A Publication of Main Line Health Hospice

# Touching Lives™

Holding Hands. Holding Hearts.

## Why Listening Changes Everything

4 Questions to Ask Your Doctor

The Power to Embrace Life

How Palliative Care Helps

Life's Most Intimate & Profound Questions

HomeCare & Hospice
Main Line Health®
Well ahead.®

# A Community of Caring…

## The Home Care and Hospice Foundation turns your generous gifts into care, comfort and hope.

The Home Care and Hospice Foundation is able to continue and enhance the services we provide with the generous help and support of patient families and others in our community.

*Gifts benefit patients and their families by allowing:*

- A **Patient Assistance Fund** that provides equipment, personal care items or services for patients with financial need who have exhausted insurance and other resources.
- **Palliative Care Education** for home care nurses so that they have skills to best support patients and their families living with advanced illness.
- Recruitment and recognition of **Hospice Volunteers** who provide companionship and respite to patients and their families.
- **Community education** to increase awareness about the benefits of hospice care.
- **Grief support services** for hospice families and the community at-large.
- **Kimberly's Korner**, a safe place for children to cope with their grief following the loss of a parent or loved one.

**Through the United Way of Greater Philadelphia and Southern New Jersey donor choice program, you can direct your United Way giving to benefit the Main Line Health HomeCare & Hospice Foundation. Simply select code 29.**

**For further details on contributing to The Home Care and Hospice Foundation, please contact Karen Gadson in the Development Office at 484.596.5638**

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The HomeCare & Hospice Foundation
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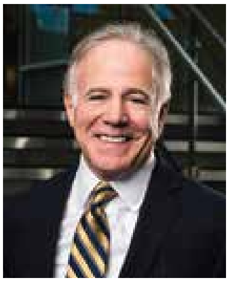
# Welcome to *Touching Lives*



Dear friends and neighbors,

We are pleased to share another edition of *Touching Lives*, a magazine designed to provide inspiring and helpful information about hospice and palliative care.

I am proud to share that Main Line Health HomeCare & Hospice earned The Joint Commission's (TJC) Gold Seal of Approval® for Hospice as well as Community-Based Palliative Care Certification—the first organization in Pennsylvania to do so. In the past year, we serviced over 2,000 hospice and 830 palliative care patients and families. As the need for hospice palliative care services continues to grow, this certification demonstrates our commitment to improving outcomes for patients and families facing serious life-limiting illness.

Over the years we have heard from so many of you about the fears and frustrations you face when making decisions about your health care. It is hard to know if you are making the right choices when you are given different options and opinions. Good information is needed to make good decisions—and yet we find that hospice and palliative care services are often not well understood. For example, the right time to consider hospice care is sometimes unclear. We developed a useful chart, found on page 18, to help you determine the right care for you and your family.

*Touching Lives* helps replace confusion with understanding. One of the great benefits of Main Line Health Hospice is that our services are tailored to meet the needs of you and your family. An example of this can be found in the article by Dana Rummery, a hospice team member, who shares her experience of using Art Therapy with patients to help bring meaning to their lives.

In hospice and palliative care, we cannot change a difficult diagnosis. But we can help change the way you live with that diagnosis. Whether you are receiving active treatment for your illness or moving toward comfort care, we offer the right amount of experience and support to help you and your family. At a time when it matters most, we are there for you.

Sincerely,

Richard Jacovini

Rich Jacovini, President

*Main Line Health HomeCare & Hospice*

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Well ahead.

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# Honoring Our Heroes

Studies now show one out of four dying Americans once served in the U.S. military, stressing the need for hospice care designed just for our heroes. The *We Honor Veterans* is a program of the National Hospice and Palliative Care Organization (NHCPO) and the Department of Veteran Affairs (VA). It helps hospice programs meet the special needs of dying military veterans. The *We Honor Veterans* program teaches hospice professionals how to comfort patients who may have been hurt physically or psychologically while serving our country. The program emphasizes respectful review, compassionate listening and grateful recognition.

Thanks to support from the HomeCare & Hospice Foundation, Main Line Health Hospice is taking part in the *We Honor Veterans* Recognition Program. Our full team of leaders, nurses, social workers, chaplains, therapists, home health aides and volunteers are involved.

Whenever a veteran is admitted to our hospice program, we discuss the kinds of experiences they had in the service. We look at illnesses and conditions related to their service that could affect their end-of-life experience. We create a care plan that takes into account possible signs of post-traumatic stress and other emotional and psychological needs. The goal is to provide the very best end-of-life care while honoring the courge and sacrifices these men and women have made.

To support this work, our staff members and volunteers attend special programs related to veterans' assessment and care. The hospice program earns achievement stars as they complete goals in the training by performing special tasks and attending education seminars. In the coming year, Main Line Health Hospice will expand its commitment by partnering with local and regional Veterans Administration offices and facilities.

With our veteran patient population now approaching 500 patients per year, Main Line Health Hospice recognizes the need to support those who have sacrificed for all of us as essential and worthwhile. If you are interested in becoming a hospice volunteer or would like to make a donation to support this program, visit our website: **mainlinehealth.org/homecare**.

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*Terre Mirsch, MS, BSN, RN, NEA-BC, CHPN, CHPCA is the Director of Main Line Health HomeCare & Hospice.*

Features of this wonderful effort include:

- *We Honor Veterans* lapel pin worn by all hospice staff and designated Veteran Volunteers
- American flag lapel pins for all patients who served in the military. The pin is presented on an acknowledgement card along with a framed certificate reflecting the patients' service branch
- Patriotic lap quilts sewn by volunteer quilters
- Volunteers who have served in the military to visit our veteran patients
- Veteran recognition activities on holidays such as Memorial Day, Independence Day, and Veterans Day

# 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***

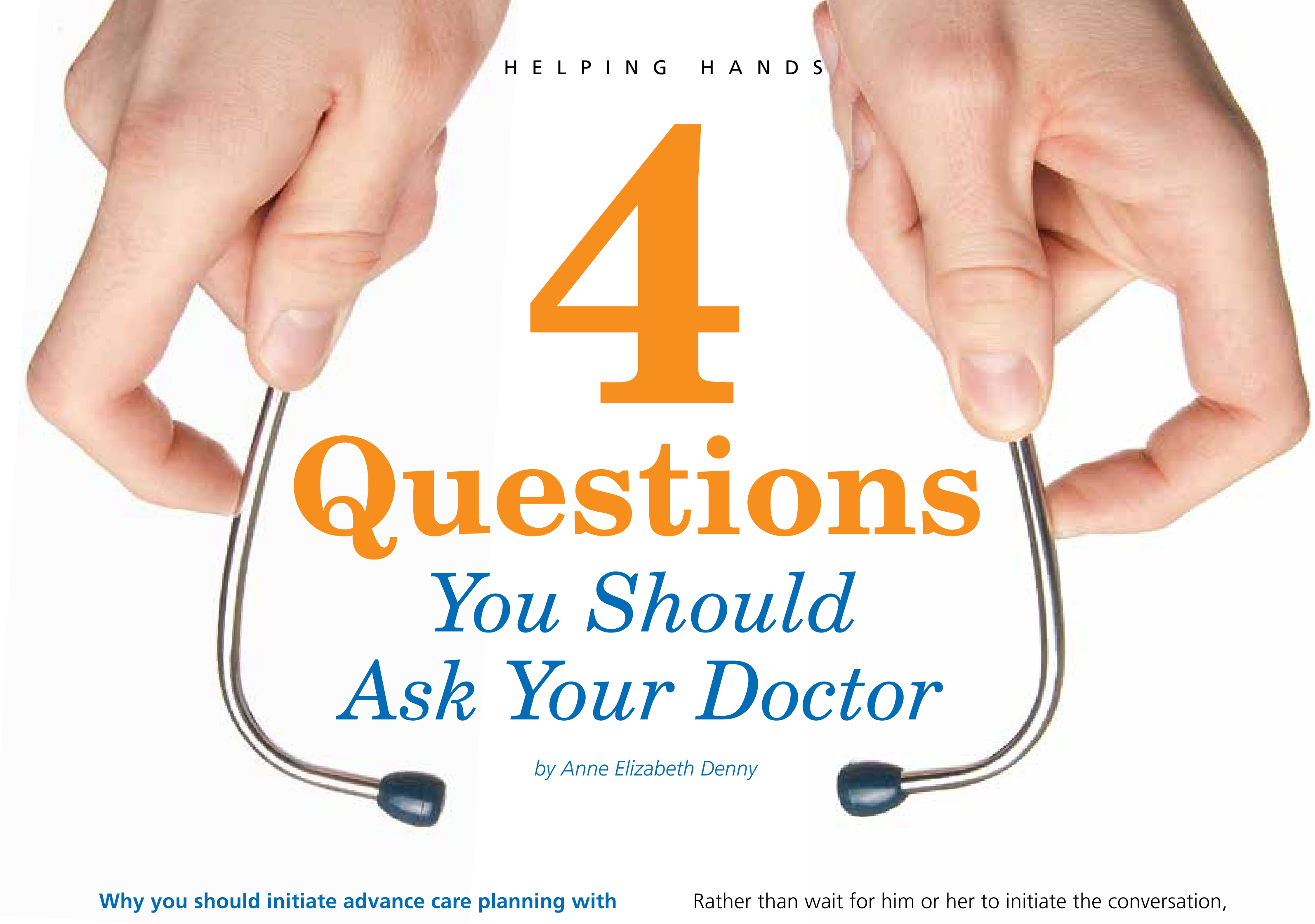
As a hospice chaplain, Kerry Egan offers prayers and sermons if they're requested. But what she's found people want most often is simply a compassionate presence as they do the "spiritual work of dying" — finding or making meaning of one's life. Her critically-acclaimed book, On Living (Riverhead Books, 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.

3 **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.

4 **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) with you on your next visit. ✻

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*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.*

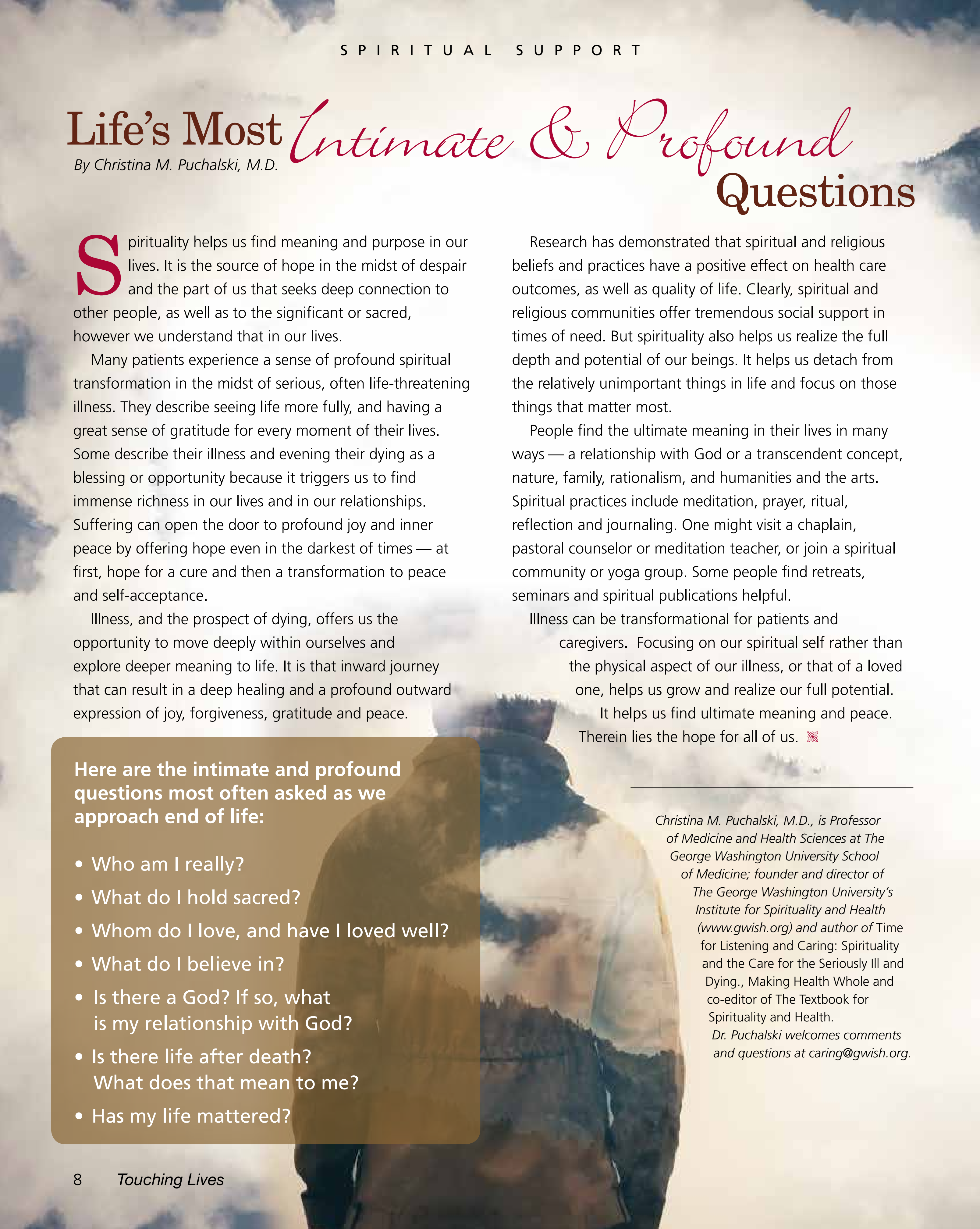
# It Takes a VILLAGE

*By Paula Spencer Scott*

Hospice 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. ✻



# Life's Most *Intimate & Profound* Questions

*By Christina M. Puchalski, M.D.*

Spirituality 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?

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*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) 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.*

# The Power to Embrace Life

by Allen Klein

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

> 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

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. ✱

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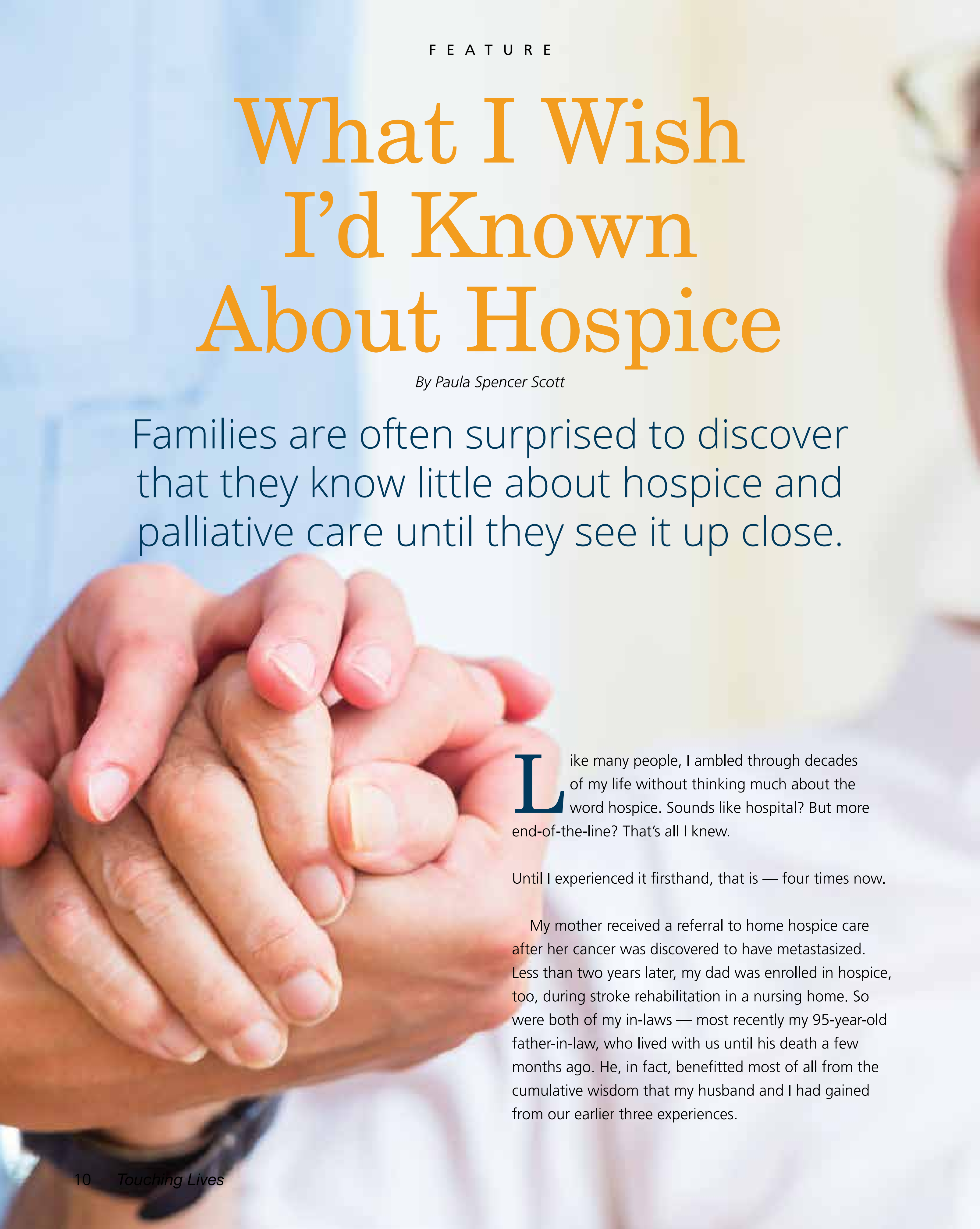
*Allen Klein, MA, CSP, is an award-winning professional keynote speaker and best-selling author (www.allenklein.com) of* Learning To Laugh Even When You Feel Like Crying.

FEATURE

# 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.



Like 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.

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 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 ▶

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 guestimate 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. ✻

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*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?**

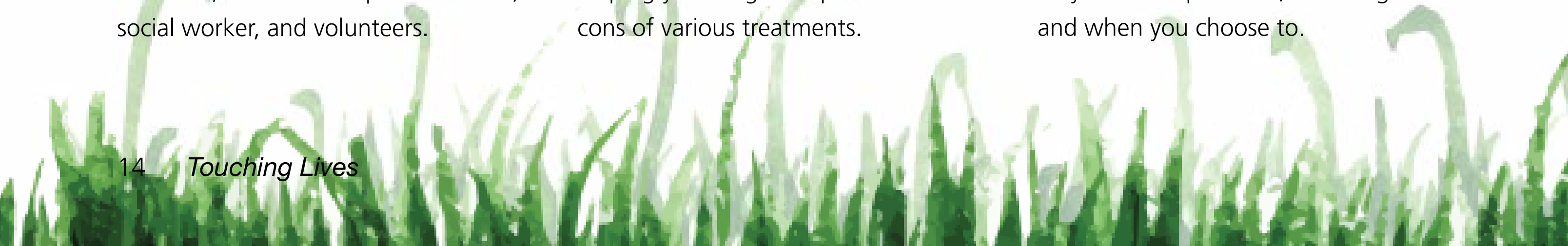
**A.** Yes, of course. But palliative doctors have special training and expertise in pain management and symptom control, and specialize in helping patients and their families cope with the many burdens of a serious illness, from the side effects of a medical treatment to caregiver stress to fears about 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.*

*(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.

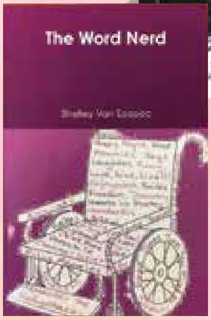
**What if the person doesn't want to talk?**

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. ⁂

# The Art of Creative Healing

*Shelley Van Scoyoc and Dana Rummery*



Shelley Van Scoyoc is a poet. But she didn't become a poet until multiple sclerosis disabled her. Shelley's art form of choice is her words, and she dreamed of being a published author before she died. As the art therapist for Main Line Health Hospice, I had the opportunity to support her on this journey. During art therapy sessions, Shelly could express her struggles, joys, and feelings to family and friends through poetry. For our last session together, we organized a book signing event. Her published books surrounded Shelley as friends and staff came to read her work and congratulate her on her accomplishment. Art therapy helped shape her creativity into a form that she could share with others.

The hospice philosophy focuses on improving quality of life, and art therapy helps give that focus a form. It is often a way for patients and families to connect with an important part of themselves that can be forgotten due to illness. While I often hear, "I'm not an artist" or "I haven't made anything since I was a kid," I work with patients and families to focus not on how good they might be at making things, but rather on its benefits. Creating with family can build lasting positive memories during a difficult time.

Art therapy in the hospice setting is as varied as the people who use the service. Patients and families find ways to express emotion, relieve loneliness, create legacy projects and simply have some fun.

That was the case for Maribel Rivera. Maribel worked with her grandchildren on making pillows. Inside their pillows she placed hearts with special messages she wrote to each of them. Her grandchildren did the same for her, and placed them in a pillow that she kept. Maribel said that making the pillows with her grandchildren was one of the best days of her life.

The most rewarding part of working with patients for me is hearing how our time together brought meaning. One patient, Eileen Doyle, shared this: "Dana has allowed me to really express myself in so many ways. You may not even know what is inside your heart, but once it comes out, it is yours forever. It has been the best medicine in the world for me."

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*Dana Rummery MA, ATR-BC, LPC is an art therapist for Main Line Health Hospice.*

> "I've enjoyed art therapy so much. Being confined to the bed, I find it rewarding to make something to give people for birthdays, Christmas, Valentines, or Easter. It makes me feel happy. I am going to keep at it!"
> – Jean Hemcher, patient

MAIN LINE HEALTH HOSPICE

# Choosing the Right Care

When faced with serious illness, it is important to know your options for care at home. Main Line Health HomeCare & Hospice offers care choices designed to meet your individual needs. Care options have recently expanded to include a special Palliative Care program, designed for those facing advanced or progressive illness. Understanding these different choices allows you or your loved one to receive the right care at the right time.

| | **Traditional Home Health Care** | **Palliative Home Care** | **Hospice Care** |
|---|---|---|---|
| **Goals of Care** | Curative or Rehabilitative primarily focused on medical needs. | Life sustaining or rehabilitative focus combined with an extra layer of support and expertise. | Holistic approach focused on comfort and enhanced quality of life for patient and family. |
| **Criteria for Admission** | Must be under the care of a physician, confined to the home, and require intermittent skilled services to promote or maintain health status. | Same eligibility criteria as traditional home health care. Designed for those with life limiting illness, who may be receiving life prolonging treatment. | Provided to persons with a life expectancy measured in months rather than years. Does not need to be confined to the home. |
| **Who Provides the Care** | A team of home care professionals including nurses, social workers, home health aides, dieticians, and therapists in collaboration with your physician. | A specially trained team of hospice and palliative care experts including nurses, social workers, home health aides, dieticians, therapists and chaplain, together with your physician. | A specially trained team of hospice and palliative care experts including your physician, hospice medical director, nurses, social workers, spiritual counselors, hospice aides, dieticians, therapists, and volunteers. |
| **What is Covered** | Skilled services as listed above. Must qualify for equipment. Medications not covered. | Skilled services as noted above. Must quality for equipment. Medications not covered. | All services, equipment, supplies, and medications related to the hospice care. Short term inpatient care, respite care, and bereavement support for family is also covered. |
| **Who Pays for Care** | Medicare, Medicaid, and most insurance companies. | Medicare, Medicaid, and most insurance companies. | Medicare, Medicaid, and most insurance companies. |

Please call Main Line Health HomeCare & Hospice at 1-888-533-3999 and our staff can help you decide which service can best meet your needs.

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