

A Publication of HopeHealth

# Touching Lives™

*Holding Hands. Holding Hearts.*

## Why Listening Changes Everything

4 Questions to  
Ask Your Doctor

How Palliative  
Care Helps

Life's Most  
Intimate &  
Profound  
Questions

The Power to  
Embrace Life

  
**HopeHealth**™  
*Touching Lives*

## FEATURE ARTICLE

### 10 What I Wish I'd Known About Hospice

By Paula Spencer Scott



## CONTENTS

#### 3 Grief Counseling Helps Heal Family Loss

By Nancy Kirsch

#### CAREGIVER'S CORNER

#### 5 Why Listening Changes Everything

By Paula Spencer Scott

#### HELPING HANDS

#### 6 4 Questions You Should Ask Your Doctor

By Anne Elizabeth Denny

#### SPIRITUAL SUPPORT

#### 8 Life's Most Intimate & Profound Questions

By Christina M. Puchalski, M.D.

#### MEMORABLE MOMENTS

#### 9 The Power to Embrace Life

By Allen Klein

#### LIVE WELL

#### 14 How Palliative Care Helps

American Academy of Hospice and Palliative Medicine

#### 17 Volunteers for Hospice Find a Rewarding Experience

By Melissa Weidman

#### 18 Caring for the Emotional Needs of the Family

By Melissa Weidman

## Welcome to *Touching Lives*



HopeHealth has been enhancing the quality of life for people experiencing serious illness and loss for more than 40 years. Since our early beginnings, we have been focused on helping individuals and families make the most of the precious time at the end of life. Today we offer a wide range of services for people with serious illness and their families specializing in hospice and palliative care, home health, and specialized services for dementia and Alzheimer's caregivers.

Our goal is to help individuals face a serious illness with strength and grace in a familiar place surrounded by their loved ones. We are here to allow those who are seriously ill and their families to choose the course of their remaining days and months, alleviate pain, listen to their concerns and do everything we can to make their final wishes come true.

We help families work through their individual grief from the loss of their loved one. The story of four young children and their father in our feature article *Grief Counseling Helps Heal Family Loss* and a caregiver struggling through multiple losses in *Caring for the Emotional Needs of the Family* provides powerful testimony to the comfort and help for healing through our grief support programs. You'll read about two volunteers from the community in *Volunteers for Hospice Find a Rewarding Experience* who offer emotional and social support and companionship, providing respite care so that caregivers can get a much needed break.

Articles by national experts share stories about the emotional and spiritual journey during end of life, the importance of advance care planning before a medical crisis, and some common misperceptions about hospice and palliative care.

We understand the stresses and uncertainties surrounding the care for people with a serious illness and at end of life. We thank you for your support and welcome the opportunity to serve you and your family now and in the future.

Warm Regards,

Diana Franchitto

President and CEO



HopeHealthCo.org

#### HopeHealth Offices

1085 North Main Street  
Providence, RI 02904

(401) 415-4200  
(800) 338-6555

765 Attucks Lane  
Hyannis, MA 02601

(508) 957-0200  
(800) 642-2423



# Grief Counseling Helps *Heal* Family Loss

By Nancy Kirsch

Where does a heartbroken widower and four bereft children turn when the center of their universe is gone? Shortly before Modinat Adebimpe died in November 2016, her husband, Yemi Emmanuel, and children—Israel, 15; twin boys Isaiah and Hezekiah, 13; and Kiki, 10—turned to Hope Hospice for support. Her death left them grief-stricken and stunned.

“We thought that she was going through a difficult time, and that everything would be OK,” recalls Yemi, the Nigerian patriarch of this close-knit, religious family. During the year between diagnosis and death, she was in and out of the hospital for chemotherapy. Yemi’s wife, and best

friend, wanted to die at home, and did so.

Sarah Cordeiro, a Hope Hospice grief counselor, met with the family just before Modinat’s death. “The Emmanuel family is incredible,” she says. “They were so supportive of one another.” Before Modinat died, Cordeiro reassured Modinat that she would help her children.

The family, remarkably open about emotions at home, was extremely private in other venues, Cordeiro realized. A frequent presence in the family’s home, Cordeiro engaged with the children, individually and collectively, to help them process their loss, and supported Yemi, as he struggled to fill his wife’s shoes.

Cordeiro intimately understands grief; at 13, she lost her 11-year-old sister to cancer. Cordeiro, whom the children call “Miss Sarah,” recommends these approaches to grieving family members:

- Accept them as they are; don’t push them to feel or do something different.
- Express interest in their activities and hobbies and talk about topics other than grief.
- Share your own experience of grief, which will assure them that they are not alone and that their feelings, whatever they may be, are totally normal.
- When appropriate and with permission from the child, serve as a conduit of information between the child and the parent to facilitate discussions, resolve problems and strengthen the parent/child relationship.
- Engage in the activities they enjoy. When you get them doing something, that’s when they talk the most since they are distracted with an enjoyable activity.
- Include a spin of grief counseling in a board or card game, which permits children or teens to have some self-reflection about their emotions.

Isaiah and Kiki recalled playing Jenga with Miss Sarah. Every time they took a Jenga block, they also drew a card with questions, such as: What’s your favorite food? What do you most miss about your mom? “Playing those games helped,” says Isaiah, who learned from Miss Sarah that talking with a close friend was beneficial. With that, Isaiah drew comfort from his best friend, in whom he now confides.



Other times, Cordeiro guided the children to create collages of their mother. Through games, art and conversation, Cordeiro established a safe and supportive relationship with the children, one that encouraged them to express their feelings openly and to reminisce about their mother. Over the months, Cordeiro has seen progress in family members, who no longer insist, “We’re fine; we’re good.” She has helped the kids work through the challenge of responding to inquiries about their mother.

The children can identify how grief counseling and support from Cordeiro, who visits every couple of weeks, has helped them begin to heal. Israel, who is something of a “second parent” to his younger siblings, credits Sarah with helping him build his confidence, despite the death of his beloved mother.

Reminiscing about her with family and friends has helped the family enormously. According to the children, remaining close-knit and helping one another achieve their goals will honor the wishes and memory of their mother. At the first Thanksgiving after she died, Yemi said that the family visited her gravesite and prepared a special meal in her honor, a tradition that the family plans to continue.

Cordeiro’s grief counseling support has rippled beyond the Emmanuel family to help others, as well. Asked what she might tell someone who has lost a loved one, Kiki says, “I would [say that] I have this great grief counselor who can help you... hospice is a great place ... and the grief counselors are there for you to share your feelings with them.” ❧



# Why *Listening* Changes Everything

Interview by Paula Spencer Scott

***Not sure what to say? Your words are less important than your ears — and your presence, says this expert on listening***

**A**s a hospice chaplain, Kerry Egan offers prayers and sermons if they're requested. But what she's found people want most often is simply a compassionate presence as they do the "spiritual work of dying" — finding or making meaning of one's life. Her critically-acclaimed book, *On Living* (Riverhead Books, 2016), is a beautiful collection of insights she's gained by listening to this journey of making meaning out of difficult life moments. We asked the Harvard Divinity School graduate about how we can all practice this simple, life-affirming skill.

**When we visit friends and relatives who are sick or dying, it's easy to wonder, "What do I say?"**

I understand why friends and family might be nervous and afraid when visiting someone who's dying. In our culture, we're not around death a lot. People put pressure on themselves to say the right thing or make it all better, and often, if they don't know exactly what to say, won't visit at all — which is the worst thing you can do. It would be a loss for both of you to avoid the person.

The solution is to understand that you don't need to say much at all. One of the best gifts is to just be present with them, and listen to what they have to say. You don't need to know the "right" thing to say. You don't need to fix the situation. Just be there, be a listening presence. *(continued on page 16)*

# 4

## Questions *You Should Ask Your Doctor*

*by Anne Elizabeth Denny*

### **Why you should initiate advance care planning with your doctor.**

Medicare's decision to reimburse physicians for end-of-life conversations beginning in 2016 is a clear victory for advance care planning. Insurance will soon cover the cost for you to speak with your doctor about your preferences for end-of-life healthcare decisions.

However, given the reality that most healthcare providers have little to no experience in the art of advance care planning and may be reluctant to initiate the conversation, we help ourselves and our families by asking questions and making decisions before a crisis occurs which could limit our ability to speak for ourselves.

### **Focus on four key questions with your doctor.**

A conversation framework developed by two prominent Harvard physicians — Dr. Atul Gawande, author of *Being Mortal*, and Dr. Angelo Volandes, author of *The Conversation* — offers both patients and physicians a place to start.

Rather than wait for him or her to initiate the conversation, begin by asking your doctor these four questions:

# 1

**Are you willing to honor what is most important to me if I am faced with a life-or-death medical emergency?**

Share your feelings about what makes life worth living for you — how you define an acceptable quality of life **even** within the context of the limitations of a disease, condition or advanced age.

# 2

**Will you help me to understand my medical future?**

Explore the possibilities with your physician of a given disease or condition with which you are living. Ask questions. Share your concerns. You might have to push your physician beyond medical jargon to reach an understanding of your medical future.



# It Takes a VILLAGE

By Paula Spencer Scott

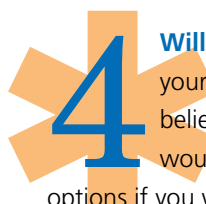
**H**ospice isn't primarily a place — it's people. Hospice care involves a team of professionals working together to support the entire family. The range of experts and services often surprises families. (You choose which services you use.)

Along with the patient and family, a hospice team usually includes:

- A nurse. To check in weekly (or more often as needed), for physical assessments, evaluate the need for equipment and services, manage pain medication, coach families on how to administer care
- A doctor or medical director. To direct prescriptions for pain and other services as needed; works closely with the nursing staff.
- A social worker. To assess goals and help develop an individualized plan of care, coordinate needed services within hospice or the community, and advise on practical matters like advanced directives, cremation and burial.
- Home health aides. To provide hands-on help with changing bedding, bathing, dressing, and personal care. They often become the everyday face of hospice for families.
- A chaplain. To provide spiritual support as requested.
- Trained volunteers. To talk, listen, and spend time with the sick person and/or the caregivers. Volunteers may do things like read aloud, help transcribe an oral history, interpret, assist with pet care, or provide transportation or respite to caregivers.
- Other therapists. As needed, the team may include occupational, speech, or physical therapists.
- Grief services. Bereavement support, counseling, and referrals to outside help can continue for up to 12 months after a death. ✕



**Will you do your best to ensure I receive all of the care — but only the care — I desire?** If you want a more peaceful passing, if you want to die at home, you can help your doctor understand where the boundary is that crosses from attempting to preserve life at all cost versus focusing on your comfort. Or, if you want to receive all possible life-sustaining treatment, your doctor needs to know that as well. This is deeply personal. Only you can convey your wishes. As hard as this is for you, recognize it will be infinitely more difficult for those left to make decisions in a crisis.



**Will you honor my beliefs?** Talk with your doctor about the values — whether spiritual beliefs, cultural norms or family traditions — that would guide your decisions about treatment options if you were unable to speak for yourself.

## The medical system may not offer a peaceful passing.

You should know that the hospital medical team will do everything possible to extend life which you may not want. Without setting limits to your care, you may receive treatments which could be painful, undesirable and unwanted. If you want a more peaceful passing, you need to ensure your doctor understands your desire for less invasive care.

## The downside of waiting.

Waiting for your doctor to ask the questions does not allow time to address issues before a crisis arises which could result in conflict over treatment options.

## Be prepared for the conversation.

Make it easy for you and your doctor by taking a one-page checklist (available at [www.anneelizabethdenny.com](http://www.anneelizabethdenny.com)) with you on your next visit. ✕

Anne Elizabeth Denny helps individuals and families preserve family unity by developing and sharing a plan for future and end-of-life healthcare decisions. To learn more, visit [anneelizabethdenny.com](http://anneelizabethdenny.com).

# Life's Most *Intimate & Profound* Questions

By Christina M. Puchalski, M.D.

**S**pirituality helps us find meaning and purpose in our lives. It is the source of hope in the midst of despair and the part of us that seeks deep connection to other people, as well as to the significant or sacred, however we understand that in our lives.

Many patients experience a sense of profound spiritual transformation in the midst of serious, often life-threatening illness. They describe seeing life more fully, and having a great sense of gratitude for every moment of their lives. Some describe their illness and evening their dying as a blessing or opportunity because it triggers us to find immense richness in our lives and in our relationships. Suffering can open the door to profound joy and inner peace by offering hope even in the darkest of times — at first, hope for a cure and then a transformation to peace and self-acceptance.

Illness, and the prospect of dying, offers us the opportunity to move deeply within ourselves and explore deeper meaning to life. It is that inward journey that can result in a deep healing and a profound outward expression of joy, forgiveness, gratitude and peace.

Research has demonstrated that spiritual and religious beliefs and practices have a positive effect on health care outcomes, as well as quality of life. Clearly, spiritual and religious communities offer tremendous social support in times of need. But spirituality also helps us realize the full depth and potential of our beings. It helps us detach from the relatively unimportant things in life and focus on those things that matter most.

People find the ultimate meaning in their lives in many ways — a relationship with God or a transcendent concept, nature, family, rationalism, and humanities and the arts. Spiritual practices include meditation, prayer, ritual, reflection and journaling. One might visit a chaplain, pastoral counselor or meditation teacher, or join a spiritual community or yoga group. Some people find retreats, seminars and spiritual publications helpful.

Illness can be transformational for patients and caregivers. Focusing on our spiritual self rather than the physical aspect of our illness, or that of a loved one, helps us grow and realize our full potential.

It helps us find ultimate meaning and peace. Therein lies the hope for all of us. ✕

**Here are the intimate and profound questions most often asked as we approach end of life:**

- Who am I really?
- What do I hold sacred?
- Whom do I love, and have I loved well?
- What do I believe in?
- Is there a God? If so, what is my relationship with God?
- Is there life after death? What does that mean to me?
- Has my life mattered?

---

*Christina M. Puchalski, M.D., is Professor of Medicine and Health Sciences at The George Washington University School of Medicine; founder and director of The George Washington University's Institute for Spirituality and Health ([www.gwish.org](http://www.gwish.org)) and author of Time for Listening and Caring: Spirituality and the Care for the Seriously Ill and Dying., Making Health Whole and co-editor of The Textbook for Spirituality and Health. Dr. Puchalski welcomes comments and questions at [caring@gwish.org](mailto:caring@gwish.org).*

# The Power to Embrace Life

by Allen Klein



**T**he thought of facing a terminal illness or losing a loved one is not easy. I know — I have had many losses in my life. The one that made the most impact on my life was my wife's death when she was 34. In addition, my mother, my father, my four grandparents, my sister-in-law, several cousins, and both my mother-in-law and father-in-law have died, as well as over 40 friends and colleagues.

I don't think we ever forget the people we lose. So, in some sense, they are never gone. But, still, it hurts not to be able to see them, hear them, or hold them again. Loss hurts. But it can also help us be stronger, wiser and more appreciative of how we choose to live life.

Every time we lose something, we are presented with an opportunity to acquire something new. With each loss, there is a golden opportunity for a new beginning. You may not realize it right now, but your loss can be a gift.

When coping with a terminal illness or losing someone who means everything to us, loss helps us think more deeply about who we are, why we are on this earth and how we should live each day. When we move beyond mourning for our loss, we wake up to the beauty of

**If you believe yourself  
unfortunate, because  
you have loved and lost,  
perish the thought. One  
who has loved truly can  
never lose entirely.**

— Napoleon Hill, American author

appreciating life more fully, cleansing through renewal of our minds and learning how to love more freely.

Crying is the body's way of dealing with loss. But after the tears we need

to let go and move on with a new attitude. As Walter Anderson, an American magazine editor said, "I can choose to sit in perpetual sadness, immobilized by the gravity of my loss, or I can choose to rise from the pain and treasure the most precious gift I have — life itself."

Laughter offers a coping mechanism and gives us a break from the pain of loss. It allows for a breath of fresh air at a time when everything seems dark and heavy. Many of the world's top comedians intuitively know how to turn to humor for comfort during difficult times.

When dealing with loss, the decision to embrace life helps us to live each day more fully. ❧

---

Allen Klein, MA, CSP, is an award-winning professional keynote speaker and best-selling author ([www.allenklein.com](http://www.allenklein.com)) of *Learning To Laugh Even When You Feel Like Crying*.

# What I Wish I'd Known About Hospice

*By Paula Spencer Scott*

Families are often surprised to discover that they know little about hospice and palliative care until they see it up close.

**L**ike many people, I ambled through decades of my life without thinking much about the word hospice. Sounds like hospital? But more end-of-the-line? That's all I knew.

Until I experienced it firsthand, that is — four times now.

My mother received a referral to home hospice care after her cancer was discovered to have metastasized. Less than two years later, my dad was enrolled in hospice, too, during stroke rehabilitation in a nursing home. So were both of my in-laws — most recently my 95-year-old father-in-law, who lived with us until his death a few months ago. He, in fact, benefitted most of all from the cumulative wisdom that my husband and I had gained from our earlier three experiences.

but they seemed to make him sicker as he got more frail. His quality of life improved when he said, 'Enough!' and people helped him come home to his garden. His last days were something we all treasured."

His experience reflects two very common surprises:

**1** That palliative comfort care is given alongside curative care. You can have both; it's not an either-or choice. Palliative medicine's emotional and physical focus is on treating the symptoms and stress that go along with being serious ill, while the rest of your medical team targets the illness or injury.

**2** That not even hospice care — which is a shift to comfort-only care — means "doing nothing." Again, there's an emotional and physical focus to managing bothersome symptoms and side effects, including pain, that can interfere with a sense of well-being. (All hospice care is palliative, but not all palliative care is hospice.)

This may be why several studies, looking at different health conditions, have found that people in hospice care lived longer than those who received standard treatment. Lung cancer patients lived two months longer, for example, and breast cancer patients more than three months longer.

**"You don't have to wait until the last days or hours to sign up—and ideally, *shouldn't*."**

Don, my father-in-law was still alert, jovial, and could bathe and dress himself when we nevertheless began noticing many stressful, dramatic changes. Although he loved eating cookies and sitting out in the sun of our California backyard, he'd been steadily losing weight — 45 pounds over six months — and sleeping more hours every day. Shortness of breath made it harder to walk (he had congestive heart failure, among other heart issues). And episodes of confusion and saying and doing peculiar things — like talking to people who weren't there, or sitting in the car and honking the horn — were on the rise.

Because past experiences had shown my husband and me how useful hospice care can be, we knew to ask his doctor he might be a candidate for hospice. At first she wasn't sure. We persisted because we knew him well ►


That's the thing about hospice and palliative medicine (the umbrella term for comfort care that hospice is part of but which isn't limited to hospice): Once you experience it, you wonder how you could have managed without.

Misconceptions are common, judging from the many conversations I've had with people about hospice — families who've used it as well as those who work in the field.

Among the things these voices of experience wish we'd known sooner:

**"I wish I'd known that choosing palliative services doesn't mean giving up."**

"I was so stuck on the idea that enrolling in hospice would be like throwing in the towel," says Roberto, whose brother had lung cancer. "We kept looking for one more treatment



and could tell these were big changes. She agreed the weight loss was worrisome, though, and had him evaluated by a hospice team, who certified him for a three-month trial of hospice care.

Sure enough, he continued to decline, and hospice was extended. He died about five months in.

Not even the best doctors have a crystal ball that reveals exactly how much time is left. To qualify for hospice benefits requires doctors certifying that a person has a life-altering condition with a prognosis of six months or less. That's just a guesstimate on their part, of course. Some people remain in hospice care for a year or even longer. You can also choose to leave hospice at any time and resume curative treatments.

Most people wait too long. In reality, one third of hospice users are enrolled for less than a week. The median time: just 17.4 days in 2014.

Earlier is also better for those receiving palliative care. Earlier palliative care has been shown to reduce depression symptoms and improve quality of life. A 2016 University of Pittsburgh review of past studies, published in JAMA, also found that people had less severe symptoms and greater satisfaction with their care and their caregivers. Palliative medicine specialists recommend engaging a consult for palliative care any time there's a serious illness or injury, whether it's curable, life-threatening, or terminal.

**“It’s like having an instant free support system.”**

Taking care of someone on your own can be incredibly taxing — “like trying to have surgery without anesthesia,” says palliative care expert Ira Byock, MD, chief medical officer for the Providence Institute for Human Caring. Hospice and palliative services focus a wide lens — on the whole family, not just the sick person.

It can be enormously de-stressing to have someone you can call 24/7 with questions about unusual breathing or how to care for a dressing. Hospice staffers also bring everything to you that you’ll need, including many items you didn’t know would help or wouldn’t know where to find — from equipment (a hospital bed, wheelchair, walker, bedside commode) to supplies (adult diapers, absorbent bed pads, rubber gloves, bandages, medications, and so on). And it’s all covered by Medicare.

“It was such a relief that the doctors and nurses comes to your home — no more schlepping to doctor’s offices,” said Arlene, whose recently widowed elderly mother had been seeing multiple specialists for her own failing health. Once she enrolled in hospice, a nurse visited weekly, along a grief counselor and home health aides who helped with bathing, shaving, and other personal care.

Each case is assigned a multi-disciplinary team of support workers. [See *It Takes a Village* on page 7.] Your original physician can also still be in the loop, if you choose.

**“I didn’t realize that pain medicine helps the person manage better — it doesn’t just knock you out.”**

Beth avoided hospice when her husband was terminally ill because, “I didn’t want him to end his life as a zombie.” She was afraid that he’d be given powerful sedative cocktails as part of hospice care, which experts say is a common fear — and a myth.

“We resisted any kind of pain medication for that reason, but the nurse explained that having pain treated well actually allows the person to feel well enough to have visitors and do things,” she says. Her husband was able to read to their daughters and be more alert for longer periods. “If we had known this, we probably would have asked about hospice sooner.”

Pain management is a centerpiece of all palliative medicine, because the distraction of pain can interfere with things people prefer to do in a crisis or at the end of life, like focusing energy on getting well, spending time with family, or reviewing their life and making peace with others. Appropriately prescribed medications don’t turn patients into addicts or hasten death, says Karen Whitley Bell, a hospice nurse for 20 years and author of *Living at the End of Life*.

**“Death becomes a little less frightening and lonely.”**

This may sound macabre until you’ve been there, but each time, I found it enormously reassuring to be given (by the hospice nurse) a phone number to call — at any hour — if any problems came up, or upon death. While using hospice care, you don’t have to deal with the scary drama of 911 and ambulances, or sitting in the house asking one another, “What do we do now?”

And hospice abruptly doesn’t end at death. Members of the hospice team continue to check in with the surviving family and offer optional services like grief counseling, even for children.

When my father-in-law died in his sleep on a dark, rainy night, all we had to do was call that number. A nurse we’d been working with arrived 30 minutes later. Even though we’d been through death before, she guided us through the steps involved — calling the funeral home, preparing his body, disposing of medications, and all the rest — a calm and supportive presence in what is, after all, a natural but unnerving event.

I flashed back to the first time hospice was broached to my family, when my mom was in the hospital — how freaked out and uncertain we all were. Now I wish I’d known to enlist palliative medicine right when she was diagnosed. And I wish I’d known that all through her last chapter, none of us would be quite so alone. ❧

---

*Paula Spencer Scott is the author of SURVIVING ALZHEIMER’S: Practical Tips and Soul-Saving Wisdom. She lives in the San Francisco Bay Area.*



# How Palliative



## Q. What is palliative medicine?

**A.** Palliative medicine is a medical subspecialty provided by doctors who offer palliative care for people who are seriously ill. Palliative care relieves suffering and improves quality of life for people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening.

## Q. What's the difference between palliative care and hospice care?

**A.** Palliative care is whole-person care that relieves symptoms of a disease or disorder, whether or not it can be cured. Hospice is a specific type of palliative care for people who likely have 6 months or less to live.

In other words, hospice care is always palliative, but not all palliative care is hospice care.

## Q. Who provides palliative care?

**A.** Palliative care is provided by an interdisciplinary team that may include a doctor who specializes in palliative medicine, an advanced practice nurse, social worker, and volunteers.

## Q. What does a palliative doctor do that's different from what my other doctors do?

**A.** Your other doctors focus on your general health or treating your disease or condition. Palliative doctors concentrate on preventing and alleviating suffering, improving your quality of life, and helping you and your loved one cope with the stress and burden of your illness.

## Q. Shouldn't all my doctors be concerned with alleviating my suffering and improving my quality of life?

**A.** Yes, of course. But palliative doctors have special training and expertise in pain management and symptom control, and specialize in helping patients and their families cope with the many burdens of a serious illness, from the side effects of a medical treatment to caregiver stress to fears about the future. Palliative doctors can assist you with difficult medical decisions, helping you weigh the pros and cons of various treatments.

## Q. If I receive palliative or hospice care, will I still be able to see my personal doctor?

**A.** Absolutely. Your palliative doctor coordinates care with your other doctors and helps you navigate the often-complex healthcare system.

## Q. Is hospice just for the last few days or weeks of life?

**A.** You are eligible for hospice care if you likely have 6 months or less to live (some insurers or state Medicaid agencies cover hospice for a full year). Unfortunately, most people don't receive hospice care until the final weeks or even days of life, possibly missing out on months of helpful care and quality time. It is your choice to enter or leave hospice care. If our illness improves or you wish to seek curative treatment, you may leave hospice care, returning if and when you choose to.



# Care *Helps*



**Q. If I agree to palliative care, does that mean I'm "giving up?"**

**A.** Not at all. The goal of palliative care is to make you comfortable and help you achieve the best possible quality of life. You can have palliative care while you are undergoing treatments that may cure or reverse the effects of your illness. In fact, palliative care can help you cope with aggressive treatments by getting your pain and symptoms under control to help you fight the disease.

**Q. How can I find palliative care?**

**A.** Palliative care can be provided at a hospital, nursing home, assisted-living facility or at home. There are a number of ways to find a doctor who specializes in palliative medicine, including asking your personal doctor to refer you to a palliative doctor or asking your local hospital if they have a palliative specialist.

**Q. Could I become addicted to the medication used for my pain and symptoms?**

**A.** Addiction to medication prescribed

for pain relief is a common fear but does not frequently occur. Palliative doctors are experts in preventing problems and side effects of strong pain medications. They also can help patients with addictions get pain relief.

**Q. Could taking pain medicine hasten my death?**

**A.** Appropriately prescribed medicine will not hasten death. Your palliative doctor has the expertise to devise a medication plan that makes you comfortable and is safe.

**Q. How do I know that I'm receiving the most beneficial or appropriate treatment?**

**A.** Palliative doctors are concerned about you as a whole person—not just the part of you that is sick. They understand that people with serious illnesses can be frightened and unsure of themselves when making medical decisions. They also understand that there is not always one right or wrong answer and that your needs and wishes may change over time. Palliative doctors consider all

of this when they help you develop your treatment plan.

**Q. Does insurance cover palliative care or hospice?**

**A.** Many private insurance companies and health maintenance organizations (HMOs) offer palliative care and hospice benefits. Medicare (mostly for people 65 and older) offers hospice benefits, and the extra Medicare plan (Part B) offers some palliative care benefits. Medicaid coverage of hospice and palliative care for people of limited incomes varies by state. ❧

---

Permission to reprint article is granted by the American Academy of Hospice and Palliative Medicine. To learn more, visit their patient website [www.PalliativeDoctors.org](http://www.PalliativeDoctors.org).



(continued from page 5)

**You write that the chaplain's role is to create "a sacred time and place in which people can look at the lives they've led and try to figure out what it all means to them." How can we help with that process?**

Dying people often do a life review, sorting through things like "Why did I do what I did? Why did God let this happen?" They're not looking for you to tell them what it all means. In fact, if you do, it can shut down conversation. That's not what they need.

Feel free to ask basic, open-ended questions. If the person brings up Great Aunt Sally and you've never heard of her before, say, "Wow, who was she? I never heard you talk about her before."

There's an old saying in chaplaincy: Before you ask a question, be sure you're ready for whatever the answer might be." Hard things happen in people's lives, and sometimes if you ask questions, you may learn about something really difficult, so be ready for that. Sometimes the work of life review can be hard or scary. They want to do it with us so they don't feel alone. Once again, just listen. They're not looking for you to solve it.

**What tactics have you picked up for being a good listener?**

Those pauses in speech — ahh, umm — signify that you're listening and thinking. So does nodding. Making eye contact is really important. That can be hard when people are dying, they don't always look great. But I've found that if you really focus on someone's eyes, they are beautiful, even if they're milky or damaged, or the whites are yellowish from liver failure. That old saying is true: Eyes are the windows to the soul.

**You write what the sick and dying most want to talk about is family: "Families are how we talk about God and meaning and the big spiritual questions." Can you say more about that?**

I think people choose this theme because our most intimate, intense interactions are with family members—mothers, fathers, children — in those relationships, people tend to have their greatest experiences of love and of pain. Those tend to be the unsettled, unresolved things. There can be both good and bad, in the same relationship.

There are times when it's undeniably sad, but also times when a visit can be undeniably joyful. People who are dying like to laugh just as much as anyone. Many conversations dying people like to have are reminisces, like when you get together with old friends at dinner. You can ask questions to help them relive it — who was there, what was the music — or you can just listen.

**What if the person doesn't want to talk?**

Beware that some people get tired when they're sick and don't feel like talking. Ask yourself, are they being quiet because they want to be alone now? Or are they happy for the companionship of us just being quiet together.

As a culture we have a hard time with silence. Many people find it uncomfortable. It's a lost art, to just together in silence not distracted by noise. It can be nice. ✕

# Volunteers for Hospice Find *a Rewarding Experience*

*By Melissa Weidman*

**H**ow can you volunteer for hospice? Isn't it depressing?" is a tough question often asked of hospice volunteers. For long-time Hope Hospice volunteers Ed Richard and Phyllis Helfrich the heartfelt response is immediate. "It's the most rewarding work I've ever done!" exclaims Helfrich. Richard adds, "Hospice is so full of love and compassion, I really enjoy being a part of that."

Both came to their work with Hope Hospice from personal experience, but each with a different twist. Richard, an IT engineer, was the caregiver for his wife, Bev, when she was in the last stage of a prolonged illness. "Hope Hospice's services made all the difference in my getting through that ordeal," Richard says. "Their bereavement services were especially helpful in my healing and moving on to the next stage of my life."

For Helfrich, a retired elementary school teacher, it was the fact that her family didn't have access to hospice services that motivates her to contribute significant time and energy to the non-profit cause. "My mother died in 1959 in terrible pain, before hospice was available in this country like it is now," she recalls. "I have always felt it was my mission to help people understand how hospice can help make this time of life easier for all involved."

Like all Hope Hospice volunteers, both went through extensive initial screening and training, and continue to

receive ongoing in-service seminars, coaching and support. Both have served as patient and family companions, giving family caregivers a needed respite from the grueling demands of caring for a loved one. But each have also developed their own volunteering specialty among the many opportunities available. Helfrich serves as co-chair

of one of the biggest annual fundraising events, An Evening by the Sea, which allows Hope Hospice to provide services free of charge. And Richard facilitates ongoing bereavement support groups, much like the ones that made such a difference to him.

"Volunteering feels so good, because you are giving back to the community," Helfrich says. "With hospice, you are lending a helping hand, learning new things and meeting new people. You get to admire how people make it through this challenging time of life. It's such a special opportunity to be there for them."

Which leads to the other most frequent comment volunteers receive: "You must be an angel to do this work!" To which Richard replies, "Well, I don't

have wings—but sometimes it sure can feel like we're helping families fly safely through this time on the strength of the compassion and caring that hospice brings."

And that feeling, both Helfrich and Richard agree, is very rewarding indeed. ❧



# Caring for the *Emotional Needs* of the Family

*By Melissa Weidman*



**C**hristine Greeley was grateful that her mother and father received the full range of Hope Hospice's services for many months, allowing both parents a peaceful passing in the home they loved. She thought at that point she had come to terms with the completion of their long and often arduous journey.

About a month later, she woke up one morning to discover she had become completely numb, barely able to move. "I didn't know what to do. Luckily, my first instinct was to pick up the phone and call Hope Hospice," Greeley says. "I had an amazing set of sessions with a grief counselor. It's quite remarkable the kind of help they have available for an extended period of time."

Hope Hospice bereavement leaders Ann Geagan and Deanna Upchurch agree that grief counseling is an essential part of the hospice experience. "People often think of hospice as just caring for the patient," Upchurch says. "But one of our key components is about caring for the emotional needs of the entire family. Sometimes the patient may only be on our service for a short time. We can provide grief support for family members for more



*Deanna Upchurch and Ann Geagan*

than a year after their loss, so that may be a far more significant involvement than the actual physical care of the patient."

Geagan says that Greeley's reaction isn't unusual, "Caregivers typically decline grief support immediately after their loved one has passed. They are exhausted and overwhelmed, unable to deal with one more new person. A month or so later, we often receive calls like Christine's. All their friends and family have returned to their normal routines, leaving them to cope on their own. We offer them someone who can meet them where they are, share what's normal and guide them on re-building their lives after loss."

Whether it's one-on-one counseling, attending one of the many grief support groups Hope Hospice offers, Camp Braveheart, a summer camp program to help children who have lost a loved one work through grief, or an adult grief camp, participants discover that grief doesn't fit a neat set of rules. "It can get really weird and messy at times," says Geagan. "None of the rules apply."

"Grief is unlike anything else you've experienced in your life," says Upchurch. "It's a lifelong process. We can remain vulnerable to triggers like holidays or milestones. Every person experiences it uniquely, like a fingerprint, based on

their own coping mechanisms. We help them find ways to strengthen the mechanisms that work for them."

For Greeley, the support of hospice professionals has made all the difference. "I feel so good now. I am able to think about my parents without bursting into tears. I have happy memories that I put together, and I really owe that all to the grief counseling and support I got from Hope Hospice. I wouldn't have traded that for the world!" 🌟

## Grief Coping Tips

- Everyone grieves uniquely
- Coping alone is not recommended; seek support
- Finding support is essential
- The grief process changes over time
- With support, most people will get through it to a new stage of life

“ When my dad got sick, we wanted to take care of him at home. We were referred to Hope Hospice by the hospital. When my dad arrived home by ambulance, we were met by fabulous people who assured us this was the best decision for him. They were the most passionate, caring group of professionals, who answered every question we had. They handled all the important issues so we could be there to take care of my dad. Supplies and medications were all taken care of, and we were instructed on what to

do. They kept my dad at peace, retained his dignity to the best level possible and kept us all sane. They took a lot of the burden away from us. To have help from people who understand and are compassionate and are there to work with you is a blessing. Hope Hospice is a great organization, and the staff is awesome! ”



*Cheryl Hulslander  
Hope Hospice family member and caregiver*

## HopeHealth is dedicated to touching lives in so many ways.

When you are facing serious illness or loss, hope is here. HopeHealth has been enhancing the quality of life for people experiencing serious illness and loss for more than 40 years. HopeHealth provides compassionate and high quality care when you, or someone you love, is diagnosed with a serious illness. Whether you need hospice or palliative care, home health care, or specialized services for dementia and Alzheimer's, HopeHealth is here to help you.

### HopeHealth's family of services

- **Hope Hospice & Palliative Care Rhode Island**  
1085 North Main Street  
Providence, RI 02904  
401.415.4200  
*Additional office in Wakefield, RI*
- **Philip Hulitar Hospice Center**  
1085 North Main Street  
Providence, RI 02904  
401.351.5570
- **Hope Palliative Care Center**  
100 Highland Avenue, Suite 303  
Providence, RI 02906  
401.383.2896
- **Visiting Nurse of HopeHealth**  
6 Blackstone Valley Place, Suite 515  
Lincoln, RI 02865  
800.696.7991
- **Hope Hospice Massachusetts**  
765 Attucks Lane  
Hyannis, MA 02601  
508.957.0200  
*Additional offices in Brockton and Martha's Vineyard*
- **McCarthy Care Center**  
73 Service Road  
East Sandwich, MA 02537  
508.957.0200
- **Hope Dementia & Alzheimer's Services**  
765 Attucks Lane  
Hyannis, MA 02601  
508.775.5656

---

Hope Hospice & Palliative Care Rhode Island is the major teaching affiliate for hospice and palliative medicine for the Warren Alpert Medical School of Brown University.