

A Publication of  
Valor HospiceCare & PalliativeCare

# Touching Lives™

*Holding Hands. Holding Hearts.*

## What People Really Want

Is Illness  
a Spiritual  
Journey?

Why We  
Need to Care

Finding the  
Comfort Zone

Learning  
to Listen



Valor  
HospiceCare  
& PalliativeCare

*Providing the Gift of Peace, Comfort and Dignity*

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## Welcome to *Touching Lives*



Dear Reader,

We plan for weddings, the birth of a child, college and retirement. Sometimes we spend months planning for vacations. Many Americans even plan for more difficult situations, by writing wills, purchasing life insurance and giving consent for organ donation.

Yet far too many people wait until they are in the midst of a healthcare crisis before determining what options are available, or what care they or their loved ones would have wanted. If these plans have not been discussed, families find that a difficult situation can become even more painful.

Only 10 percent of us will die suddenly. The other 90 percent will be aware that we have most likely begun the final phase of our lives. Hospice is here to provide guidance and support through that journey.

Valor HospiceCare & PalliativeCare's vision is to be the recognized experts in hospice and palliative care in the communities we serve. Our growth is directly related to recruiting excellent staff and volunteers who are extremely passionate about providing exemplary home hospice care. We thank the community for making us one of the largest, most respected organizations in Southern Arizona.

With less than 20 percent of Medicare beneficiaries utilizing their hospice entitlements, we are focused on providing intensive community education programs to ensure that everyone is fully aware of our wonderful services.

As we continue to grow our home hospice service areas in Arizona and the Southwest United States, including planning for expanded physician palliative care programs, hospice house centers and the *Valor Institute*, we look forward to serving those in need. We hope that this *Touching Lives* magazine provides you valuable information for you and your loved one's life journey.

Warm regards,

Grant A. Rowe, MBA  
President



For more copies of this FREE *Touching Lives* magazine or to find out more about what services we can offer, call us at 1-877-615-3996.

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<b>Metro Tucson:</b> 1760 E. River Road, Suite 230 Tucson, Arizona 85718	<b>Green Valley/Nogales:</b> 1131 S. La Cañada Drive, Suite 103 Green Valley, Arizona 85614	<b>Sierra Vista:</b> 500 E. Fry Boulevard, Suite L-11 Sierra Vista, Arizona 85635
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# Making the Most of *Every Day*



**V**alor HospiceCare and PalliativeCare began serving Southern Arizona in 2005 with our first office in Tucson for service in Pima and Pinal Counties. Our first patient was on our service for one and a half hours and according to our patient's daughter, "Valor's care was wonderful in an extremely difficult time. I just wish our doctor would have referred us to hospice six months earlier." These comments are echoed everyday by families through our service evaluations.

We've recently added locations and teams in Green Valley and Sierra Vista to provide our unique programs to communities in Santa Cruz and Cochise Counties.

Medically-directed, our teams of physicians, nurses, social workers, spiritual care providers, certified nurse assistants and trained volunteers provide physical and emotional comfort during advanced chronic illnesses and through the final months of life.

Three years later, thousands of patients and families have received our quality care in Southern Arizona. Valor's unique programs have been created to enhance the level of care beyond the standards of traditional hospice services, including a palliative care program, new bereavement programs such as *Getting Ready to Go* and *Walking Through Jello*, an integrative therapies and medicine program and the *Valor Institute*.

Our *Valor Institute* was created to fulfill many needs by establishing a curriculum of comprehensive training with over 80-hours of module-based courses for new and existing staff. Further, it also allows for a framework for training area medical professionals with C.E.U. credits regarding key knowledge in the areas of evidence-based clinical guidance for hospice, palliative care, social services and related fields.

The company also collaborates with our hospice 501(c)(3) foundation to provide for areas such as indigent care, grants for employee education and for funding community outreach programs.

Led by our Medical team, our "Philosophy of Care" Charter is focused on outcome-based approaches to practicing medicine with an "integrative attitude." This alone is changing and enhancing the way hospice is organized, planned and delivered in our markets. As an innovative, academic-based leader in evidence-based approaches to palliative care, we are uniquely positioned to utilize cutting-edge research from our partnerships with universities to support the community. ❖

*"Valor's care was wonderful in an extremely difficult time."*





# Did you know...?

- Hospice Care is a covered benefit of Medicare Part A, Medicaid (AHCCCS) & most insurance companies.
- In the past year, less than 20% of patients who were diagnosed terminally ill in Arizona, actually utilized the hospice benefit.
- Over 95% of hospice patients receive this benefit FREE with NO out-of-pocket expenses for the diagnosis.
- Enrolled Medicare patients are entitled to a minimum benefit of \$4000 per month, including the coverage of medications, medical equipment and supplies directly related to the hospice diagnosis.
- Care is provided in the patient's home during normal business hours and on an on-call basis 24 hours a day, 365 days a year.
- Hospice patients may visit their primary physician for any symptoms not related to their hospice diagnosis. Non-hospice diagnosis related care is provided additionally by the patient's Medicare Part A & B coverage or other qualified insurance plans.
- Of the over \$240 billion spent annually by Medicare, less than 2% is used for hospice services (annual health-care spending in the US has topped \$2 trillion).
- People who receive hospice have a higher quality of life, lower medical costs and, according to a recent study, may live longer.

## Hospice Level of Care Service

When a referral is made, the admissions team, along with the patient's Attending Physician and Hospice Medical Director, will decide the level of care needed. The following levels as certified by Medicare include:

- **Routine Care:** Over 96% of all hospice care is provided intermittently in the comfort and security of the patient's home.
- **Continuous Care:** Only used for a period of crisis, this level of care is covered as necessary to maintain the patient at home.
- **Inpatient Care:** Utilized only in emergencies for pain and symptom management within a specialized inpatient unit or a contracted Medicare-certified skilled nursing facility or hospital.
- **Respite Care:** This level of short term care is used when necessary to relieve the family members or other persons caring for the individual.
- **Private Pay:** Arrangements can be made for additional palliative services beyond the plan of care.

# What People *Really* Want

By Stephen P. Kiernan

**T**he projector cast a stark question on a screen at the front of the room: “*Where would you want to spend the last days of your life?*”

The audience of 189 people did not gasp or recoil in any way. Instead, they bent silently over the wireless voting devices in their hands and pressed a button corresponding with one of the options on the screen before them: *at home, at the home of a friend or family member, in an inpatient hospice facility, in an assisted living facility, in a hospital or in a nursing home.*

The mere posing of such a question in a public forum shows how far America has come in facing the challenges of mortality today. The audience participating in this survey at a community college in Nashua, New Hampshire, was indisputably clear about what they want at the end of their lives: They do not want excessive treatment, misery or expense. They want their lives to end in the peace and comfort of home.

For a growing number of people, that ideal is increasingly possible because of the existence of hospice.

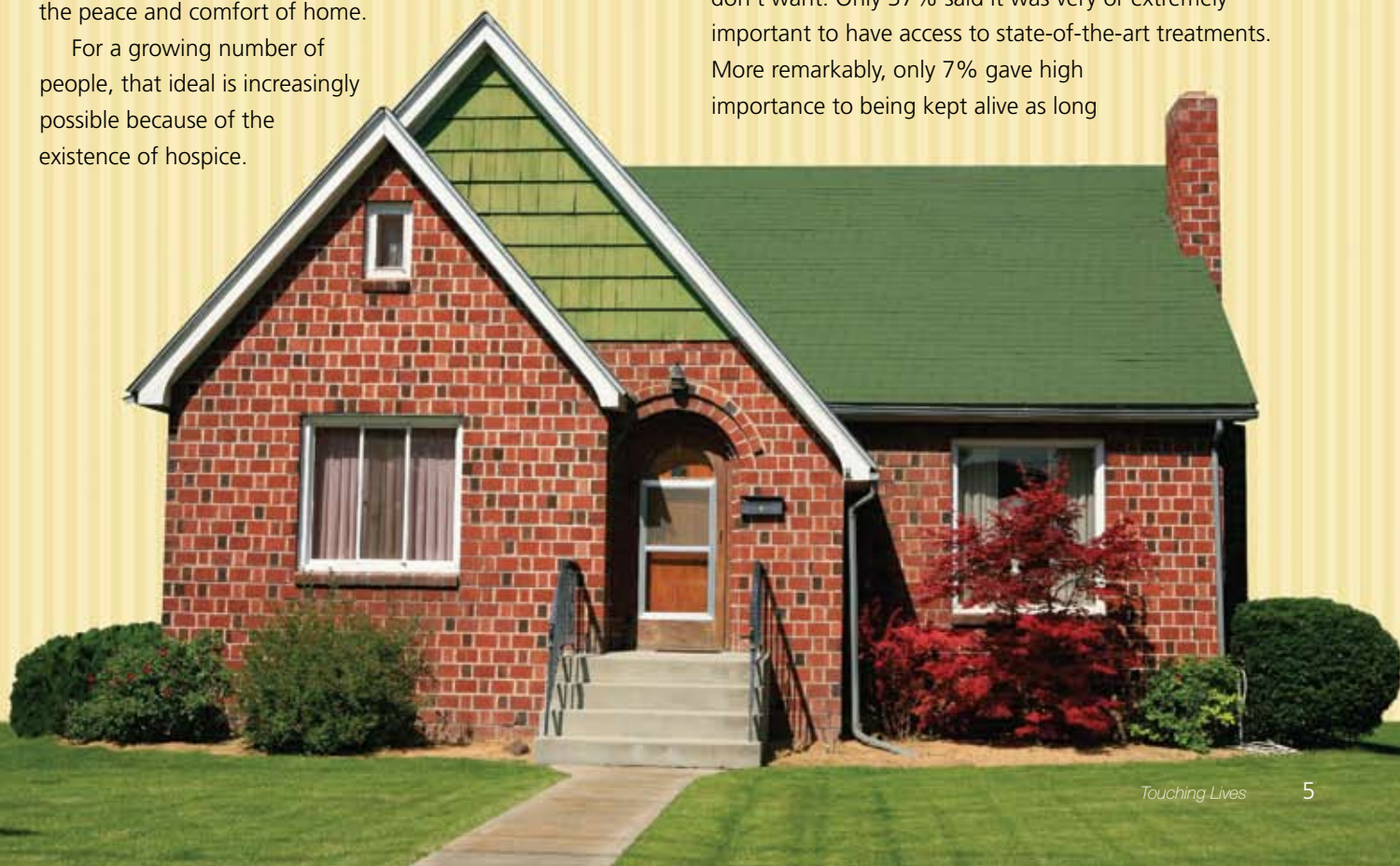
## Straight-talk about end of life

The audience that evening was one of eight forums taking a survey conducted by Reclaiming the End of Life Initiative, a New Hampshire-based project to build political activism over the care of people near end of life.

The results of the survey—that the vast majority of the participants want to spend their final days at home—should inspire hospice advocates and offer insight as to what people *really* want in their final days.

Ninety-six percent of the participants also said that clear communication from their medical caregivers is very or extremely important to them; 91% said having their pain controlled was very or extremely important. Essentially, people said they can handle the truth, and they want access to the excellent pain medications that are now available.

The participants were equally clear about what they don’t want. Only 37% said it was very or extremely important to have access to state-of-the-art treatments. More remarkably, only 7% gave high importance to being kept alive as long



as possible. Over and over, people favored dignity and control, over more tests and greater medical intervention.

As for the question of where people want to spend their last days, the results were stark: hospice care at home (71%), inpatient hospice facility (15%), home of a family member or friend (7%), assisted living facility (4%), hospital (1%) and nursing home (0%).

This order of priorities says some significant things about dying in America:

- First, it echoes how most Americans died a century ago—about three-quarters of them at home or with friends, rather than in a medical institutional setting.
- Second, what people want is the inverse of what they typically experience: Today, only 29% of Americans die at home.
- Third, a health care issue that has concerned visionary medical thinkers for some time has now reached everyday folks. In 1997, the Institute of Medicine of the National Academy of Science declared that America was approaching a crisis in the care of people who are dying. Too many people, an Institute report said, endure needless physical pain and preventable emotional suffering.
- Fourth, the hospitals of the nation need to take note: Resources that people count on in emergencies are simply not desired when someone is in the final stages of a chronic disease. For people dying of slow causes like cancer and Alzheimer's disease, the critical care model—using all available treatments, prolonging life regardless of its quality, treating dying as a failure rather than an inevitable life passage, sparing no expense regardless of the eventual outcome—is no longer what patients and families want.
- Fifth, even though more Americans are likely to die in nursing homes, no one in this survey wanted that end for themselves. The gap between the quality of care and the public's standards appears to be vast.

Above all, a growing number of people are embracing the hospice philosophy. Numerous studies have found that the

hospice care model vastly improves the likelihood that people will indeed finish their lives as they wish.

### The team approach

Hospice provides medical care foremost, but it is more than treatment. Rather, hospice is a philosophy of care that emphasizes immediate attention to a patient's comfort

rather than exhaustive efforts to find a cure. For example, about 2% of patients in hospice care experience physical pain at the end of their lives, compared with 48% in hospitals.

But hospice's aim goes beyond the patient's physical predicament. Many people have unfinished, emotional business at the end of their lives: relationships to be mended, apologies to be said, forgiveness to be offered, last

wishes to be fulfilled, spiritual doubts to be assuaged. Sometimes, making peace with an estranged relative is more important than any medical concern.

To address needs like these, hospice involves a team of doctors and nurses, as well as clergy, social workers, family members and friends. While regular medicine concentrates exclusively on a patient's physical ailments, in hospice the whole person receives care. And interestingly, in light of the survey preferences, 76% of the people who live their last chapter in hospice care do complete their lives at home.

People do not want to end their lives at home out of whimsy, or denial of their real medical needs. If anything, the survey results imply the opposite. When calmly considering the fact of their mortality, the vast majority of people are not interested in fighting for every last possible second.

They would rather finish life as they have lived it—in their own bed, with their art on the walls, their loved ones nearby, the family dog underfoot, their favorite music playing and, from the kitchen, the scent of something good on the stove. ✕




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*Stephen P. Kiernan is the author of Last Rights: Rescuing the End of Life from the Medical System.*

# Finding the Comfort Zone

By Maggie Callanan

**H**aving developed an amazing skill for identifying his visitors by their footsteps, Danny called out triumphantly, “Here comes Nurse Ratched!”

I chuckled as I walked down the hall. The brain tumor that had destroyed Danny’s sight early on could not overcome his irrepressible humor.

“Who do you look like today?” he asked, as he did on every visit.

“Pamela Anderson,” I replied with a grin, which delighted my 25-year-old patient. Last time, it was Elizabeth Taylor.

Identifying where I was by my talking, Danny pulled a water pistol out from beneath the covers and blasted me as if I were a bull’s eye. My gasps of disbelief seemed to be the highlight of his day.

“I did it! I did it!” he yelled in delight. I blotted the water from the front of my blazer, now realizing why he had asked to see me at the end of the work day instead of our usual morning visit.

“OK, Danny, you’ve just declared war! So buckle your seat belt, fella. We hospice folks have our ways!” I announced dramatically, trying to remember where to buy a whoopee cushion for my next visit.

“Ohhh nooo, not war!” he said with glee.

Is this a fine example of the expertise hospice brings to its patients and families? No. Does it represent the best nursing techniques I have to offer after years of education? No. Does it change the fact that this wonderful young man is dying from an aggressive tumor in his brain? No. But does it help Danny feel better? Absolutely.

Laughter can release endorphins (known as the “happy hormones” in the brain) that contribute to a sense of well-being. And beyond that, for a few moments in time, Danny and I stepped out of our roles and enjoyed a little break from the relentlessly unwelcome tragedy that had been forced upon him.

For a brief time, he was once again a young man known for his crazy practical jokes. And, for another moment, he

had the upper hand against his raging cancer. Now my team and I would add a new dimension to his Plan of Care—one that involved plots and plans, “partners in crime,” and lots of laughter.

It is commonly recognized in hospice that people die as they live. The personality traits or style we seem to be born with, help carry us through the ups and downs of life. This style intensifies as we face our ultimate life challenge—dying.

So, basically, nice people get nicer. Busy folks get busier, even if only in their dreams. Quiet patients may become more introspective and thoughtful. Demanding people often increase their expectations of others. Manipulative ones might surpass their past controlling behaviors. And, as with Danny, funny people look for humor in the face of tragedy, and in the most interesting and amusing ways. In this way, they ask us to participate in lightening their burden—even for just a few minutes.

Understanding these dynamics helps clinicians, families and friends better understand how to deal with the unique needs of each patient—patients who are simply trying to live as long as they can, and as well as they can, according to their own unique style and comfort level. That is what we do. That is what makes us different. That is why we’re hospice. ❖

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*Maggie Callanan, R.N., is the author of Final Gifts and Final Journeys, and has specialized in the care of the dying since 1981.*



# If



# You're

# Thinking



# of Hospice

By J. Donald Schumacher, Psy.D.



## **How is hospice different from the typical care I might get in a hospital?**

Unlike a hospital, hospice is not a place. It is a special kind of care that occurs wherever the patient needs it. Hospice does not focus on curing but helps people live as fully as possible up until the end of their lives.

Hospice and palliative care involve a team approach to expert medical care, pain management, and emotional and spiritual support, tailored to a person's needs and wishes. Support is provided to the patient's loved ones as well.

About 80% of hospice care takes place in the home, which research has shown is where most Americans would prefer to spend the final part of their lives. Hospice works to make this happen:

- Hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.
- Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion or race; hospice is available to people with any life-limiting illness.

## **Does it mean a person has "given up" if they choose hospice care?**

No. In fact, a study published in the *Journal of Pain and Symptom Management* (September 2004) found that hospice patients lived longer on average than patients who chose curative care. This ranged from 20 days for those with a diagnosis of gallbladder cancer to 69 days for breast cancer patients.

More than 1.3 million Americans with a life-limiting illness were served by our nation's hospices last year—a number that continues to grow as more families discover the value of hospice care.

## **Who pays for hospice?**

Hospice care is covered under Medicare, Medicaid, most private insurance plans and other managed-care organizations. If a person does not have insurance coverage, the hospice will work with him or her and the family to provide the needed services. Under Medicare, the family may be responsible for a small co-payment for outpatient drugs and inpatient respite care.

### What services does hospice provide to the patient and family caregivers?

Among the major services the hospice interdisciplinary team provides are:

- Easing the patient's pain and symptoms—hospice professionals are experts at this;
- Supporting the patient with the emotional and spiritual aspects of dying;
- Providing needed drugs and medical supplies and equipment to the patient in the home;
- Teaching the family about the best ways to care for their loved one;
- Delivering therapies such as speech and physical therapy, when needed;
- Making short-term, inpatient care available when pain or symptoms become too difficult to manage at home or when respite time is needed; and
- Providing grief support to family and friends.

It is important to know that different hospices may have different services available. If there is more than one hospice in your community, you may want to call and ask what services they would offer for your family's situation.

### Is hospice available 24 hours a day, seven days a week?

Yes, members of the hospice team make scheduled visits and are available by phone as well. Even if the administrative office has closed, hospice is available by phone seven days a week, 24 hours a day. Staff can make a visit, if needed, at night or on the weekend.

### What happens if I cannot be cared for at home?

While most hospice care is provided in the patient's home or the home of a family member, a growing number of hospice programs have their own facilities or have arrangements with nursing homes, hospitals or inpatient centers, for people who cannot be cared for at home.

### How does a family arrange for hospice care?

Many people begin by talking with their doctor, and he or she can make a referral. However, anyone can call the hospice to ask about services and request a visit.

No matter who calls first, the family or the doctor, the hospice staff will immediately set up an initial meeting to review the patient's symptoms and care needs, discuss the services they can offer, and review the consent forms needed for care to begin. Usually, care starts within a day or two of a referral. However, in urgent situations, service may begin sooner.

### When is the right time to start thinking about hospice care?

As soon as you find out you or a loved one is facing a serious illness, you should learn about the benefits of hospice care. People plan for weddings, the birth of a child, college and retirement; rarely if ever do we plan for what we would want in the final phase of our lives. Far too many people wait until they are in the midst of a serious medical crisis before thinking about what options are available or what care they or their loved ones would want. It's never too late to talk with your family and loved ones about the care you would want.

Your local hospice, as well as programs like the National Hospice and Palliative Care Organization's Caring Connections, can help you with information about care options and choices that will ensure you live as fully as possible, throughout your entire life. ❧



Staff can make a visit, if needed, at night or on the weekend.

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*J. Donald Schumacher, Psy.D., has 25 years' experience in hospice and palliative care leadership. He is president and CEO of the National Hospice and Palliative Care Organization, the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the world. NHPCO's Caring Connections program offers a range of educational materials and information about serious and life-limiting illness, hospice, and care planning. Visit Caring Connections online at [www.CaringInfo.org](http://www.CaringInfo.org) or call the HelpLine at 800-658-8898.*

# Why



# We Need to Care

By Ira Byock, M.D.

*People* who are being cared for with help from hospice at times may feel discouraged about the unwanted turn their lives have taken, or depressed about becoming dependent on others.

Such feelings are normal, but that doesn't make them any easier. For some reason, our modern culture can make people who are ill and in need of help, believe they have lost all worth and value.

"If I continue to get weaker, I'm afraid I'm going to become a burden to my family," is a sentiment I hear a lot. The feelings are real, but the assumptions that underlie them are false.

The truth is that we are inherently connected to the people we love. One person gets a diagnosis, but an entire family experiences illness. When someone we love hurts or is struggling, we suffer, too. At various times in life, we are burdens to one another. It's no one's fault. In fact, if you are looking to assign blame, I suggest that love is at the root of this dilemma.

If you are the one who is ill, you may want to protect your loved ones by not talking about your problems, but you can't stop them from worrying about you. You may resist their offers of help because you don't want to disrupt their busy lives. But as a physician who has been practicing in hospice and palliative care for 30 years, I promise you, their lives are already disrupted.

If you've been keeping your worries to yourself, your family has probably been keeping their feelings under wraps as well. In palliative care, we call this the "conspiracy of silence," and it's an all-too-common cause of unnecessary suffering.



# Cora's Story

Cora is 78 years old and looks as if she has spent most of those years out of doors.

The sun and wind have etched lines in her eyes and mouth that give the impression of smiling, an indication of the feisty determination with which she has lived. When her husband became physically disabled after an injury at age 38, Cora held down a full-time bookkeeping job, while doing most of the chores on the small dairy farm they owned in northern Vermont.

I came to know Cora (not her real name) as our palliative care team helped her cope with the effects of chronic lymphoma. We were able to treat her pain, yet she was gradually becoming weaker. Eventually, the lymphoma would claim Cora's life—but not for a while.

At the time of our conversation, she had been hospitalized for two days with pneumonia, which had rapidly improved with IV antibiotics and was nearly ready for discharge. She was getting physically stronger every day, but her spirit was at an all-time low.

Cora usually bantered with me, teasing me about growing up in New Jersey and

wanting to know if I was a "shyster." That afternoon, her mood was somber. I told her that it was probably no longer safe for her to be at home alone.

Her eldest daughter and son-in-law had repeatedly asked Cora to come live with them in southern Vermont, but she resisted. Mostly, she said she just wanted to stay in her own home. Sitting in the recliner chair in her hospital room, Cora confided in me, "I'm worried that I'll become a burden to my family."

I decided to respond to Cora with gentle humor. "You needn't worry," I said. "I assure you, you already are."

She chuckled and wryly smiled. "Oh, thanks a lot. That makes me feel much better." The old sparkle returned to her eyes.

I explained to Cora that her family already owned her illness. "How could it be otherwise? Your children love you, and it's natural for them to worry about you. Do you really think it is easier on them with you so far away, living by yourself? The truth is, what they may need most is to take care of you."

She listened thoughtfully. "Cora," I continued, "didn't you tell me you had cared for both of your parents during the last part of their lives?"

"Yes." She nodded.

"And you cared for your husband for nearly 10 years, including the months before his death. Was that important for you to do?"

Nothing I said or asked that afternoon

There is something inherently healing in sharing troubled feelings with people we love. When people have a chance to comfort one another, perhaps even cry together, their fears and darker feelings lose power and occupy less space. It's not something that is forced or even intentional—it just happens. Laughter, joy, even just plain silliness, simply cannot be suppressed forever.

When you've confronted the tough things, the time you spend together takes on an air of celebration. There is a sense that each day together is a gift. It may be a ride in the country, or watching a movie or ball game, or sharing a

cup of tea, but each moment together has its own inherent value. It always has, of course. But the busyness of our lives often makes it difficult to appreciate how much we mean to each other.

In the midst of serious illness, love can be the cause of the pain we feel, but it is also the cure. ❧

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*Ira Byock, M.D. is director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in New Hampshire, a professor at Dartmouth Medical School and the author of *Dying Well* and *The Four Things That Matter Most*.*

moved Cora as much as that question.

"Yes, it was really important." She nodded again.

"When your children were born, they required hours of care and kept you up many nights. Wasn't that a wee bit of a burden?" She kept my gaze but wasn't going to concede the point.

"And when your husband was injured and you became the breadwinner for your family, as well as tending the farm, all the while caring for him—wasn't his condition and need for help a burden?"

"Never for me!" she shot back.

"How about for him? Did he ever express feeling that he was a burden on you and your family?" She looked down and, after a moment, nodded as if in a conversation with herself.

"Yes, he did," she said. "For me, it just wasn't even a question. I loved him and did what I had to do."

"Cora, my sense is that you have just described how your daughters feel now. You are their mother, and they want to care for you. The fact is, they need to care for you, for their own emotional well-being. Their worst fear is having you die alone, maybe even on the floor of your farmhouse, with them miles away, unable to help.

"Like it or not," I continued, "you and your family are in this together. Their lives are already disrupted by your illness. You can't fix that, but you can help make the

best of it. Consider that just possibly the best thing you can do for your children and family is to let them take care of you. They may need to pamper you just to express their love." I paused, before adding, "And there are still lots of things you can do for your family that no one else can do."

**“THE  
FACT IS,  
*they need to care  
for you, for their  
own emotional  
well-being.*”**

"Like what?" she asked with a skeptical expression; she'd been fooled by guys from Jersey before.

"For one thing, you can tell your stories. Maybe your daughters know the details of

your life, but do their husbands? Have your grandchildren heard the history of where you grew up, who your brothers and sisters were, your best friends? Can they even imagine what your school was like, or your first job? Do they know the story of you and your husband meeting and falling in love?

"You get my point. These are your stories, but in a sense, they are theirs, too. Often, we help people record their stories, usually just with a microphone, sometimes with the help of a family photo album."

"Boy, you're good! You could probably sell snow to the Eskimos." She shook her head and laughed. I noted that her remark changed the subject. Teasing me allowed her to avoid agreeing to anything.

Still, something began to shift within Cora that day. I telephoned her a couple of weeks after she left the hospital just to hear how she was doing. She said, "As well as you could expect, I guess." The friendly sarcasm in her voice let me know she was glad I called.

She's allowed more paid help into her home. One daughter is now staying with her on weekends. And, yes, she's begun recording some of her stories with her hospice volunteer.

I asked her whether it was hard for her to accept help from her daughters since she was so used to living independently.

"I don't like it," she said, adding, "But I guess that's life."

# Is Illness a Spiritual Journey?

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 divine or sacred.

Some religions believe that illness and dying can be a blessing 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 life's most intimate and profound questions:

- *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?*

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 comfort in retreats, seminars and books on spirituality.

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. ☮

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*Christina M. Puchalski, M.D., is associate professor of Medicine and Health Science at The George Washington University Medical Center; executive director of The George Washington 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. Dr. Puchalski welcomes comments and questions at [caring@gwish.org](mailto:caring@gwish.org).*

# Why Caregivers Become Volunteers

By Beverly Crowl

Margaret's experience with the hospice team that cared for her husband, Tom, was so profound that it transformed her fear of hospice into a lifetime commitment as a hospice volunteer.

"Making that first call to hospice for help with Tom was like taking a giant step into a dark and scary abyss," recalls Margaret. "What a marvelous surprise to realize we had fallen into the arms of angels!"

More than 400,000 volunteers provide 16 million hours of service in U.S. hospices. Like Margaret, many of them became volunteers after a personal experience.

For Margaret, the urge to volunteer stems from a deep sense of gratitude and a wish to give something back to the organization that met her family's critical physical and emotional needs so completely.

Margaret recalls how, at first, she and Tom didn't want strangers in the house. But once they made that call, their hospice team responded immediately with compassion and love that transcended any sense of having "strangers" in their home.

"Our nurse, Robin, was a ray of sunshine, who always brought a smile to Tom's face as she checked his progress, replenished medication and patiently guided us through the phases of his illness," Margaret says. Robin made the couple feel as though they were her only responsibility, and her level of care never waned, whether she came by early in the day or on her last stop of the evening. "She laughed with Tom and cried with me, and her hugs got me through many difficult days."

Carla, their nurse's aide, helped with personal hygiene. Initially, Tom, with his strong modesty issues, resisted her care, but that didn't deter Carla. She always came at her appointed times and helped out as much as he would allow. Eventually, she was able to fully tend to Tom's care and always treated him with the utmost dignity.



"It wasn't easy for us to talk about our situation in the beginning. Each of us avoided upsetting the other, by carefully sidestepping around issues, until Tim appeared as our hospice chaplain. With each visit, he gently encouraged us to share our thoughts and enabled us to find peace and true comfort," Margaret recalls.

The expert, sound advice of Cheryl, the hospice social worker, carried them through many rough spots, as they dealt with emotional and practical family issues. "She kept us grounded and sane through it all."

Equally important, Sam, a hospice volunteer, shared Tom's passion for fishing and hunting. He effortlessly lifted Tom's spirits as they swapped stories during Sam's weekly visits. Those priceless hours also allowed Margaret to venture out of the house for some shopping or relaxation.

"We didn't know much when faced with Tom's illness, only that he wished his final days to come gently at home. Our hospice team enabled us to fulfill that wish and more, as we spent our most precious moments together, free of fear and reveling in the special love we had for each other."

Margaret says she will be forever indebted to hospice care. "My decision to become a hospice volunteer serves as a very small reimbursement to that huge debt. And that itself is offset by the joy I get from my volunteer work. You always receive more than you give when you are able to somehow ease the burden of a family who bravely 'makes that call.' " ❄

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*Beverly Crowl has 25 years' experience as a writer and editor in corporate, academic, scientific and nonprofit venues.*

# Learning to Listen

By David Kessler

**R**ichard Phillips and his sister Paula greeted me as I stepped off the elevator on the second floor of the hospital where their mother, Frances, was being treated for advanced cardiac disease.

"My mother can't talk about the fact that she's dying," Paula said, as we sat in the sparse hospital family room.

"Our mother is incredible. She's a true survivor," Richard began, recalling how she worked at JC Penney to support her five children when their father left.

"After all that," Paula said, in tears, "I can't believe that she could be leaving us now."

"I'd like to meet her," I said. As they walked me to the room, they cautioned me, "Remember, she doesn't know she's dying."

I saw Frances Phillips' blue eyes light up as her children introduced me. When they left to go to the cafeteria, she looked at me as if to let me in on a secret.

"If you're here to tell me I'm dying, I know. Nobody wants to die, but it's not like I didn't know this was coming at some point. It's amazing how people talk around it." She smiled and said, "I bet you can talk about it."

Indeed I could, I told her. Then I asked if I could tell her family that she knew she was dying and could talk about it.

"I guess it's time," she said, as if the charade was up. When Richard and Paula returned, we went into the hallway.

"She knows she's dying," I told them. "She knew long before I got here."

"Our mother, who can't talk about dying, told you, a complete stranger, that she's dying?" Richard said.

"Maybe because I'm a complete stranger, it's easier for her," I replied.

"Well, what do we do now?" Paula asked. "Do we still tell her to try to get better? Or do we say, 'Sorry you're dying?' Now I'm more confused than ever."

"Maybe you can say something like, 'Mom, I hope you can make it through this, but if that isn't meant to be, I'm here, whichever way this road goes.' "

## When you don't know what to say

Like Frances' children, many of us are unsure what to say to the dying. We are afraid what we say will be either too threatening or too trivial. We wonder if talking about the things they loved to do will cheer them up or make them sad.

It's fine to say, "I don't know what to say to you." And it's all right to talk about dying. Avoiding a conversation about death won't make it go away, but talking about it can bring life into your relationship.

Listening is a powerful way to offer comfort. Listen to them complain. Listen to them cry. Listen to them laugh. Listen to them reminisce. Listen to them talk about death.

Remember the days when we would take family members to the airport and wait at the gate until they left? And when they returned, we'd meet them at the gate, not curbside or in the baggage claim area.

The concept of "walking to the gate" symbolizes the way we should approach life and death. Today's newborn is "met at the gate" by his father in the delivery room, not in the waiting room. We should do the same for the dying.

We walk our loved ones to the gate when we bring them home to die. We walk them to the gate when we let them know we will be with them. We finish our unfinished business when we say what needs to be said. We cry with them and for them, and we hold their hands as we walk them to the gate. ❧

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*David Kessler is a hospice director of Palliative Care in Los Angeles and author of The Needs of the Dying and co-author with Elisabeth Kubler-Ross of Life Lessons and On Grief and Grieving.*



# What is Palliative Care?

**V**alor HospiceCare & PalliativeCare is accepting the challenge of open access by extending services to patients, family members and caregivers.

Palliative (pronounced pal'e - a tiv) care is medical care focused on relieving suffering and improving the quality of life for anyone dealing with a serious illness, at any time, regardless of diagnosis, prognosis or treatment. Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process.

## Physician Palliative Care Evaluation Services

Palliative medicine evaluation services are available to assist community physicians for patients in physician practices, private homes, adult care homes, assisted living facilities, skilled nursing facilities and hospitals. Upon request, a Board Certified in Hospice & Palliative Care Physician will make a patient visit to assess complex symptoms and discuss findings and suggestions with the requesting physician.

These evaluations are available for all patients, regardless of age, and are not limited to those patients considered hospice-appropriate.

Benefits include:

- Diagnosis and Prognosis Discussions to Determine Hospice Eligibility
- Pain and Symptom Management
- Developing Goals of Care based on a Holistic Attitude Towards Care
- Preparation and Management of the Dying Process
- Advance Care Planning
- Issues with Other Aspects of Care that Affect Quality of Life
- Interdisciplinary Team Approach of Physicians, Nurses, Social Workers, Spiritual Care Providers, Other Hospice Professionals and Volunteers

We have also partnered with local and national commercial insurance firms to provide services for new programs that follow Medicare Advantage services. Please contact us for eligibility.

Pre-hospice evaluations are fully covered by Medicare Part A, Medicaid (AHCCCS) and with prior approval, most commercial insurance companies.

## Future Palliative Care Services

Additional Valor PalliativeCare Programs are in development for seeing and following patients with other physicians and nurse practitioners and at nursing homes, assisted living facilities and hospitals. In the meantime, if patients are not eligible to receive hospice services at this time or are in need of palliative pain and symptom management, Valor will coordinate care with our authorized, qualified geriatric and long term care groups.

## Interactive Website

Please visit our website, [www.valorhospicecare.com](http://www.valorhospicecare.com) for information on hospice and palliative care services. ✂



Photo by Scott Taras

# Frequently Asked Questions



## ■ *Who is eligible for hospice care?*

A physician must certify that a hospice patient has an incurable illness and an estimated life expectancy of six months or less if the illness runs its normal course. The patient must agree to hospice care. We accept everyone who meets these criteria, regardless of the patient's financial situation or insurance coverage. The patient does not have to have family caregivers in the home.

## ■ *Can we keep our own doctor?*

Yes. If this is not possible or preferred, specially trained hospice physicians can assume patient care and treatment.

## ■ *Where is hospice care administered?*

The majority of hospice care is provided in the patient's home, with family and friends acting as caregivers. If there is no private residence, the hospice can provide resources to assist the family with locating nursing homes or other types of care facilities.

## ■ *Does most hospice care involve inpatient care in a facility?*

In the case of patient emergencies, less than 3% of hospice care involves inpatient hospital or skilled nursing facility care.

## ■ *What if the patient's condition improves?*

Occasionally, hospice care can lead to improved life expectancy. When this happens a patient can be discharged from the hospice program. Later, when a patient becomes eligible for hospice, they can re-elect the hospice benefit and be admitted to the program again.

## ■ *Do hospice medical directors have specialized training?*

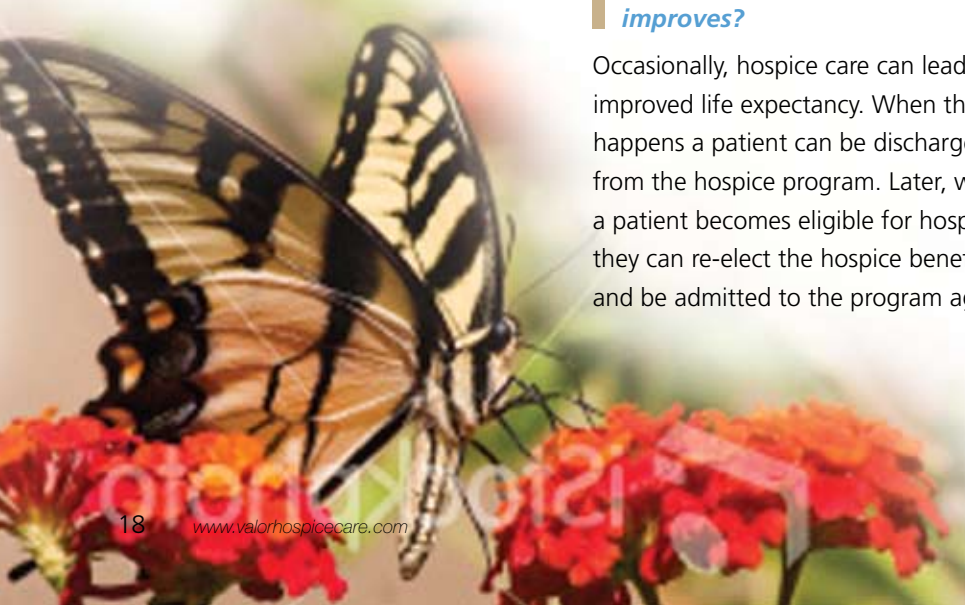
Our Medical Director and Associate Medical Directors are board certified. All of our medical directors participate in ongoing training, research and education to keep their knowledge current.

## ■ *Does the hospice staff address pain that is not of a physical nature?*

We recognize that not all pain is physical. We have spiritual care providers, social workers and bereavement counselors to address spiritual and emotional distress, not only with patients but also with their families and loved ones.

## ■ *Are all hospice and palliative care services the same?*

Hospice programs are the 'shining star' of the health care community. However, providing hospice and palliative care services can vary as much as hospitals, physicians, and other professional services. Our programs go beyond the standards of certification to provide exemplary care





from our staff and unique programs to support the varying needs of patients, caregivers and families. The best choice is to choose a Medicare-certified and licensed hospice and palliative care program for the comprehensive benefits that are offered.

***Are patients and family caregivers told how many visits they can expect from hospice staff?***

We provide a written care plan and establish a schedule of patient visits.

***Are medications and equipment delivered?***

Yes, we deliver to the home, nursing and long-term care facilities, or wherever the patient resides.

***Does hospice staff respect the patient's preferences for daily activities and schedules?***

We encourage patients to do all that they can to live life to the fullest and we provide care according to their wishes. ❄

## Bereavement & Memorial Services

Valor HospiceCare & PalliativeCare provides grief education and bereavement services to our families and the community. A comprehensive 13-month bereavement program is offered to family members and loved ones of the patients whom we have served. Support groups in various formats are offered to share your feelings and stories, including:

### **Walking Through Jello**

*Walking through Jello* is a 5-week class in various communities to teach skills to help process loss. It is based on learning to be aware and will address emotions, safe places to find support, attention to mind, body and spirit as loss is processed, respecting and honoring the past, hoping for the future and living in the present.

### **Getting Ready to Go - Exploring End-of-Life Issues**

Valor HospiceCare & PalliativeCare, in conjunction with local churches and health care organizations, provides all day Saturday *Getting Ready to Go* conferences on relating to end-of-life issues, such as: legal and funeral planning, health care options, hospice, pain control, organ donation, grief and bereavement, planning ahead and what to do when decline begins.

### **Bereavement Grief Support Groups and Memorial Services**

Monthly support groups are offered in all of our communities, as well as Memorial Services to recognize patients and families whom we have served. Please visit our website ([www.valorhospicecare.com](http://www.valorhospicecare.com)) for further dates and times.



*Teresa Wachala, Bereavement Care Coordinator with Memorial Service Mobile*



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