

A Publication of InFinity Care of Tulsa

# Touching Lives™

*Holding Hands. Holding Hearts.*

## Yes, A Time for Hope

In This  
Together

Sibling Rivalry  
...or Revelry?

Finding Grace  
and Peace

7 Ways to  
Celebrate  
A Life



Faith, Dignity, Comfort, Purpose...Infinite Care

[www.infinitycare.com](http://www.infinitycare.com)

# We will provide the right care, for every patient and family, every time.

**T**here are many misconceptions surrounding the Hospice Benefit, which prevent access to the support structure it establishes. Embracing hospice care is **not about giving up hope and does not mean that death is imminent**. It is giving up the burdens of pain and isolation, both for you as a patient, your loved ones and caregivers.

InFinity Care Of Tulsa provides end-of-life care that meets the physical, emotional, and spiritual needs of our patients and their families. Many of the caregiving responsibilities that fall to family members—such as bathing, grooming and dressing—can be shared with the hospice team. Getting Hospice involved as early as possible, means maximizing the support of the benefit. We help individuals live their lives as fully as possible.

We believe the emotional and spiritual journey in life is as significant as the physical. We are committed to providing care that supports and embraces the spirit, faith, and purpose of all patients and their families. We believe you can never have too much care and compassion, as these qualities help ease pain and heal hurting hearts.

At InFinity Care Of Tulsa, our number one priority is providing the right care for every person, every time. Our caregivers work together to provide physical, emotional, and spiritual care focusing on faith, dignity, comfort, and purpose.

## Hospice is Often Misunderstood.

- Hospice is affordable! Hospice care, including medications, medical equipment and supplies, is **100 percent covered by Medicare, as well as by most commercial insurances**.
- Hospice Care is for those who medical science cannot cure and choose to focus on maintaining the best comfort and quality of living with a terminal disease.
- Patients who live beyond six months, as many do, continue to receive hospice care when eligibility criteria are met with no maximum to number of days on hospice service.
- Hospice care is provided wherever the patient is currently living, whether in a home, retirement center, nursing home or hospital.
- Hospice even **supports patients and families in the ICU**, to assist with any and all clinical questions, counseling, resourcing and guidance.
- Hospice patients and their families remain in control of treatment. InFinity Care Of Tulsa works with the patient, the family and the patient's physician to develop an individualized treatment plan and deliver the most appropriate care to meet the goals of the patient and family. ✨

*Our Mission: To deliver high-quality, inclusive, and compassionate end-of-life care, serving humanity and supporting hope.*



## Letter from the CEO



Recently while discussing with my sister the death of a 49 year old friend, she commented the experience had taught her a valuable lesson regarding the need to have one's legal, financial, and healthcare decisions in order no matter of your age. Somewhat surprised to hear this from my sister, since I am a hospice owner and have had these conversations with my family members a number of times, the comment did

make me realize that it is usually when our self or someone we care about is hurting that a message really becomes relevant to us.

Most people never realize the relevance of stating their wishes in writing and sharing their wishes with family and their doctor. As hospice professionals who advocate for our patient's wishes, too often we begin hospice care with individuals who were never approached about these decisions, or if they were... "did not see the relevance." For those patients with a diagnosis of Dementia, by the time they are eligible for hospice, it is too late to cognitively make these decisions. And for others, the relevance of these decisions is often confused with "giving up," proving the studies which demonstrate the need for these discussions when we are not in a healthcare crisis. We know it is our responsibility to guide our patients and families through these decisions, and we do so with an open mind. It has been our experience that finalizing these decisions gives the patient a sense of empowerment and allows for every moment that follows to be truly appreciated and enjoyed.

Every year, on April 16th, we participate in "National Healthcare Decisions Day", which over the last 4 years has assisted more than a million people with executing Advance Directives. This national initiative is one of many opportunities for the public to better understand the "relevance" of stating in writing how they want to live should they become incapacitated, what medical interventions they want or do not want, and who if needed will make decisions for them as a "healthcare proxy."

Have you addressed this most important and valuable gift to those you love? If not, visit our website [www.infinitycare.com](http://www.infinitycare.com) and locate information which will help answer your questions, and assist you in moving towards empowerment...even if and when you are incapacitated. It is a true gift to your family, to know these decisions in advance and to be able to focus on the important moments to come.

Deborah Brazeal

Founder / CEO, InFINITY Care of Tulsa



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Why researchers say life's last chapter can be a time of optimism.

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# You humble me...

## A glimpse on the inside...

an email from InFINITY Care's Founder/CEO  
to the staff of InFINITY Care...

Sent: Friday April 1st, 2011 at 6:27pm

Title: You humble me...

To Every InFinite,

Before I leave the office tonight, I want to take a few minutes to express my heartfelt appreciation for your commitment to our patients, their families and to InFINITY Care of Tulsa. I have been brought to tears a number of times this week, as you worked alongside one another; volunteering for support care, visit coverage and going above and beyond to support the needs of our patients and families.

I have never felt so totally "in love" with the staff of InFINITY Care as I do at this moment, ending this week and looking towards next week. From the care each of you extended to every patient this week, to the extra care and time you spent with Mr. R.C., to the extra care and time you are spending with Mr. M.S. tonight...and the care you have shown to one another. I cry as I am writing this, because I know you feel what I do...that our patients are not just names...they are people, who once had hopes and dreams. They deserve to be treated with respect. But more importantly, they deserve to not be alone when they die. That is what we all deserve and should expect as our life journey ends.

We may not always find this work easy, but when our patients need us, I know you will make sure they receive the care they deserve. Thank you so much. I feel truly blessed to work with each of you...especially when things are hard. And I am so humbled by your commitment to being there when our patients' journeys end. You are truly the best, most compassionate hospice team in the world!

Have a blessed and restful weekend. My prayer for all of you is that you be kept safe by God's angels and restored by his grace when you are weary.

*Deborah Brazeeal*  
CEO, InFINITY Care of Tulsa



# In This Together

Three ways hospices help not only patients, but their loved ones, too.

by Paula Spencer

**M**yth about hospice care abound: That it's just for the last days of life. (People with a prognosis of six months or less are eligible, though there is no time limit, and it is not unusual for a person's health to improve while in hospice care.) Or that it's expensive. (Hospice care is covered by Medicare and private insurance.) Or that signing up means "giving up." (It doesn't!).

Here's one more misconception that you may be surprised to learn is untrue: That hospice is just for the dying person. In fact, **hospice care is designed to support the entire family at the end of life.**

Hospice is a special concept of care designed to provide comfort and support to patients *and their families* when a life-limiting illness no longer responds to cure-oriented treatments, according to the Hospice Foundation of America. "And their families" is no casual choice of words.

## Here are 3 ways hospice supports loved ones, too:

### Hospice helps relieve overall stress.

Most Americans have limited experience with terminal illness. Coping with difficult medical decisions, fear and worry, and great sadness—usually while trying to continue some semblance of everyday life—can exhaust anyone. A hospice team tackles the situation with diverse resources, both on site and a phone call away. Net result: Sadness obviously remains, but the shared burden means stress levels plummet.

Studies link hospice care to better quality of life not only for the terminally ill, but for their families as well. A 2010 study of more than 700 cancer patients, for example, found that those whose loved ones died in intensive care units

*(continued on page 16)*

# Sibling Rivalry...or Revelry?

How to set aside old habits and come together for a parent's care.

by Melanie Haiken

**C**oping with a parent's illness is hard enough. But in too many families, resentment, guilt, past problems, and hurt feelings among siblings amp up the stress level. "Every issue from the original family can come back into play," says Francine Russo, author of *They're My Parents Too: How Siblings Can Survive Their Parents' Aging without Driving Each Other Crazy*. "And as the parent's condition worsens, the feelings get more intense."

How to escape old rivalries in a crisis and come together for the common good?

## If You're the Sibling Who Lives Nearby...

### Understand that you all accept things at different paces

Someone who lives close to parents and sees them frequently may be more aware of their declining health. So when bad news arrives, it may come as a much bigger shock to more distant brothers and sisters. The opposite can also occur; a sibling who visits after an absence may pick up on a new symptom that you've grown used to without "seeing" it.

### Talk about who wants to know what, and when

When a parent's health reaches a crisis or decision point, when do your siblings want to be called? Do they want to be included in consultations with doctors and social workers,

possibly by conference call? Or are they comfortable with you making the decisions and relaying information?

Some distant siblings may want to be informed every time there's a new test result or medication change, while others may find that level of involvement overwhelming. Respect their wishes—but first you have to know them.

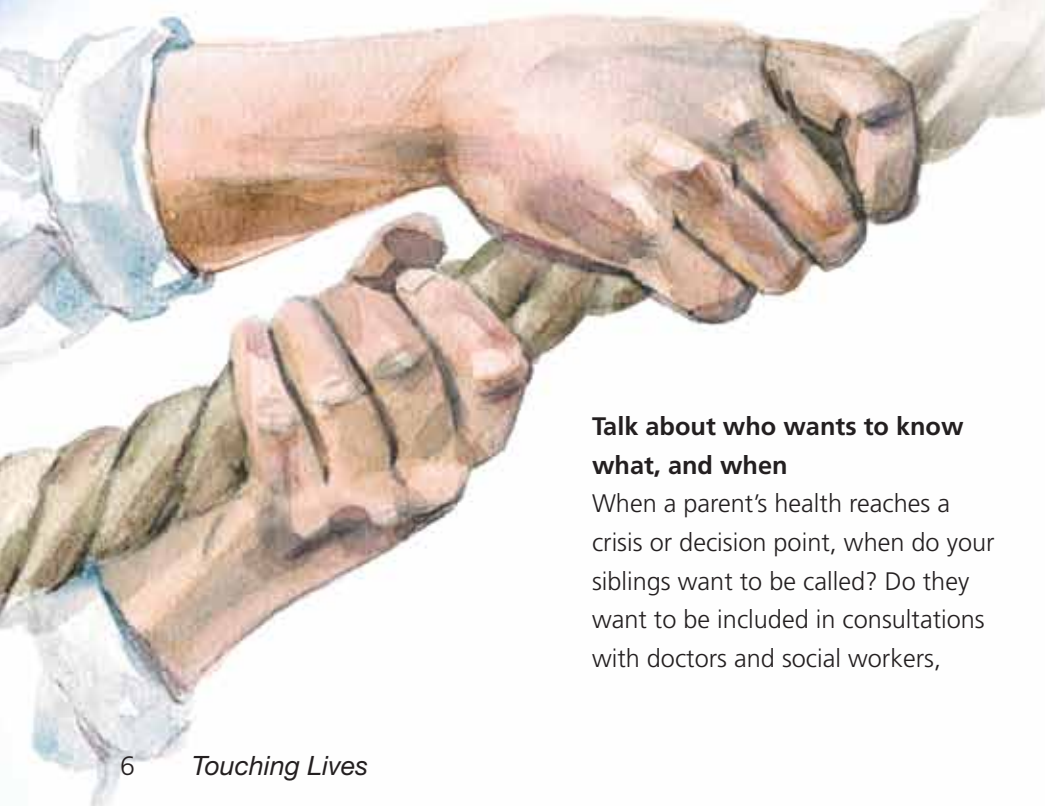
### Consider bringing in a neutral party to aid decision-making

A family meeting or conference call with a social worker, geriatric care manager, or hospice coordinator helps everyone feel included. This objective third party can lay out the realities and suggest ways to work together.

"A professional who's experienced in family relations can keep any sibling issues that are coming up from overwhelming the discussion," Russo suggests.

### Share the care (even when it's hard)

For some hands-on caregivers, it can be hard to step back and let others in. If you're feeling resistant, ask yourself why. Because you're worried others are less capable? Because you're seeking validation from a parent who's always withheld approval?



"It takes a lot of soul searching to examine your motivations, which may not even be conscious," Russo says. But if you can let go of past needs, you can better accept help in the present moment.

## If You're the Sibling Who Lives Far Away...

### Trust the messenger

Beware of "distrusting the messenger," the phenomenon where a healthcare professional delivers difficult news to the local sibling, who in turn communicates what she's been told—and is promptly dismissed. "Fear, combined with old family patterns, can lead us to have responses like 'Oh, she exaggerates,' or 'She's a drama queen,'" Russo says.

Unfortunately, responding with doubt or loads of skeptical questions puts the messenger on the defensive. So if you find yourself reacting this way, take a deep breath and remind yourself that your sibling is doing the best he or she can with a thankless job. If you feel you need to hear the news directly from the doctor, ask to do so. Otherwise treat the communicator with trust.

### Don't take "I'm Fine" for an answer

"Most people have trouble saying they need help, so you may need to probe

harder than asking 'Are you okay?' or 'What can I do?'" Russo says.

### A few ideas:

- Send small gifts, particularly those geared towards stress relief and self-care: A gift certificate for a massage, fresh fruit, a relaxing CD.
- Treat your sibling to a nice dinner when you're in town.
- Time your visits so that you can give your sibling a break away.
- Help pay for respite care or your parents other financial needs.

### Let your sibling vent

An empathetic ear may be what your sibling needs most. "Just by being available to listen when your sibling tells you how awful her day

was, you're making an enormous contribution to her emotional health," Russo says.

But take care to avoid the pitfall known as "anger-guilt gridlock." It's natural to hear your sister's complaints as accusations and go straight to guilt. But that's not her goal. She just needs validation of her feelings. By setting aside your reaction, you can give that to her.

### Focus on the ultimate goal:

#### Your parent's care

Stop tension in its tracks by reminding yourself that right now, the focus should be on your parent, not your own drama. Concentrate on your shared concern for your parent. That's good for everyone's well being. ✕

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Experienced family caregiver Melanie Haiken writes about health and travel from Marin, CA.

*take a deep breath and remind yourself that your sibling is doing the best he or she can*

# Yes, *A Time for Hope*

Why researchers say life's last chapter can be a time of optimism.

*by Paula Spencer*



In his mid-80s, Ned was diagnosed with a fast-growing brain tumor. Eventually, he and his oncologist decided no more treatments existed that could either cure his cancer or prolong his life. So he quit curative care and entered a hospice program.

Not a very auspicious beginning to a story about hope, is it?

Yet Ned, it turns out, was exceedingly forward-thinking, even though he knew he was nearing his end due to a fatal disease. He bought a camcorder to record stories for his grandchildren, to whom he wanted to pass on his knowledge. He also decided he wanted to leave a legacy of his trademark humor. So he began writing down all his jokes. By the 150th, his hands were too shaky to continue, so he dictated another 200. Then, noticing that musicians sometimes entertained at the hospice, he asked to perform a stand-up routine. Except Ned could no longer stand, so the audience came to him—doctors, nurses, aides, volunteers, and fellow patients gathered around his bed. Ned was a riot; the room filled with laughter.

"Now I know my jokes will live on," he smiled with satisfaction and optimism as he gripped the hand of a hospice counselor.

### Hope helps all through life

"Dying is not an inherently hopeless state," says David Feldman, Ph.D., assistant professor of counseling psychology at California's Santa Clara University and the author of *The End of Life Handbook: A Compassionate Guide to Connecting with and Caring*

for a *Dying Loved One*. Yet too often, doctors and families fear that once the patient goes off a curative path, he or she will fall into a state of despair.

"There's no evidence to support this," Feldman says. "What happens is that people re-define hope. Hope is invested in different goals other than a cure."

"If all we hope for is to live longer, always, then at some point we will all become hopeless," says Ira Byock, MD, director of palliative medicine at Dartmouth-Hitchcock Medical Center and the author of *Dying Well*. "But I am sure it's possible for hope to shift, because I've seen it over and over in 30 years as a doctor."

These new hopes can take limitless forms because individuals' aspirations and goals are as unique as they are.

Here are some common themes:

- To reconcile with someone or make amends
- To have good pain control
- To experience something one always wanted to do
- To leave a legacy of some form
- To help others
- To take up a hobby
- To have dignity
- To do a favorite thing one last time
- To be out in nature
- To enjoy intimacy with loved ones
- To build a good relationship with God
- To pass on one's knowledge or expertise
- To distribute possessions meaningfully
- To carry out some hope from the past.

## What, exactly, is hope?

Psychologists' definitions vary, but a standard one is this: Hope exists when three conditions are met:

- 1. Goals** – having something to hope for. Call 'em dreams, aspirations, desires. They can be big or small, and concern any arena of life.
- 2. Pathways** – having a plan or strategy that will get you to your goals. Not having any idea how to reach a goal would contribute to hopelessness, not hope.
- 3. Agency** – having the energy or motivation to go after your goal. Without an urge to make it happen, you can't feel hopeful.

Having goals, a pathway to make it happen, and the desire to follow through make people feel hopeful at any life stage. A large body of positive psychology research on healthy people links hopefulness to less depression and anxiety, stronger cardiovascular health, an ability to tolerate pain better, a greater sense that life has meaning and purpose, more contentment, and better coping with stress, adversity, and trauma.

Hope likely holds similar benefits for the terminally ill, Feldman, Byock, and others believe, although there's less data so far because this is a fairly new way of looking at the end-of-life mindset. Hopelessness—which is one of the hallmark symptoms of depression—has been linked with thoughts of suicide and assisted suicide in the terminal and elderly.

Interestingly, people in hospice seem to have more goals, and in more areas of life, than those who continue on a curative path, preliminary results from Feldman's own research have shown. This may even be a contributing factor to why studies show hospice patients live longer and report better quality of life than those who receive standard care.

## What hope *isn't*.

"Hopeful thinking is not the same as wishful thinking or the so-called 'power of positive thinking,'" Feldman says.

Consider the long-married Harold and Helen. While Harold underwent treatment for bladder cancer, Helen refused to talk to him about anything negative—not his pain, not his nausea, not his hair falling out—for fear it would bring him down. Meanwhile, Harold felt unsupported because his partner wouldn't listen to him. Their relationship struggled at the very time they needed one another. "Helen's way of thinking wasn't positive thinking, it was denial," Feldman explains.

Denial denies and distorts reality. It says: "I will ignore reality to maintain a positive outlook." Hope builds on reality. It says, "I will face reality, admit the prognosis, and then ask, 'Now what?'"

## How families can help.

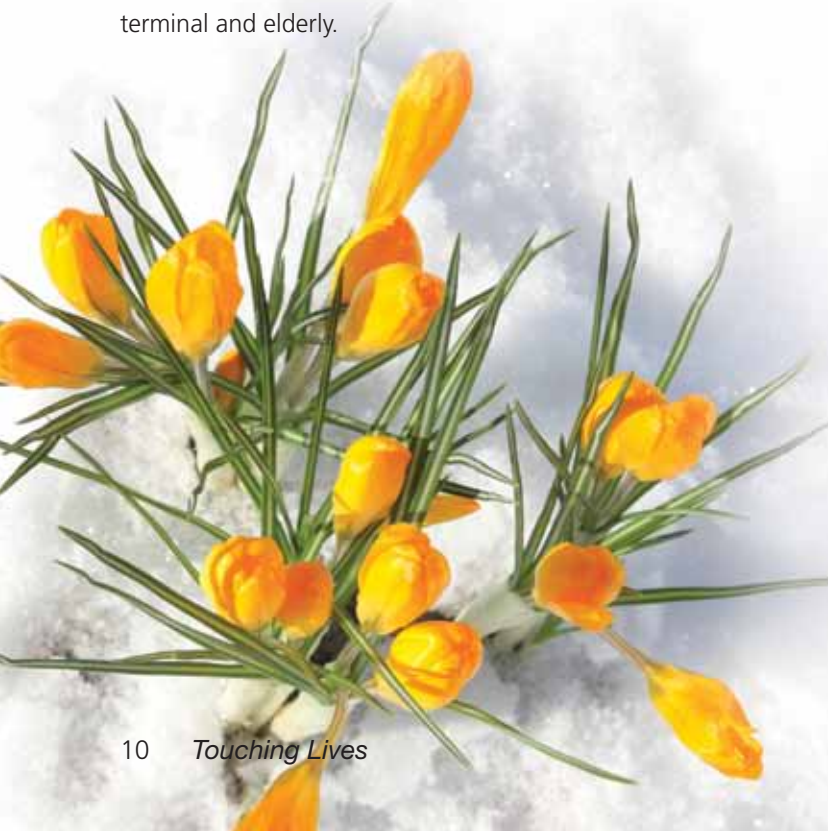
"The challenge at the end of life is not so much protecting or restoring hope as diversifying and redirecting hope," Mark J. Sullivan, MD, PhD, summarized in an influential 2003 *American Journal of Geriatric Psychiatry* article about hope and hopelessness at the end of life.

And that's where loved ones come in. What can you try?

## First, make sure pain management is appropriate.

When someone is in pain, they can't focus on their desires and they certainly don't have energy to make them happen. In fact, Feldman calls pain one of the biggest roadblocks to hope. (The other is having your family be in denial about death.)

A cornerstone of hospice care is addressing pain so that the person is always comfortable and can have a better quality of life.



### Ask leading questions.

Talk openly with your loved one. Ask, *what are your hopes right now? What's important to your life? What gives you a sense of meaning? What would you like to do in the time you have left? What would be left undone if you were to die sooner rather than later?* (See sidebar on this page, "Nothing Critical Left Unsaid.")



### Be a cheerleader.

Sometimes the dying have doubts about what's possible or appropriate. Encourage that sense of motivation: "Sure you can do it; we'll help!" "You don't want to pressure the person into anything, just give gentle encouragement," advises Feldman.

### Look for ways to make dreams and plans come true.

When someone expresses a desire, take it seriously. Try to find ways to build a pathway for it to happen. One 90-year-old yearned to drive a Ferrari before he died; his family and hospice coordinator worked with a local dealership to make it happen. (His oxygen tank sat in the passenger seat next to him!)

But know that many wishes are more basic and easy, if no less heartfelt. Perhaps your loved one wants to reconcile with an estranged sibling or child. Or meet with a clergyperson one-on-one. Or take up birdwatching.

Or tell jokes.

Dave Feldman was the hospice counselor whose hand Ned, in the opening anecdote, clutched after his bedside comedy routine. "It was an amazing moment of immense hope," he says. "You could see it on his face."

And that, as they say, beats the alternative. ✂

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Paula Spencer is the editor of *Touching Lives* and a senior editor of *Caring.com*. She specializes in writing about life stages.

## Nothing Critical Left Unsaid

The refusal of family members to accept end of life is one of the biggest obstacles to hope for the dying, studies show. "A conspiracy of silence," Ira Byock, MD, calls it. The remedy: Talk about what's happening.

"I'm not sure we have to be happy about it, but we do have to acknowledge we're mortal," says Dr. Byock, professor at Dartmouth Medical School and author of *The Four Things That Matter Most*. When families avoid talking about impending death, he says, the inability to be truthful puts up an emotional wall that separates them from one another. "Everyone puts ever more effort into ignoring the obvious." He suggests a better way:

**Stay attuned to ice breakers from the dying person that can be openings for frank, loving conversations.** Some examples: "I wish it would be over." "I think the doctor is just trying to make money off me." "I hope I can live to see Julie's baby born."

**Resist the common impulse to deflect such comments with a quick, "Oh don't talk like that!"** Instead, try a response that sounds more like an invitation for sharing: "That sounds hard." "I'm so concerned and I'd love to hear how you're really feeling." "I hate to see you going through this." "I can't imagine how you're going through this."

**Also use "I" statements to open up to other family members.** Because you're talking about your own feelings—"I'm worried Bill's getting weaker"—this way of speaking is less threatening than saying, "Bill's sicker, we need to talk about his dying!"

# FINDING

*The Touching Lives Interview:  
Insights from spiritual adviser and  
author Kathleen Dowling Singh*

**What do those who haven't witnessed much of it misunderstand about the experience of dying?**

Dying is often a radiant and grace-filled moment. It is a privilege to be present with it. Entering this mystery, and being able to stay present with it, calls forth our own courage and calls forth deep compassion and common humanity. We see the quieting, in another, of the striving and the grasping and the tension that characterize the majority of the moments of most of our lives. We see, finally, the ease and surrender that herald entrance into our essential nature, buried for most of us beneath layers of constructed identity.

**Why are many people afraid of dying?**

The most beneficial way to understand this question is to ask it to ourselves: *Why am I afraid of dying?* See what arises. For most of us, even the asking of the question stirs up deep feelings of attachment, of aversion, of uncertainty. If we ask the question and ponder the response with a willingness to be attentive to what arises, most of us will notice attachment to this sense of self,

attachment to this sense of body as "me," attachment to loved ones, attachment to this beautiful planet, attachment to what we know. Most of us will observe our own aversion to the unknown, aversion to physical pain, aversion to perceived loss.

It's an epic inner struggle to come to peace with a deep realization that we are mortal beings, that we have a shelf life. Most people avoid the questions and the struggle, which only makes our dying more filled with emotional anguish.

**Describe what you call the "nearing death experience."**

The nearing death experience can occur weeks, days or only moments before we enter the phase of active dying. It has powerful parallels with deep experience of spiritual realizations. It's characterized by qualities of relaxation, of withdrawal from worldly activities, of brightness or radiance, of a sense of attention drawn inward in a concentrated way, of silence, of the sacred, of transcendence of who we have believed ourselves to be and of all the places in our lives where we've been "stuck," of knowing rather than simply

# Grace AND Peace

believing, of intensity, of merging, and of perfection.

These are qualities not ordinarily experienced by our separate sense of self. They are the qualities of grace. The very presence of these qualities suggests that their source is in our essential nature, far beyond the conceptual image of the self.

Whether death occurs slowly from a disease or quickly from an accident, these qualities seem to emerge. They're identical to the qualities necessary for deep spiritual insight and cultivated by spiritual practitioners from every tradition.

Dying is the most profound spiritual experience of a lifetime.

**You talk about transforming death, in our perceptions, from a time of tragedy to a time of grace. What can families do to help foster such a shift?**

Discriminate between the time of sickness and the time of dying. In the former, it's appropriate to help a loved one fight to stay alive, be present and supportive. In the latter, it's appropriate to help a loved one let go and face death, be present and supportive.

Also, do our own work. Honestly look at our own fear, attachment,

worries, and sadness, and, to the degree we are able, let go. May we approach each other at our deathbeds with less fear and preoccupation and with more clarity and compassion.

Affirm these things: "I love you." "I'm grateful you love me." "I forgive you." "Please forgive me." "You can go."

Give the gift of our attention. May we assure our loved ones of our presence, without clinging or control... just with love.

May we exercise true compassion and allow the dying person to turn inward. Let us help them unbind all that binds them to attachment to this body, this lifetime, this self.

Be present.

**What else helps one more peacefully surrender the body and the ego at the end of life?**

Prepare for death while in the midst of life, far before the moment of a terminal diagnosis. Just as we often inventory our worldly possessions, accounts, and advance directive wishes, how beneficial it would be if we conducted a spiritual inventory.

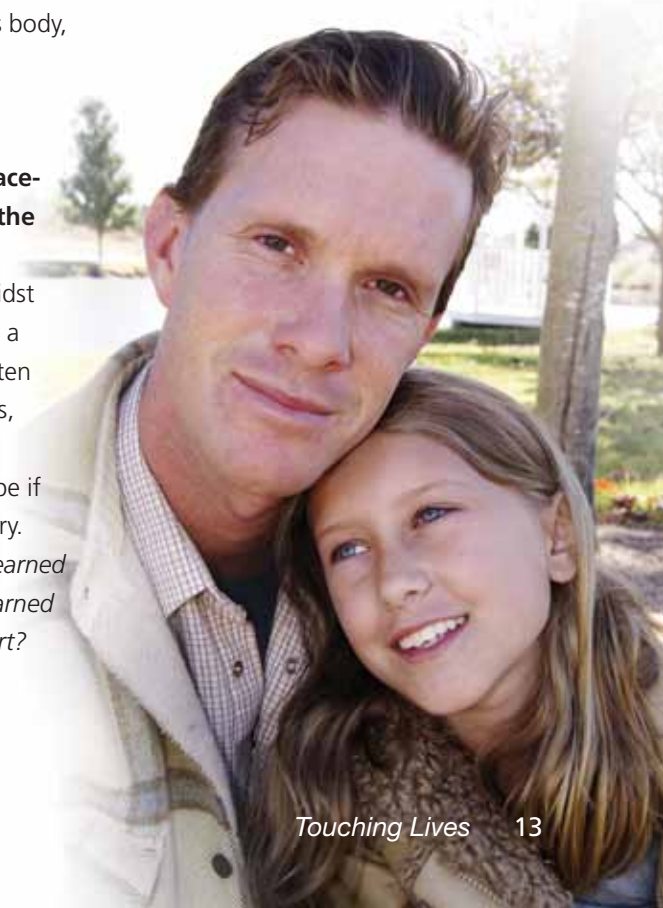
Sit and ask: *How well have I learned to love? How truthfully have I learned to live? How generous is my heart?*

*How honest is my self-inquiry? What do I know of my own depths? How thorough is my forgiveness? How deep is my gratitude? How mindfully am I living each moment?*

Investigate the "who" it is we think will die. Practice living a life only lightly dusted with form. Practice letting go. Letting go not only makes dying easier; it brings much more joy and ease to living. ✨

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Spiritual adviser and former hospice worker Kathleen Dowling Singh, Ph.D., is the author of *The Grace In Dying: A Message of Hope, Comfort, and Spiritual Transformation*.





# 7 Ways to Celebrate a Life

by Marlene Prost

**P**eering into the past and examining the events that gave life meaning can be a surprisingly uplifting experience. Many families find that celebrating the life of a terminally ill loved one brings everyone closer. It can inspire candid talk and laughter. What's more, the process gives the ill person, who may be feeling vulnerable, a sense of control over his or her own legacy.

These seven loving ideas can help you all cherish old memories while creating new ones.

## **I** Create a memorial DVD

Thanks to video and digital technology, families can select photographs, slides, and action shots of their loved one and put them to favorite music on a DVD that the "star" can enjoy now.

Helping to plan the DVD gives a dying person a sense of control at a

time when they are losing control over many things, said Carol Weaver, director of enrichment at a hospice for the past 10 years. "They're leaving a living legacy for their children and grandchildren," she explains. "And it's something for family members to keep and cherish."

## **2** Record a life review

We all want to know that our life mattered. That's why the formal "life review" has become a popular process. Prompted by prepared questions, a dying loved one is encouraged to talk about life experiences, from early childhood on, while the family records the conversation.

"Just give suggestions, like when were you born? What was the favorite toy you played with? What are you afraid of?" Weaver says. "Not just facts and figures. Evoking emotions presents a more comprehensive view of their life."

## **3** Share a personal message

Sometimes it's awkward to tell even your most beloved relative or friend how you really feel. Another way: Make an audio or video recording of yourself sharing reminiscences and feelings. Weaver recalls a young woman whose taciturn grandfather wouldn't let her talk about her feelings for him. Putting them on tape, she told Weaver, allowed her the opportunity to have closure.

"Patients are reassured that their life had meaning, and that they are loved and respected," she adds—even those who are reluctant to hear it face-to-face.

# Some of our happiest family memories are of everyday life: Going fishing, watching a child's music recital, playing ball.

**4 Weave tangible memories**  
Tributes can take non-media forms, too. For example, family and friends who live too far to visit can contribute to a quilt made up of fabric squares that capture memories and sentiments. Send everyone a square to embellish or decorate with ink, embroidery, or other mementoes. A T-shirt collector saw his favorites assembled into a blanket, which was passed on later to his son.

Another popular trend: Huggable memorial teddy bears made out of a loved one's clothing.

**5 Record day-to-day living**  
Some of our happiest family memories are of everyday life: Going fishing, watching a child's music recital, playing ball. One grandmother asked for a videotape of herself baking cookies with her granddaughter. Try turning on a camera set up on a tripod during dinner on a good day. Play back these relationship-building moments later, on not-so-good days.

**6 Leave a work of art**  
Few of us ever get to write that novel or record that hit song. But the creative process can take on urgency when time grows short. One 35-year-old hospice patient wrote a book for

his five-year-old son, explaining every step of his illness. Weaver says her hospice's bereavement department still uses the book.

Music was a big part of life for another 39-year-old father who was debilitated by strokes. With the help of his music therapist, he surprised his eight-year-old daughter with a song about a father putting his daughter to bed. The song ended with words she'd always say: "I love you all the way to God and back."

"This is a CD just for her, she'll have the rest of her life," Weaver says.

**7 Make a wish list come true**  
Many of us carry around a "bucket list" of things we've always wanted to do, or would love to do one more time. Often you can find ways to turn even unlikely wishes into realities, with a few modifications.

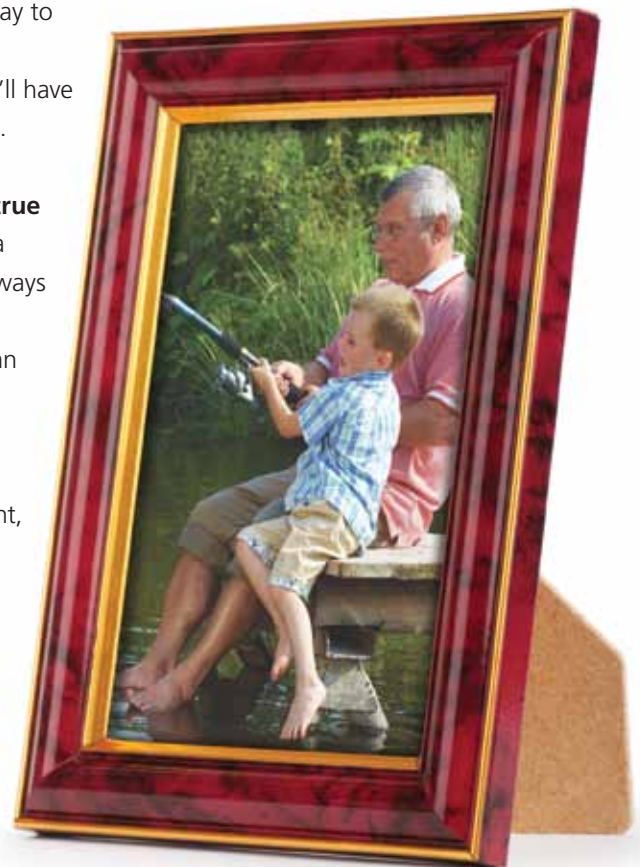
One 92-year-old hospice patient, a former flight instructor who once owned an airport, wanted to fly again—something he hadn't done in more than 40 years. His loved ones arranged for him to go up in a four-seat plane with a flying instructor, his daughter, and a nurse. In mid-flight,

he leaned over and said, "I haven't felt this young in a long time." He even took over the controls for 20 minutes.

You can bet those are 20 minutes both he and his daughter will cherish forever. ✖

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Marlene Prost is a freelance writer who specializes in writing about health care issues.



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suffered more physical and emotional distress than those whose kin died with hospice services.

When Jennifer Wall Alamdari was 16, her 56-year-old mother was dying of cancer at home in Crutchfield, Kentucky. “My father and I were completely unequipped to take care of her,” she remembers. “It was such a relief to know that someone skilled was coming to take the weight off of us and that mom was being properly cared for.” Because her dad had another adult to talk to and consult with, Jennifer felt she gained some space “to be a kid again.”

She also learned ways to cope with impending loss. “Our hospice nurse showed me ways to be close to my mom and give her comfort: massaging her hands and feet with lotion, reading to her, buying her a new nightgown, making food that was easy for her to swallow (her throat was raw from the radiation),” she says. “Hospice helped us find ways to be there for her and ourselves.”

### Hospice helps with hands-on guidance.

When Alicia Garate-Golembiewski’s mother was dying at her San Francisco home of mesothelioma, a rare form of cancer caused by asbestos exposure, she liked her hospice caregivers so well she called them her “angels.” For Alicia, these angels were teachers as well.

That’s because in addition to providing hands-on care like bathing, changing sheets, and medication dispensing, hospice workers also show curious families how to manage common situations when they can’t be present.

“When I would try to lift my mom to take a shower, she’d cringe,” Alicia says. “The nurse would show us how: ‘Put your arm like this, let her move with you, move the sheets this way.’ I loved that they took the time to show us all those little things. And I could



Hospice care is designed to support the entire family at the end of life.

call any time with questions—they truly were angels.”

### Hospice helps with grief support, both now and later.

Grieving doesn’t begin at a loved one’s death. “Grief started the day Steve was diagnosed,” says Tyra Damm of Frisco, Texas. Her 39-year-old husband of 15 years eventually died of a brain tumor they soon referred to as the “Damm spot.”

The emotional pain of losing a loved one, felt before death, is called *anticipatory grief*. A 2001 study in *The Gerontologist* called anticipatory grief equivalent in intensity and breadth to the response to death. It’s real grief—and not surprisingly, it’s very common among those who care for the terminally ill.

Beginning while Steve was in hospice care and for 11 months after he died, hospice grief counselors met with Tyra and her two children, Cooper, then 8, and Katie, 4. The children’s therapy included music and artwork—“things they could control, when they couldn’t control everything else going on,” Tyra says. “They helped me work through things like Steve’s first birthday without him and what was normal for grieving kids when I wondered about how to discipline,” she says.

“I was surprised to get grief help for both me and the kids even before Steve died,” Tyra adds. “We all needed it.” ✖

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Paula Spencer is a writer based in San Francisco and Chapel Hill, North Carolina. When each of her parents used hospice services, she gratefully experienced the hospice care described in this article.



# Facing Serious Illness...

*Is help available?*

**L**iving with a serious illness can present many challenges for patients and their families. The demands of locating the resources available to help support each specific situation, is often a tedious and exhausting task in the midst of coping with the illness itself. When your physician says it is time for hospice, the burden of resourcing support is assisted by your hospice provider. However, when the time for hospice is unclear or seems too far in the future, patients and families take on this responsibility of locating additional support needs, often without the knowledge of exactly what support might be out there.

The *InFINITY 360 Support Program* is designed for just this purpose. When a patient and family are uncertain about hospice, or do not qualify, the *InFINITY 360 Support Program* can assist in resourcing additional support for the patient and family. Our assistance includes identifying and accessing

local resources, as well as emotional support and getting answers when questions arise. The program is designed to preserve quality of life by providing education and maximizing the community services available. The *InFINITY 360 Support Program* will provide practical help and emotional support to individuals coping with serious and life threatening illness. Medical and nursing care is not part of our scope of services, but we do assist our clients in accessing the level of care needed.

The *InFINITY 360 Support Program* is offered at NO charge and is supported through the InFINITY Foundation... because we believe it is vital in preventing and relieving suffering in those who are not on hospice care. ✘

# Volunteer!

Becoming a hospice volunteer is a unique and special way to enhance the life of another person, as well as your own. Many people have thought about and would like to volunteer, but do not know how to get involved. If you are interested in volunteer opportunities in Hospice, we encourage you to get involved by visiting our website or calling 918-392-0800. Every day, Volunteers make a positive difference in the lives of others!





# Speaking with your Physician about End-of-Life Decisions

by Edward E. Rylander, MD, Board Certified in Hospice and Palliative Medicine, Medical Director InFINITY Care Of Tulsa

One of the most important times in your life may be the last few months you have. It is up to you to take the initiative and express your end-of-life wishes. After speaking with your family and loved ones, the next most important thing to do is to speak with your physician. Chances are that they are waiting for you to start the conversation.

## First, address your most important concerns and choices:

- Ask your doctor to explain treatments and procedures that may be confusing.
- Talk about pain management options.
- Let your doctor know that you are completing your advance directives and make sure your doctor is willing to follow your directives. **The law does not force physicians to follow directives if they disagree with your wishes, for moral or ethical reasons.**
- Assure your doctor that your family and your appointed healthcare agent know your wishes. (Make sure they know)
- Don't be afraid to ask questions, this is your time.

## You will need to ask your doctor specifically:

- If they are willing to talk openly with you and your family about your illness.
- What decisions will your family and you have to make, and what kinds of recommendations will they give to help make these decisions?
- What will your physician do if you are in pain or present other uncomfortable symptoms?
- To inform you if treatment isn't working, so that you and your family can make appropriate decisions, such as making hospice arrangements.

To ensure your wishes are followed, execute a living will or advanced directive while you are able to do so. This allows you to document your wishes concerning medical treatments at the end of life. In addition, this will give your family and healthcare agent reference to your wishes.

Be sure your doctors have a copy of your advance directives. Give copies to everyone who may be involved with your healthcare, such as your family, clergy, or friends. Your local hospital may also be willing to file your advance directives, in case you are admitted in the future. ✕

***The best time to begin this conversation is now!***

Special thanks for the materials and information used in the preparation of this discussion are made to the National Hospice and Palliative Care Organization and the Robert Wood Johnson Foundation, Princeton, New Jersey. [www.rwjf.org](http://www.rwjf.org)



# The InFINITY Foundation

The InFINITY Foundation is committed to providing charitable funding to those who are embracing the opportunities to celebrate and engage in lifelong learning, those struggling with grief, and those with extraordinary needs, not available through other resources.

## The InFINITY Foundation exists for two reasons:

- ◆ Supporting those hospice patients and families with exceptional needs; which exceed the services hospice would normally provide.
- ◆ Supporting the community's need for End of Life education, and developing innovative approaches to meeting those needs.

## The InFINITY Foundation's charitable funding is based on the kindness and support of those who also find joy in giving and who believe in our mission.

- ◆ The InFINITY Foundation's corporate support was founded by InFINITY Care of Tulsa.
- ◆ The InFINITY Foundation accepts gifts and grants from individual donors, other organizations, other foundations, and corporations.

## Supporting The InFINITY Foundation

The InFINITY Foundation relies upon the support of others to provide for special needs and end of life education in our community. The Foundation accepts gifts and grants from individuals, corporations, foundations and other organizations.

For relatives and friends who have lost a loved one, a gift to the Foundation represents a significant and enduring commemoration that helps benefit the lives of others who are facing the same passage.



To make a donation, go to [www.infinitycare.com](http://www.infinitycare.com).

There you can download and print the form, then mail in your kind donation.

**For more information, contact  
The InFINITY Foundation at (918) 392-0800.**

*I have found the paradox; when I  
love until it hurts, there is no more  
hurt...only more love."*

*— Mother Teresa*