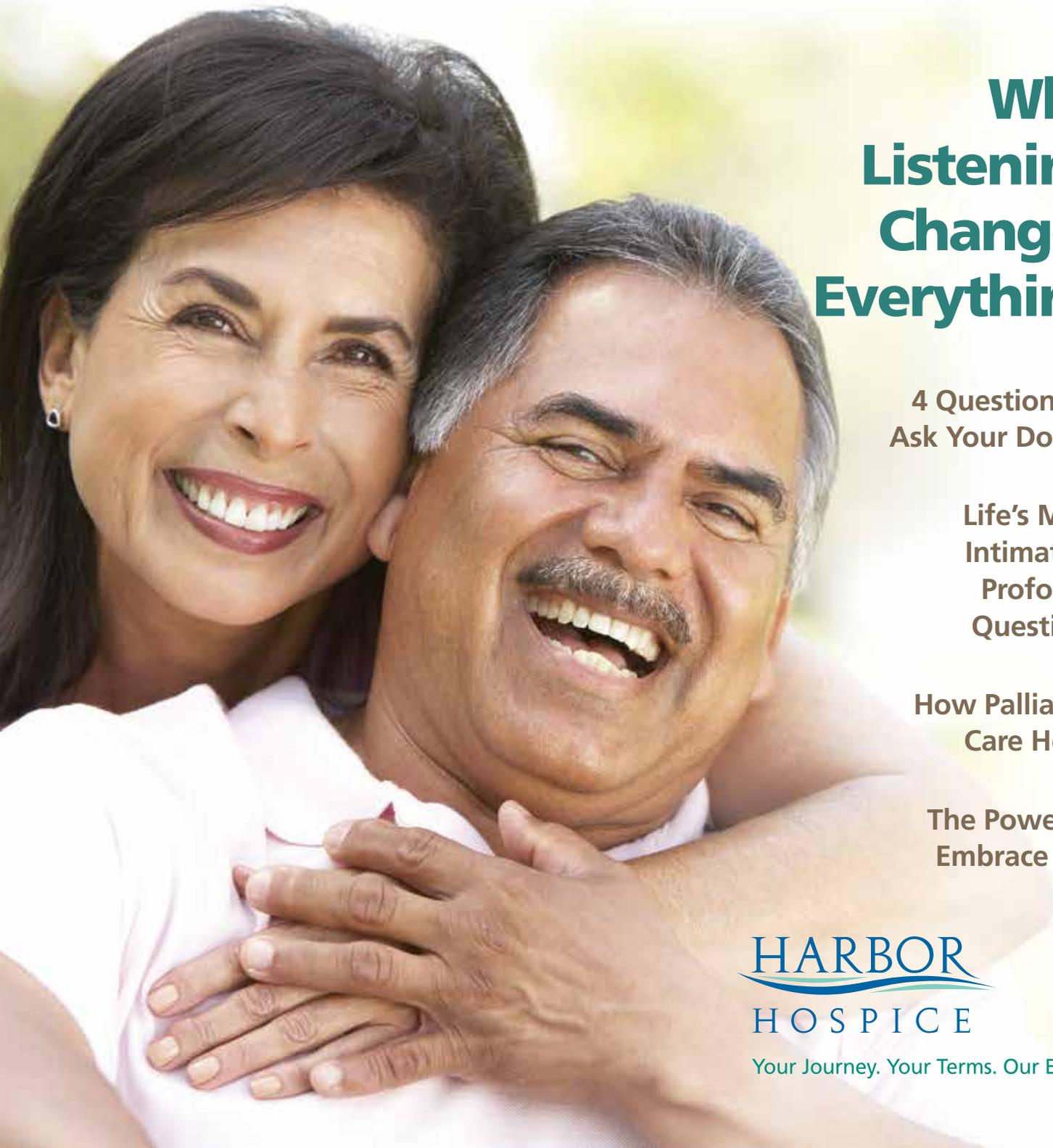


A Publication of Harbor Hospice

# Touching Lives™

*Holding Hands. Holding Hearts.*



## Why Listening Changes Everything

4 Questions to  
Ask Your Doctor

Life's Most  
Intimate &  
Profound  
Questions

How Palliative  
Care Helps

The Power to  
Embrace Life

**HARBOR**  
HOSPICE

Your Journey. Your Terms. Our Expertise.

## FEATURE ARTICLE

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

By Paula Spencer Scott



# CONTENTS

- 4 **Following a Harrowing Wartime Rescue, a Delightful Island Life in the North Channel**  
By Susan Newhof

- 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 **Brayden's Journey**  
By Melanie Dekkers, LLMSW

- 19 **Focusing on Philanthropy—Harbor Hospice Foundation**

## Welcome to *Touching Lives*



Dear Friend,

The life stories that Harbor Hospice patients and their families tell us are remarkable, as you'll discover in this issue of *Touching Lives*. And that we can capture these stories and share them with you is testimony to the meaningful relationships our volunteers and staff develop with the wonderful people they care for.

It takes a unique person to work in hospice care.

Each member of our team has chosen this role because of something special in his or her heart. They value the opportunity to provide comfort and support at a very delicate time in a person's life—the last months and weeks and hours. They deliver their care with skill, grace, joy and compassion, and they consider it an honor to do so.

I am both grateful and proud that we can ease the challenges and shoulder the worries for our patients and their families.

I am grateful to you, too. Because of your support, we can offer hospice services to every individual in our region who needs it, *regardless of their ability to pay*. From children to centenarians, we believe everyone has the right to the best end-of-life care available, to die peacefully, painlessly and with dignity, surrounded by love. That is our mission, and you make it possible. Each time we visit a patient at home or in the Poppen Residence, each time we talk with grieving families and help them cope, you are there alongside us. Thank you.

As we proof these stories for the last time and send this issue of *Touching Lives* off to press, we feel both sadness for those who have passed and joy for all we shared with them. This work is a marvelous calling. We do it 24 hours a day, and we wouldn't have it any other way.

With warmest regards,

Lisa McMichael  
President and CEO



**Harbor Hospice**  
1050 W. Western Avenue, Suite 400  
Muskegon, MI 49441  
800.497.9559  
HarborHospiceMI.org

Your Journey. Your Terms. Our Expertise.

# Following a Harrowing Wartime Rescue, a Delightful Island Life in the North Channel

By Susan Newhof

**D**on Goulding's fingers brush lightly over the stack of yellowing news clips, photos and documents on his lap as he tells of the events that let up to a day in 1953 that was nearly his last.

He had grown up wanting to fly airplanes, he recalls. "My brother operated a flight service. I went to work for him and decided to be a pilot."

He enlisted in the Air Force, where his natural talent for mechanics was a big asset, and he was assigned to aviation training in Biloxi, MS.

Eventually, Don found himself flying the SA 16 Grumman Albatross, an amphibious airplane used for air-sea rescue. On a bitter day in January, with a cold wind and choppy seas, he and a co-pilot, and a crew of four, were sent to rescue a pilot whose plane was going down in the waters off the west coast of North Korea.

"I radioed to the pilot that we could do a better job getting him if he bailed out of the plane before it hit the water, but he didn't want to do that. He went down with the plane...he was still in it when it hit the water," Don remembers. Tragically, although they were right alongside the area where the plane went in, they could find only parts of it. The pilot was gone.

By the time they called off the rescue mission, powerful waves were battering the plane causing a heavy buildup of ice on its wings. It was impossible to get the plane back up in the air.

Don and his crew put out a call for help and several boats in the area headed toward them. A Navy ship began communicating with them, and by the time it reached the plane, the seas were rocking waves of eight to ten feet. Even though they were wearing float suits to stay dry, many of the airplane's crew were suffering from severe cold,



and they were scared.

"It felt like the plane might come apart," says Don, who remembers the ordeal with stunning clarity. "The Navy crew started shooting lines—ropes—to us, hoping we could grab them and secure the plane to the ship, but their attempts were complicated by the huge waves and the cold. After several tries, we got the plane tied on with its nose facing the propeller of the ship."

As Don describes it, each member of his crew, one at a time, was passed a rope to tie around his body. Then each was jerked up off the plane, over the propeller of the ship, and, literally, dropped on deck. The ship's crew had pulled out their bedrolls and covered the deck to soften the landing, and they tried to catch each man as he hit.

When it was Don's turn, he slipped on the plane's icy surface and found himself suddenly heading into the propeller. As he put up his arms to fend off the blow, he heard someone yell, "PULL!" The quick action was enough to lift him up out of harm's way and drop him safely on to the ship.

The rescue took nine long hours.



Don hoped the hobbled Albatross could be towed to shore, but deteriorating weather conditions and that menacing ice on its wings were taking a toll. According to the ship captain, the plane rolled over and sank about five minutes after the last man was taken off. He estimated that it was coated with five tons of ice.

Don smiles and says quietly, "We were lucky."

Life became a lot more fun after the war. Don and his wife, Marilyn, and another couple purchased a three-and-a-half-acre island in Georgian Bay.

They named it *Golden Summer* at the suggestion of Marilyn's mother, as a combination of the last names of the two owners, and they enjoyed summers there. The Goulding's daughter, Colleen, and son, Chris, loved their rugged, unconventional island upbringing. Don chuckles when he tells the story of the local "school bus" driver who transported children from the area's islands by boat.

In 1980, the Gouldings purchased Moon Island Lodge, also in Georgian Bay, which they lived in year round and operated for 15 years. When Don and Chris took their customers fishing, Marilyn sent along potatoes and onions, fresh bread, coleslaw and homemade cookies, and at noon, the fishermen were treated to a feast with their catch. The whole family agrees it was a good life.



These days, Marilyn and Don live in a lovely condo overlooking the channel in the busy port city of Ludington. Water views have been a part of their life for a long time,

and here it includes the seasonal arrivals and departures of the historic passenger ferry, the *S. S. Badger*. Colleen is an RN and naturopath. Chris works in construction.

Don has been dealing with the effects of cancer for a while, and not long ago, Colleen gently suggested to her parents that they could use a little extra help. She encouraged

them to call Harbor Hospice.

"Don was skeptical at first," remembers Marilyn. "And I knew nothing about hospice care, except I thought they were a group you called in at the end. A staff person came to talk with us, and before she left, Don told me he felt the timing was right. The Hospice experience has been very good. Our social worker Melanie, the chaplain, the nurse, everyone is wonderful. We're learning that every day is a blessing, and I'm telling my friends to *find out what Hospice is all about!*" ❄

---

*(A few weeks after Don enthusiastically shared his stories with us and reviewed the draft for this article, he passed away peacefully at home, surrounded by family.)*





# 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.

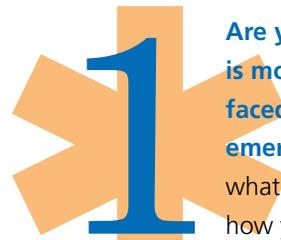
Medicare's decision to reimburse physicians for end-of-life conversations beginning in 2016 is a clear victory for advance care planning. Insurance will soon cover the cost for you to speak with your doctor about your preferences for end-of-life healthcare decisions.

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.

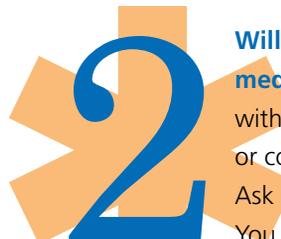
Rather than wait for him or her to initiate the conversation, begin by asking your doctor these four questions:



### 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.



### 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?”

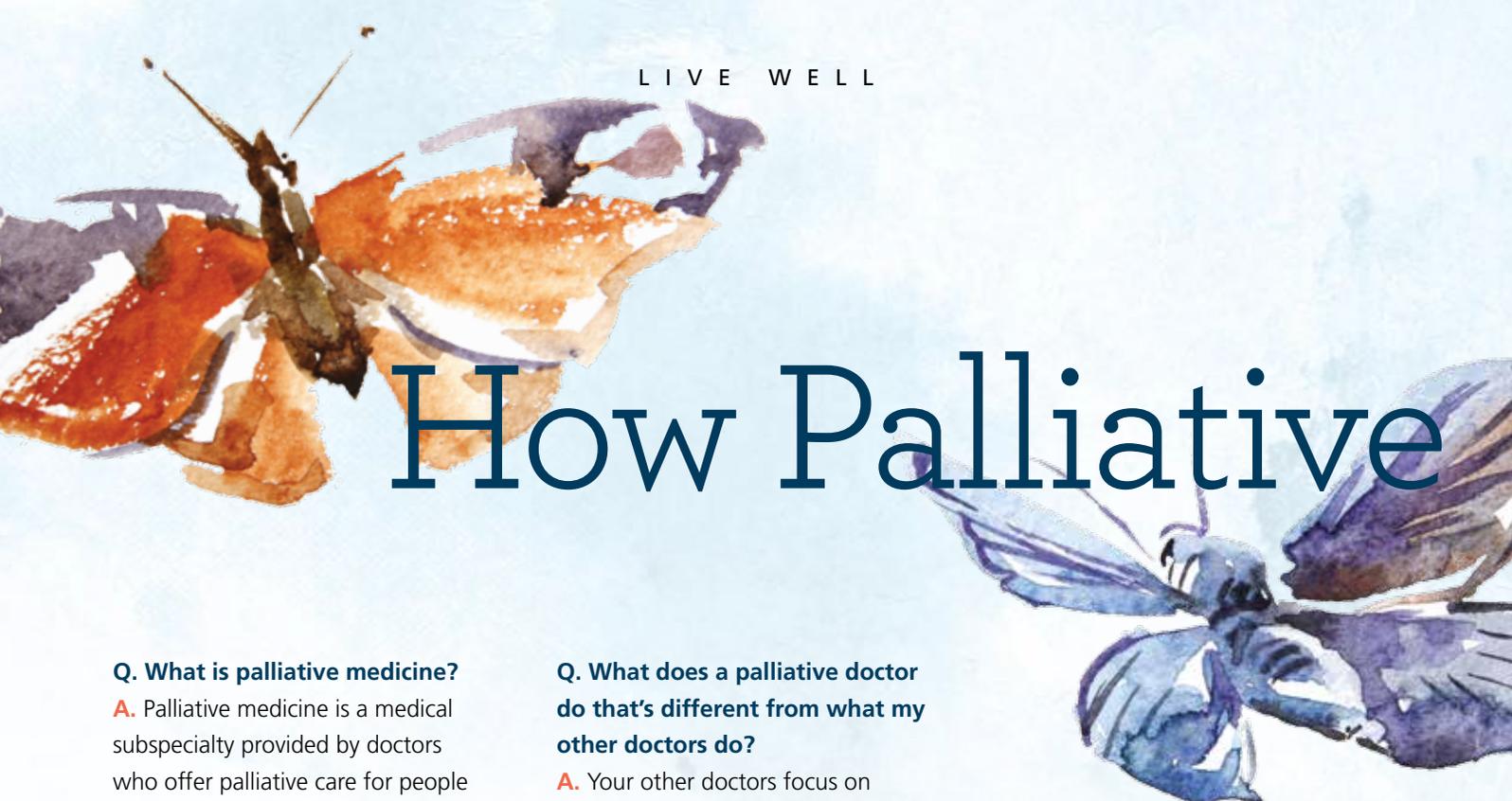
And hospice abruptly doesn’t end at death. Members of the hospice team continue to check in with the surviving family and offer optional services like grief counseling, even for children.

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. ✕

---

*Paula Spencer Scott is the content chief of the family resource Kinstantly and the author of *Surviving Alzheimer's Practical Tips and Soul-Saving Wisdom for Caregivers*.*

# Brayden's Journey



*By Melanie Dekkers, LLMSW*

**B**rayden answers the phone and sounds every bit an eight year old.

"Hello, it's me, Brayden."

When I ask if he remembers me from Camp last year, he says no. That's not surprising. It was almost a year ago. Many other things left an impression, however. Brayden wishes he could attend Camp again this year, and his mother tears up with happiness at how far Brayden has come in his grief journey.

Brayden attended Camp Courage in 2016 with his older brother Austin after the death of their grandfather in 2015. Camp Courage is a weekend-long camp specially designed for kids ages six to twelve who have experienced the death of a loved one. Like many kids, Brayden was initially reluctant to attend. Yet, almost a year later, he has different feelings about Camp.

"What was Camp like for you," I ask.

"Amazing!" He says exuberantly. "It was so fun!"

Brayden says his favorite parts were playing games and meeting new friends. He says he especially loved playing a

game in the Lodge. Little does he know this game had been created on-the-spot by co-director Stephanie Weesies when another planned activity had finished early. All Brayden knows is he had fun being a kid at camp.

Brayden says he also liked some of the more serious activities. "I still have my pillowcase," he says. Pillowcases are pre-printed with photos of the child's loved one, and at Camp the children are given fabric markers to decorate the picture. This is one of the most popular activities at Camp, and each child puts in a lot of time and effort to showcase their



loved one through artwork. Brayden was no exception and proudly showed his finished pillowcase to other kids and counselors. The pillowcase now sits on his bed.

Brayden also recalls the candle-lighting ceremony held around the campfire. This gave him the idea to set up a candle at home, which he lights often in memory of his *Grandpie*.

"My Grandpie died by suicide," Brayden reminds me. "I miss him a lot."

"We went camping, watched TV, and drove all the way to Oregon together. We even rode a shark!" Brayden recalls. They even visited the famed Wall Drug in South Dakota. These are precious memories that bring a smile to Brayden's face.

The two were very close and spent a lot of time together.

"He was more like a father figure to Brayden," Heather explains.

Initially hesitant to tell her two boys how *Grandpie* had died, she later realized they understood more than she knew. One day on a car ride, she overheard both boys talking about it in the back seat, and she decided it was time for a family discussion. "They now know



Grandpie was ill and needed help because he was not thinking right," she says.

Brayden has had to deal with a lot in his young life. In the past year Brayden's *Great-Grandpie* and a beloved baby-sitter died, both of whom he was close to. And Heather reports there have been fourteen deaths-by-suicide in his school system since last September.

"He hears about suicide a lot now, and understands it much better," Heather says.

Brayden has struggled since *Grandpie* died, and in the last year he began working with a counselor. One night he told his mom, "If I was sick, I would be ok, because my counselor would help me."

"My boys are the oldest in the family, and I see them using what they learned at Camp to help their younger cousins with these new losses," Heather says.

Brayden and his brother Austin have been invited to come to Camp again this year, but a family vacation is already planned for that same weekend. And Brayden knows all too well how important it is to spend time making memories with family while he can. ❧



Camp Courage is a three day, weekend-long camp for children ages 6-12 and Junior Counselors ages 15-19 who have experienced the death of a loved one. Harbor Hospice hosts Camp Courage every June in the beautiful outdoor setting of Pioneer Trails on Big Blue Lake in northern Muskegon County. Through a safe, supportive environment with specially trained counselors, Camp helps children and teens connect with others who truly understand, share and explore individual grief experiences, and learn healthy ways to cope. Kids grieve differently than adults and often in "chunks" of time. Camp Courage alternates grief-based activities with active, fun games; reading grief stories, kayaking, sharing loss experiences, playing gaga ball, riding therapy horses, swimming, and memorializing loved ones through a candle lighting ceremony. Camp Courage is going into its 25th year in 2018! Thank you to all those who have shared their children, stories, and lives with us!



## Focusing on Philanthropy



Look up the word “hospice” and you will find many definitions including the phrase: *a lodging for travelers*. Those words capture perfectly the homes, nursing facilities and the Poppen Residence where more than 800 children and adults each year travel the last leg of their earthly journey enfolded in the compassionate care of Harbor Hospice.

We consider it an honor to be a part of the lives of our patients and their families—an honor to help make the process of dying a little easier so they can focus on living.

We believe that everyone, regardless of age or their ability to pay—has a right to the best hospice care available, to live their last months and days without pain and surrounded by those who love them. We are also committed to offering support and counseling to those who lose a loved one so they can move through their grief to a place of peace.

That is why we never turn away a patient or family regardless of their ability to pay for hospice care, and why there is no charge at all for grief counseling. To ensure those services are always available, and to provide an additional layer of support for long-term maintenance of The Leila and Cyrus Poppen Hospice Residence, we encourage and nurture philanthropic giving through the Harbor Hospice Foundation.

In addition to appealing to you each year for support of programs such as Camp Courage for children who have lost a loved one, we roll out some of the most exciting fundraisers in the region!

- The Event of Events *Summer Splendor*—a glorious evening that features specialty foods, live entertainment, auctions and raffles at The Event Center at Fricano Place in Muskegon.
- A sailing race that hosts hundreds of sailing fans along the shores of Muskegon Lake for an annual Harbor Hospice Regatta at the Muskegon Yacht Club. This enormously popular race is part of the National Hospice Regatta Alliance that has raised more than \$23 million for hospice services across the country, including more than \$300,000 to support hospice care here in our five-county West Michigan region.
- An annual Purse Auction sponsored by our friends in White Lake benefiting Camp Courage.

...and more, including an annual bowling tournament to a long-distance memorial bicycle ride!

Come join us at these exciting events as we celebrate the lives of those we care for and make sure that every adult and child in Mason, Muskegon, Oceana, Ottawa, and Newaygo Counties has access to the best end-of-life care possible.

So what does it take to be someone who visits hospice patients, whether they are at home or in a residence?

“It’s not that difficult—sometimes, all you have to do is hold somebody’s hand, and be there”

Lynne Cavazos  
Harbor Hospice Volunteer, since 2008



Imagine how helpful it would be if someone delivered hospice medications right to your door; or if someone could stop and visit your loved one when you couldn’t be there. Harbor Hospice volunteers do all that – and so much more including patient visits, phone calls, support groups, veteran pinning ceremonies and more.

In 2016, 100 Harbor Hospice volunteers like Lynne Cavazos gave us over 10,000 hours of their time to help us with our mission of providing empathy, excellence, and expertise to end-of-life caring.

If you or someone you know would be interested in becoming a hospice volunteer, call 800.497.9559 or visit [HarborHospiceMI.org](http://HarborHospiceMI.org).

**HARBOR**  
HOSPICE

Your Journey. Your Terms. Our Expertise.