting fate."*

<sup>1</sup> Jessica Doolen, MSN, APRN-C; Nancy L. York, PhD, RN. "Cultural Differences With End-of-Life Care in the Critical Care Unit." *Dimensions of Critical Care Nursing* Vol. 26, No. 5, September/October 2007.

<sup>2</sup> J. Carole Taxis, PhD, RN, CNE; Teresa Keller, PhD, RN; Victoria Cruz, MSN, RN. "Mexican Americans and Hospice Care: Culture, Control, and Communication." *Journal of Hospice and Palliative Nursing* Vol. 10, No. 3, May/June 2008.



## Making Help Helpful: Offering Sensitive Care

Here are some suggestions for ensuring that the help you're offering to a patient or family is truly helpful — whether you are a friend, a hospice professional or a volunteer.

**Ask.** Don't assume that you know what is needed or that one family's needs will match another's. Ask what's needed, and how a patient and family would be most comfortable accepting the help that is offered.

**Listen.** Pay attention not only to what is said, but how it's said, and what's not said. Again, if you're not sure what a patient really wants, or if you don't know exactly how to provide it, ask...and listen closely to the response.

**Respect.** Honor each person's values, history, wishes and customs. Don't suggest what they might like "instead of" or "in addition to" what they've asked for. Set your own preferences aside.

**Accept.** Understand that each family is formed in its own way, with its own structure and practices, its own legacy and dynamics. Receive it with an open mind and spirit, with an authentic desire to provide support in the way each individual person needs.



**J. Donald Schumacher, PsyD**  
President and CEO  
National Hospice and Palliative  
Care Organization

# HOSPICE IN AMERICA:

## FACTS AND FIGURES

### U.S. HOSPICES HAVE DRAMATICALLY

increased services, access and meaning for patients nearing the end of life and for their families, friends and other loved ones. At the center of hospice care is the belief that all people have the right to die pain-free and with dignity, and that their families will receive the necessary support to assist them.

**Facts and Figures:** Hospice Care in America is compiled annually by the National Hospice and Palliative Care Organization and provides an annual overview of important trends in the growth, delivery and quality of hospice care across the country. The numbers and analysis below are just a few of the topics covered in this comprehensive report. You can view the entire 2010 report online at [www.nhpco.org](http://www.nhpco.org).

### HOW MANY PATIENTS RECEIVE HOSPICE CARE EACH YEAR?

In 2009, an estimated 1.56 million patients received hospice services. This includes:

- » 1,020,000 patients who died under hospice care.
- » 294,000 who remained on the hospice census at the end of 2009.
- » 243,000 patients who were discharged due to an extended prognosis, the decision to pursue curative treatment and other reasons.

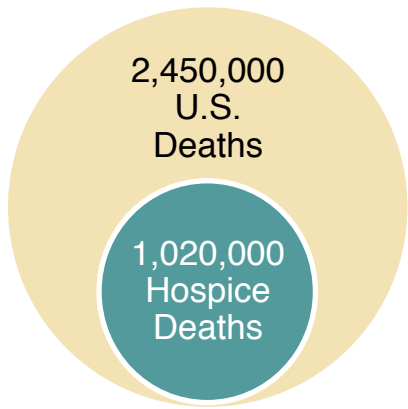
### WHAT IS HOSPICE CARE?

With a focus on caring, not curing, hospice is considered the high quality, compassionate model for people facing a life-limiting illness. Hospice provides expert medical services, pain management and emotional and spiritual support expressly tailored to the patient's needs and wishes, along with support for the patient's loved ones. In most cases, care is delivered in the patient's home but may also be provided in freestanding hospice centers, hospitals, nursing homes and other long-term care facilities. Hospice services are available to patients with any terminal illness.

### The Hospice Team



*In 2009, 1.56 million patients received hospice services, and 41.6 percent of U.S. deaths were under the care of a hospice program.*



### WHAT PROPORTION OF U.S. DEATHS IS SERVED BY HOSPICE?

For 2009, the NHPCO estimates that 41.6 percent of all deaths in the United States were under the care of a hospice program.

### HOW LONG DO MOST PATIENTS RECEIVE CARE?

The total number of days that a hospice patient receives care is referred to as the length of service (or length of stay). Length of service can be influenced by a number of factors including disease course, timing of referral and access to care. The median (50th percentile) length of service in 2009 was 21.1 days, a slight decrease from 21.3 in 2008. This means that half of hospice patients received care for less than three weeks and half received care for more than three weeks. The average length of service decreased from 69.5 days in 2008 to 69.0 in 2009.

### CAN HOSPICE EXTEND A PATIENT'S LIFE?

Hospice and palliative care may prolong the lives of some terminally ill patients. In a 2007 study, the mean survival was 29 days longer for hospice patients than for non-hospice patients. In other words, patients who chose hospice care lived an average of one month longer than similar patients who did not choose hospice care. Longer lengths of survival were found in four of the six disease categories studied. The largest difference in survival was observed in congestive heart failure patients, where the mean survival period jumped from 321 days to 402 days. The mean survival period was also significantly longer for hospice patients with lung cancer (39 days) and pancreatic cancer (21 days).

In a 2010 study published in the *New England Journal of Medicine*, lung cancer patients receiving early palliative care lived

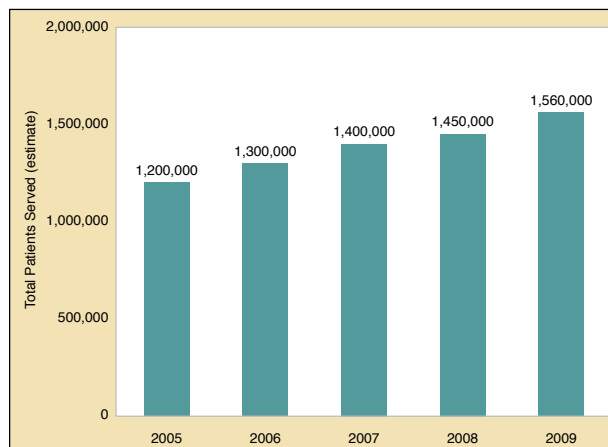
23.3 percent longer than those who delayed palliative treatment as is currently the standard. Median survival for earlier palliative care patients was 2.7 months longer than those receiving standard care. The study authors hypothesized that "with earlier referral to a hospice program, patients may receive care that results in better management of symptoms, leading to stabilization of their condition and prolonged survival."

### WHAT'S THE MOST COMMON DIAGNOSIS AMONG HOSPICE PATIENTS?

When hospice care in the United States was established in the 1970s, cancer patients made up the largest percentage of hospice admissions. Today, cancer diagnoses account for about 40 percent of all hospice admissions, with fewer than 25 percent of all U.S. deaths caused by cancer. The top four non-cancer primary diagnoses for patients admitted to hospice in 2009 were for an unspecified condition, heart disease, dementia and lung disease.

### HOW MANY HOSPICES WERE OPERATING IN 2009?

The number of hospice programs nationwide continues to increase, from the first program that opened in 1974 to approximately 5,000 programs today. This estimate includes both primary locations and satellite offices. Hospices are located in all 50 states, the District of Columbia, Puerto Rico, Guam and the U.S. Virgin Islands.



*Cancer diagnoses account for about 40 percent of all hospice admissions, with fewer than 25 percent of all U.S. deaths caused by cancer.*

# facts and figures

*In 2009, 468,000 hospice volunteers provided 22 million hours of service to patients and families.*

## DOES HOSPICE SAVE MONEY?

Findings of a major study demonstrated that hospice services save money for Medicare and bring quality care to patients with life-limiting illness and their families. Researchers at Duke University found that hospice reduced Medicare costs by an average of \$2,309 per hospice patient. Additionally, the study found that Medicare costs would be reduced for seven out of 10 hospice recipients if hospice was used for a longer period of time. For cancer patients, hospice use decreased Medicare costs up until 233 days of hospice care. For non-cancer patients, there were cost savings seen up until 154 days of care. While hospice use beyond these periods cost Medicare more than conventional care, the report's authors wrote that, "More effort should be put into increasing short stays as opposed to focusing on shortening long ones."

## WHAT ROLE DO VOLUNTEERS PLAY IN HOSPICE?

The U.S. hospice movement was founded by volunteers, who continue to be essential

to hospice's interdisciplinary care model. NHPKO estimates that in 2009, 468,000 hospice volunteers provided 22 million hours of service. Most volunteers were assisting with direct patient care (57.6 percent), 21.5 percent provided patient care support and 20.9 percent provided general support.

Hospice is unique in that it is the only provider whose Medicare Conditions of Participation requires volunteers to provide at least five percent of total patient care hours. In 2009, 5.6 percent of all clinical staff hours were provided by volunteers. The typical hospice volunteer devoted 46.6 hours of service over the course of the year, and patient care volunteers made an average of 18 visits to hospice patients.

## HOW DO HOSPICES SUPPORT THE BEREAVEMENT PROCESS?

Hospices have a deep commitment to bereavement services for both family members of hospice patients and for the community at large. For a minimum of one year following their loved one's death, grieving families of hospice patients can access bereavement education and support. Last year, for each patient death, an average of two family members received bereavement support from their hospice. This support included follow-up phone calls, visits and mailings throughout the year. Almost all agencies (91.9 percent) also offer some level of bereavement services to the general community. In 2009, community members accounted for about 18 percent of those served by hospice bereavement programs.

## WHAT DO FAMILIES SAY ABOUT HOSPICE CARE?

According to NHPKO Hospice Performance Measures, in 2009 more than three-quarters of families rated the patient care received as "excellent," and practically all (96.6 percent) said that their hospice team clearly explained the plan of care. More than 70 percent of families said that the patient's pain was brought to a comfortable level within just 48 hours of admission to hospice.

Performance Measure		2009	2008
<b>Family Evaluation of Hospice Care (FEHC)</b>			
Hospice team clearly explained plan of care.	% "Yes"	96.6%	96.5%
Rating of care patient received under care of hospice.	% "Excellent"	75.6%	75.4%
Hospice response to evening/weekend needs.	% "Excellent"	66.4%	65.9%
<b>Family Evaluation of Bereavement Services (FEBS)</b>			
How well services met the needs of bereavement client.	% "Very Well"	76.9%	76.7%
<b>End Result Outcome Measures</b>			
Patient's pain brought to a comfortable level within 48 hours of admission to hospice.	% "Yes"	70.5%	71.8%

## THE BOTTOM LINE

There's no doubt that hospice care is steadily improving the end of life experience for millions of people. While it's tempting to add up all the numbers and reports, the statistics and the stories, the state of hospice in America will ultimately be measured individually, uniquely and personally by each family and each patient it touches.

"As valuable as our specialized training, knowledge, skills, and experience all are, we ultimately become specialized one patient and family at a time," writes Ira Byock, M.D. "At the end of the day, it is not our segmented programs and specialties that matter, but the special expertise we bring to the collaborative process of patient and family care." ❖

*More than three-quarters of families rated the patient care received as "excellent."*

<sup>1</sup> Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three year window. *J Pain Symptom Manage.* 2007 Mar;33(3):238-46.

<sup>2</sup> Ternel JS, Greer JA, Muzinkansky A, et. al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med.* 2010 Aug;363(8):733-42.

<sup>3</sup> Xu J, Kochanek KD, Murphy SL, Tejada-Vera B. Deaths: Final Data for 2007; National Vital Statistics Reports; vol 58 no 19. Hyattsville, MD. National Center for Health Statistics, 2010

<sup>4</sup> Taylor DH Jr, Ostermann J, Van Houtven CH, Tulsy JA, Steinhauer K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? *Soc Sci Med.* 2007 Oct;65(7):1466-78.

<sup>5</sup> *Palliative Care and Oncology: Growing Better Together.* Journal of Clinical Oncology, Vol. 27 No. 2, January 10, 2009.

## What Makes Us Different

At Evercare Hospice & Palliative Care, we are committed to providing the best hospice and palliative care experience available. In every area of hospice care, we try to do more than what is required — and expected. The desire to do more can be seen in the passion and commitment of our staff and volunteers. It can also be measured by the services we offer, which go above and beyond what typical hospices offer.

That commitment is expressed in our Seven Point Pledge. Evercare™ Hospice & Palliative Care pledges to:

- 1. Admit all hospice-eligible referrals the same day,** unless requested otherwise. Patients deserve timely care and action, especially as they approach end-of-life.
- 2. Provide direct, extensive physician involvement in the care of each patient.** Experts highly trained in hospice and palliative care are involved and available to make personal visits.
- 3. Achieve acceptable pain control on all patients.** No patient should live in pain. That's why we place such an emphasis on delivering pain management in a timely and caring manner.
- 4. Respond to all patient-related calls within 15 minutes,** 24 hours a day, 7 days a week. A patient's condition doesn't take a day off, and neither do we.
- 5. Provide a hospice staff presence at the time of death.** We'll be there at this important time, as we have throughout the process, to provide comfort and support.
- 6. Maintain an Unrestricted Options Philosophy regarding patient admissions.** We believe in making hospice care available to all those who are eligible.
- 7. Offer palliative care consults and advanced care planning services.** These continuing health care services are important, so we offer expertise in both areas.



# TAKING TO THE AIRWAVES:

## A DIALOGUE ON HOSPICE AND PALLIATIVE CARE

**W**HILE HOSPICE AND palliative care continue to expand and serve a growing number of patients and families, many people are still unaware of — or have misconceptions about — how these quality models of compassionate care can improve the lives of people with serious illness.

*Connie Harbaugh, executive director of Evercare Hospice and Palliative Care in Phoenix, recently took part in a live discussion about end-of-life care on KJZZ-FM, a National Public Radio member station, and answered questions from local callers.*

*Connie is an outstanding, thoughtful leader in the field of hospice and palliative care, and we're thrilled to be able to feature excerpts from her NPR member station appearance. Read on to hear Connie's first-person perspectives on enhancing quality of life through hospice and palliative care.*

**PAUL ATKINSON, of KJZZ's Here and Now:** The term "palliative care," I don't remember hearing before until really, last year. What is palliative care, and why is the term used now more often?

**CONNIE HARBAUGH:** Palliative care is specific care focused more on comfort care as opposed to curative care. It's focusing on providing comfort and controlling symptoms, like pain management, bringing comfort and relief, whatever symptoms that the patient happens to be suffering from. Studies show the main thing that people are afraid of in

the dying process is not necessarily of dying, but it's dying in pain. So palliative care brings comfort to the patient and manages their pain at the end of life.

**PAUL:** What's the advantage for UnitedHealthcare getting into this level of care that previously had been the domain of a separate entity?

**CONNIE:** Well, the advantage that a company such as UnitedHealthcare sees with hospice care is several things. It actually has been proven that patients preferred to die in their home, so it's a quality and a comfort for the patient to be able to die and choose, through advanced planning, to die in a way they want to die. That's first and foremost. But it also has an advantage of being very cost effective health care at the end of life. Medicare does fully reimburse this for all patients regardless. They give the same reimbursement to every company, whether you're for profit or not for profit.

**PAUL:** Connie, let me have you talk about the decision on what kind of care is provided, and do doctors decide at some point that a patient should go back to the hospital once they've started hospice care?

**CONNIE:** The care is always patient driven. There's constant collaboration between the patient, the family, the physician, the medical director. There's a team approach; they are always collaborating on what the patient wants. At any point, when the patient says, "I

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*Studies show the main thing that people are afraid of in the dying process is not necessarily dying, but dying in pain.*

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no longer want hospice care, I prefer to go to the hospital,” or the symptoms can no longer be managed safely in the home, and we feel they can be managed better in a hospital setting or in an inpatient hospice setting, then we will transfer the patient at no cost to the patient to a hospital if that’s what they choose. It’s through education and collaboration.

I’ve been a registered nurse for 30 years. I’ve worked in the acute care hospitals as well as hospice settings. As you choose a hospice, you need to ask them about the qualifications of the staff who are going to be caring for them. There’s a lot of hospices to choose from, and you need to ask about the qualifications of the staff, just like as you would any health care provider.

**PAUL:** One of the things I want to get into is, beyond the care for the person who’s dying, the care that’s given to the family members. Talk about what’s done for them in helping them prepare for what’s going on.

**CONNIE:** There’s a lot done with the families. In fact, I think one of the biggest advantages

of hospice care is the family’s very informed from the very beginning about what to expect. They’re given a lot of information verbally as well as a lot of written materials of what the dying process may look like. The psychological support, there’s a whole team of professionals who go in and support that family through a social worker, chaplains, counselors, CNAs, registered nurses, physicians coming to the home, in your own setting where they will spend up to an hour with that patient to inform them about what to expect, what they want, what their goals are.

(By respecting a patient’s goals), family can be around them and have a quality of life and be able to have home meals and rest as they need it, because any of us who have been in the hospital setting know that there’s not a lot of rest, and you’re on the hospital’s schedule. To be in the comfort of your own home at this critical time where grandchildren can visit, and you can have your pets and have things around you that bring you comfort, be in your own garden or whatever is so important, and that, for most patients and families, that’s what they want. 🌟

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*Care is always patient driven. There’s constant collaboration between the patient, the family, the physician.*

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## A Caller’s Perspective

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During the interview, Connie helped field questions from local listeners who shared their experiences and questions about hospice and palliative care. Here’s one comment from Pat, a local nurse who called the show to offer her thoughts.

I am a nurse myself, and I had the opportunity to experience it from the family perspective just recently with my mother. Everything that I found myself telling families echoes so true with us. It was such a tremendous relief for my family, and for me, to have mom in the care of such

professionals. It gave me an opportunity to be the daughter and not just another nurse in her care.

Mom had COPD, which is a respiratory disease, and I know that if she had not been on hospice, she would have been in and out of the hospital multiple, multiple times. It was a tough course for her to go, and the team worked very hard to manage her symptoms. I’m grateful she was on hospice long enough that we were able to get things controlled and to have the support that hospice offered.



# MOVING THROUGH GRIEF:

## EXERCISE AND BEREAVEMENT

**W**E ALL KNOW EXERCISE is “good for you,” but did you know that physical activity has been proven to help with symptoms of depression and anxiety? And since many of those symptoms are the same for grief, exercise can be a powerful aid in coping with the loss of a loved one.

For many years, experts have known that exercise enhances the action of endorphins, chemicals that circulate throughout the body! Endorphins improve natural immunity and reduce the perception of pain. They may also serve to improve mood. Another theory is that exercise stimulates the neurotransmitter norepinephrine, which may directly improve mood.

A study published in the *Archives of Internal Medicine* in 1999 divided 156 men and women with depression into three groups. One group took part in an aerobic exercise program, another took the SSRI sertraline (Zoloft), and a third did both. At the 16-week mark, depression had eased in all three groups. About 60 to 70 percent of the people in all three groups could no longer be classified as having major depression. In fact, group scores on two rating scales of depression were essentially the same.

A follow-up to that study found that exercise's effects lasted longer than those of antidepressants. Researchers checked in with 133 of the original patients six months

after the first study ended. They found that the people who exercised regularly after completing the study, regardless of which treatment they were on originally, were less likely to relapse into depression.

Of course, in the very first difficult days and weeks of acute grief, mourners are essentially immobilized. Sleeping and eating are difficult enough. There is no leftover energy for exercise.

As the months pass, however, exercise can play a powerful role in re-engaging with life. Dr. Judith Pierson, a licensed psychologist who works with people in grief, explains, “Exercise gives people energy again. Inertia is such a part of grief. Making your body move makes you feel better. It lifts your mood and helps you sleep better.”

Dr. Pierson advises people to start gradually. She says, “I often tell clients to just walk 10 minutes in one direction and then turn back. That’s 20 minutes. Even that amount will improve their moods.”

For those who are ready to do more, the National Hospice Foundation’s Run to Remember® athletic fundraising program provides a perfect opportunity. With Run to Remember, individuals choose a race of any length, from the 5Ks that Evercare Hospice & Palliative Care will participate in this May all the way up to marathons. They run (or walk) in memory of a loved one and raise money to support hospice care. To join an Evercare team, visit [www.runtoremember.org/evercare](http://www.runtoremember.org/evercare)

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*Inertia is such a part of grief. Exercise can play a powerful role in re-engaging with life.*

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for more information. For individuals running on their own and not with an Evercare team, register at [www.runtoremember.org](http://www.runtoremember.org).

The value in running in memory of someone is two-fold. First, as Dr. Pierson notes, "When running, it is a time to be with your feelings. If the run is dedicated to their loved one, then the runner's mind is probably even more on the person they lost. If the runner can get into a meditative, quiet space, it lets them get into their feelings and thoughts. It helps them with the grieving process." Past Run to Remember participants have said things like, "I never really grieved my father fully until I ran 'with' him on all those long runs."

The second benefit is that it provides people with the chance to do something meaningful to honor their loved one. That is an important part of the grief process.

Of course, not everyone likes to run or walk. Exercise of any form will bring mental and physical health benefits. The key is finding something you enjoy and then sticking with it 🌟

<sup>1</sup>Harvard Medical School. Special Health Report, "Understanding Depression." [www.health.harvard.edu/UD](http://www.health.harvard.edu/UD), accessed Dec. 21, 2010.

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*By running or walking in memory of a loved one, you can create a positive legacy.*

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## Benefits of Exercise in Coping with Grief



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Vicki Costa, a Licensed Clinical Social Worker who works with people in grief, offers these benefits of using exercise to cope with loss and depression.

1. **It takes you outside of your head.** If you look around you, at the natural setting, or the others in the gym, you see something bigger than you and your individual pain.
2. **It can restore a sense of control.** Grief is a mystery; it moves at its own pace and it can be hard to see progress. However, exercise can give you a sense of mastery and confidence.
3. **There are physical benefits.** Exercise releases endorphins, which can increase your sense of well-being.
4. **It is perfect for the "masculine" griever.** Both men and women can be "masculine" grievers. It refers to folks who are "head-

oriented" and don't want to talk about their feelings. They are more "task-oriented" in their grief process. They want something to *do*.

5. **It is perfect for the "feminine" griever.** As above, both men and women can be "feminine" grievers. This refers to people who are "heart oriented". They are emotionally expressive and want to talk. For them, exercise can provide a way to connect with others and have a sense of community.
6. **A memorial exercise activity has additional benefits.** By running or walking in memory of a loved one, you can create a positive legacy. You are also connecting to the community, which can reduce the feelings of isolation so often felt in grief.

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*The key is finding something you enjoy and then sticking with it.*

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community  
involvement

# RUN TO REMEMBER®

WITH EVERCARE HOSPICE & PALLIATIVE CARE

**P**ICTURE THE SCENE. IT'S A warm May morning. Passionate hospice supporters are gathering in 16 cities or towns served by Evercare Hospice and Palliative Care.

Each group is diverse in age, gender, shape and size. Many of the people work for hospice or another part of UnitedHealth Group. Many others know Evercare Hospice because someone they loved received hospice care. This morning, people are smiling and happy.

They are waiting for the crack of a starting gun. Then they will set out either running or walking a 5K race. This morning's athletic effort will be the culmination of several months of training and fundraising.

This winter and early spring, each Evercare Hospice and Palliative Care program across the country is forming a team of runners and walkers to participate in the National Hospice Foundation's Run to Remember program. A 5K has been selected in each town or city, and each Evercare Hospice program is recruiting a team. In May, each team will run or walk together, in a large group, signaling support for hospice and generating community awareness about Evercare Hospice and Palliative Care.

The goal is to raise \$25,000 in support of the National Hospice Foundation's campaign to support the National Center for Care at the End of Life. That goal will be achieved by individual runners and walkers asking their friends and family to support their 5K.

Each Evercare Hospice program has its own online fundraising page where people can easily make donations. You can view the complete list of those websites, along with registration information about Evercare Hospice's 2011 Run to Remember, [runtoremember.org/evercarehospice](http://runtoremember.org/evercarehospice). In order to provide non-athletic options for helping to meet the division's fundraising goal, each site will likely also organize other activities like bake sales or raffles.

## THE NATIONAL CENTER FOR CARE AT THE END OF LIFE: COLLABORATION, COORDINATION

The National Center for Care at the End of Life is in Alexandria, Virginia, very close to Washington, DC. It houses four organizations: the National Hospice and Palliative Care Organization (NHPCO), the National Hospice Foundation, FHSSA (which began as the Foundation for Hospice in Sub-Saharan Africa) and the Hospice Action Network.

Each of these affiliated organizations share the same vision for patient-centered and family-focused care. This vision, of course, matches that of Evercare Hospice and Palliative Care's mission of providing the best hospice and palliative care experience available.

Two years ago, the opportunity to create the National Center for Care at the End of Life became a reality. The building establishes a permanent location. It provides optimal space for NHPCO and its affiliates and—perhaps most importantly—end the cycle of leasing. This cost savings will allow valuable funds to go back to programs and resources that benefit NHPCO members, including Evercare Hospice and Palliative Care. At the National Center, professionals work on issues relating to quality, research, regulatory, advocacy, education and philanthropy. All this work touches providers, volunteers, patients and families. The ultimate goal is to come together to accomplish the transformational work of care and love at the bedside.

"Participating in Run to Remember with the National Hospice Foundation is a wonderful way for Evercare Hospice and Palliative Care to have an impact on hospice care nationwide and far into the future," notes Patricia Ford, vice president of operations. She adds, "It also provides our bereaved families a unique way to honor their loved ones, by walking or running in their name. And, the physical fitness aspect of it fits beautifully with UnitedHealth Group's focus on well being at all phases and stages of life." ❖❖

### Run to Remember: Any Race at Any Pace

Run to Remember® is the athletic fundraising program of the National Hospice Foundation. If you would like to participate in a race longer than a 5K, or after May, register yourself at [runtoremember.org/evercarehospice](http://runtoremember.org/evercarehospice). The program is "any race at any pace" and welcomes runners and walkers all across the country. To learn more about the National Hospice Foundation, visit [nationalhospicefoundation.org](http://nationalhospicefoundation.org).



# CONTACT US

TO LEARN MORE ABOUT EVERCARE™ HOSPICE AND PALLIATIVE CARE, PLEASE VISIT US ONLINE AT **EVERCAREHOSPICE.COM**, CALL **1-877-765-3917**, 24 HOURS A DAY OR CONTACT ANY OF OUR PROGRAM OFFICES.

## ALABAMA

### BIRMINGHAM

Local: 205-437-8655  
Toll Free: 800-985-3305

## ARIZONA

### PHOENIX

Local: 602-749-5900  
Toll Free: 866-658-4658

### TUCSON/GREEN VALLEY

Serving Southern Arizona and surrounding areas  
Local: 520-407-8000  
Toll Free: 877-233-2902

## CALIFORNIA

### CONCORD

Local: 925-246-7600  
Toll Free: 877-416-8555

## COLORADO

### DENVER

Local: 303-714-2400  
Toll Free: 888-437-4673

### COLORADO SPRINGS

Local: 719-265-1100  
Toll Free: 866-840-9253

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Toll Free: 888-866-8286

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Toll Free: 888-909-4474



Melissa D.A. Carlson

# ADVANCES IN CARE:

## HOSPICE DISENROLLMENT TAKES A PHYSICAL, FINANCIAL TOLL

**ACCORDING TO A RECENT STUDY<sup>1</sup>** led by researchers at the Mount Sinai School of Medicine, patients with terminal cancer who disenroll from hospice care have significantly

higher rates of hospitalizations — including admission to the emergency department and intensive care unit — than those who remain under the care of hospice. Additionally, patients who disenroll from hospice are more likely to die away from their home, in the hospital, than patients who remain with hospice until their deaths.

“Our data suggest that oncologists should be aware of the dramatic financial and physical toll that disenrolling from hospice can have on a patient with cancer,” said Melissa D.A. Carlson, PhD, Assistant Professor of Geriatrics and Palliative Medicine and a lead author of the study.

The October 2010 study, which was published in the *Journal of Clinical Oncology*, found that:

- » 33.9 percent of the patients who disenrolled from hospice care were admitted to an emergency department, compared to only 3.1 percent of hospice patients.
- » 39.8 percent of disenrolled patients were admitted to the hospital as an inpatient, in contrast with only 1.6 percent of hospice patients.
- » Disenrolled patients spent an average of 19.3 days in the hospital, while hospice patients spent an average of 6.7 days.

» 9.6 percent of disenrolled patients died in the hospital, compared to only 0.2 percent of hospice patients.

» Costs of care for patients with cancer who disenrolled from hospice were nearly five times higher than for patients who remained with hospice.

Wrote the paper’s authors, “Rather than focusing on how to decrease Medicare expenditures by restricting access to the Medicare Hospice Benefit, policy makers should focus on how to decrease the potential barriers to remaining enrolled with hospice until death, with an eye to both decreasing Medicare costs and potentially improving patient and family outcomes.”

The authors also recommend that oncologists explore outpatient palliative care services that offer multidisciplinary care, symptom control and end-of-life planning expertise in a way that enables a patient and family to maintain contact with the oncology clinic. ❖

<sup>1</sup>Melissa D.A. Carlson, Jeph Herrin, Qingling Du, Andrew J. Epstein, Colleen L. Barry, R. Sean Morrison, Anthony L. Back, Elizabeth H. Bradley. “Impact of Hospice Disenrollment on Healthcare Use and Medicare Expenditures for Patients With Cancer.” *The Journal of Clinical Oncology*, Aug. 30, 2010.

*Oncologists should be aware of the dramatic financial and physical toll that disenrolling from hospice can have on a patient.*



To view the article abstract and learn more about this study, visit <http://jco.ascopubs.org/content/early/2010/08/23/JCO.2009.26.1818.abstract>.

# RESOURCES

VISIT THESE WEBSITES FOR COMMUNITY SUPPORT AND VALUABLE INFORMATION ABOUT HOSPICE, PALLIATIVE AND LONG-TERM CARE.

» **EVERCARE™ HOSPICE & PALLIATIVE CARE** ([EvercareHospice.com](http://EvercareHospice.com) or **1-877-765-3917**) offers education, resources and services for patients and families through its interactive website and 24-hour phone line.

» **CARING CONNECTIONS** ([www.caringinfo.org](http://www.caringinfo.org) or **1-800-658-8898**) is a program of the National Hospice and Palliative Care Organization, providing extensive resources and support for patients and families who are coping with end-of-life issues.

» The **NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION** ([www.nhpco.org](http://www.nhpco.org)) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. It offers education and information for practitioners, patients and families.

Through the NHPCO website, you can search for a hospice or palliative care program in your community. Use the “Find a Provider” search page at [www.iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx](http://www.iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx).

» The **NATIONAL HOSPICE FOUNDATION** ([www.nationalhospicefoundation.org](http://www.nationalhospicefoundation.org)) supports quality and research initiatives, hospice and palliative care provider education activities, consumer engagement and caregiver services, and the FHSSA Impact Fund supporting hospice care in sub-Saharan Africa.

» **MEDICARE** covers most hospice services for eligible beneficiaries. You can view a special publication online for more information about Medicare hospice benefits at <http://evercarehealthplans.com/pdf/MedicareHospice02154.pdf>.

» **AGING WITH DIGNITY** provides practical information, advice and legal tools on end of life and long-term care issues, including the Five Wishes planning document at [agingwithdignity.org/5wishes.html](http://agingwithdignity.org/5wishes.html).

» **CARINGBRIDGE** ([caringbridge.org/evercare](http://caringbridge.org/evercare)) helps you stay connected with friends and family during an illness through a free, personalized website.

» **LOTSA HELPING HANDS** ([www.caregiver.lotsahelpinghands.com](http://www.caregiver.lotsahelpinghands.com)) is a private, web-based tool that allows you to share your needs and let family, friends, neighbors and colleagues assist with daily caregiving tasks.

» The **DREAM FOUNDATION** ([www.dreamfoundation.org](http://www.dreamfoundation.org)) is the first and largest national nonprofit wish-granting organization for adults with life-limiting illness. Dream Foundation has been designated as one of the recipient organizations of donations received by Evercare Hospice & Palliative Care.

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