

A Publication of HopeHealth

# Touching Lives™

*Holding Hands. Holding Hearts.*

## **Making Peace With Our Biggest Fear**

**7 Ways to  
Celebrate Life**

**The Best  
Plan For You**

**Spiritual  
Comfort**

**Learning  
To Listen**

  
**HopeHealth**™  
*Touching Lives*

## FEATURE ARTICLE

### 10 Making Peace with Our Biggest Fear

By Dr. Ken Druck



## CONTENTS

#### 3 The Five Stages of Life Reconciliation

By David Kessler

#### SPIRITUAL SUPPORT

##### 5 Spiritual Matters

By Beth Carlton

#### MEMORABLE MOMENTS

##### 6 Learning to Listen

By David Kessler

#### LIVING WELL

##### 8 7 Ways to Celebrate Life

By Marlene Prost

#### CAREGIVER'S CORNER

##### 14 Sibling Rivalry...or Revelry?

By Melanie Haiken

#### HELPING HANDS

##### 16 The Best Plan for You

By Domenica Rafferty

##### 17 How to Get Through—Not Over—Grief

By Deanna Upchurch

##### 18 Father's Day

By Edward W. Martin, MD, MPH, FAAHPM

## Welcome to *Touching Lives*



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

Our goal is to help individuals face a serious illness with strength and grace in a familiar place surrounded by their loved ones. We are here to help families focus on what matters most to them, alleviate pain, listen to concerns and do everything we can to make final wishes come true.

Sharing *Touching Lives* with you is one of the many ways HopeHealth helps families as they experience loss. The aspects of a life review are explained in *The Five Stages of Life Reconciliation*. Navigating the grieving process is the focus of *How to Get Through—Not Over—Grief*. And a personal reflection by our Chief Medical Officer and long-time hospice physician is featured in *Father's Day*.

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

Warm Regards,

Diana Franchitto

President and CEO



HopeHealthCo.org

# The Five Stages of Life Reconciliation

By David Kessler

**O**ur belief systems shape our lives. We believe that if we are educated, we will get a good job. If we accumulate money, we will be safe from hunger. If we eat right and exercise often, we will be healthy. We believe that pills will work, that medical technology will keep disease at bay, and that doctors will save us and our friends and family. Inevitably, our beliefs fade as we realize that we will not live forever, no matter how smart, rich, or healthy we may be, and no matter how good our doctors are. As we must let go of everything we have known, faith allows us to escape the fear that all is random and meaningless.

My co-author of two books, Elisabeth Kübler-Ross, has described the five stages we go through as we face death: denial, anger, bargaining, depression, and acceptance. She always said they are not linear, not everyone goes through every stage, and they are as unique as we are. There is a similar approach to aspects of life reviews that our loved ones may go through. They are aspects of a large life review that will sometimes challenge our loved ones the most. It is helpful to understand these five in particular: expression, responsibility, forgiveness, acceptance, and gratitude.

## Expression

**1** Many people have trouble accepting the demise of their physical selves because they're blocked by anger. Being human, we all make judgments, we all hate, we all blame others, we all become furious, and we all behave in petty ways. Sometimes we're justified in doing so; more often, we're not. As far as healing is concerned, it doesn't matter. For healing to take place, we must overcome our taboos and express our feelings. We fear that we will be punished if we express our "ugly" feelings, but in fact the opposite is true. We are rewarded for releasing our anger, by making ourselves ready for peace. You don't have to tell your father or sister that you hate them. You can say it to a trusted friend, you can whisper it into the air, or you can scream it into your pillow. Once you do, the angry thoughts begin to dissipate. The hate that held you hostage disappears. You can also tell God why you're upset, if that's the case. Anger toward God is a problem for many. I've worked with people from various faiths, and I've found that they often need permission to become angry with God. God understands that you need to express and release your feelings in order to love.

## Responsibility

**2** People have often said that facing a life-challenging illness has improved the quality of their lives. Specifically, it helped them take responsibility for their actions, thoughts, and lives. They know that they're not to blame for their diseases and that dying does not mean that they have somehow failed. They also understand that they have played a role in all that has happened to them in life.



## Forgiveness

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To forgive does not mean to accept bad behavior. When we forgive, we release ourselves from the binds of hates and hurts. We forgive ourselves and others because we want to die whole. We're afraid that forgiving the people who have hurt us is the same as absolving them of their misdeeds. But we forgive for our own sake, when we realize that holding on to grudges forces us to live in unhappiness. When people are reluctant to forgive, I tell them, maybe it's not up to us to punish. Meanwhile, this is your death. Forgiving ourselves is just as much a part of spiritual growth as forgiving others. Our loved ones are often very hard on themselves at the end, remembering all the things they've done wrong, whether little or large, and wondering if they can ever be forgiven. I tell them that if they feel that they cannot forgive themselves, they should simply ask their God or Higher Power for help. We can die in unforgiveness; that's an option, and some people do die that way. But many choose to make way for inner peace by forgiving.

## Acceptance

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I remember very well the stout, 42-year-old banker who grasped his dying father's shoulders as the older man lay in his hospital bed and practically shouted at him: "Dad! Fight it! Fight it! You've been a fighter all your life. You can beat this!" We live in a fix-it society, with the technology to repair many broken things at our fingertips. We forget that we've all been deliberately designed to "end" one day. When that ending happens, there's nothing to fix. Optimism and a fighting spirit are good things, but at a certain point, optimism becomes denial. It's important that our loved ones be willing to fight when fighting is appropriate, but they will all face that moment in life when it is time to stop fighting, to stop treating death as the enemy. This is not giving up. It's accepting what is happening, riding the horse in the direction it's going. Once the final death process has started, it cannot be stopped, any more than a woman in labor can be prevented from delivering her child.

We don't have to like what we accept. Accepting that life is complete is perhaps the most difficult of the steps toward spirituality. There may be things we wish had happened—more time, more opportunities, and more experiences. But their absence doesn't mean that a life was incomplete.

## Gratitude

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Having expressed one's feelings, taken responsibility for all that has occurred, forgiven oneself and others, and accepted what is now occurring, the person on a spiritual journey becomes profoundly grateful for his or her life, for both the good times and the bad.

Grateful for the bad times? Yes. Fifty-four-year-old Mark, who lost his eyesight in an accident at age 15 and was now dying of lymphoma, told me he remembered the colors. His favorite was blue. "Some are born blind. They have never seen blue. I am so thankful; I can still see it in my mind."

Expression, responsibility, forgiveness, acceptance, and gratitude all lead to reconciliation. As friends and family, we are the best and safest support our loved ones have for these possible reviews. These are the challenges I've seen countless people take on the road to spirituality. And the peace they attain is medicine for their souls. ✕

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David Kessler is author of *The Needs of the Dying* and co-author of *On Grief and Grieving*, with Elisabeth Kübler-Ross.



# Spiritual Matters

By Beth Carlton

**A**ccording to a survey by the Pew Research Group, 89% of Americans say that they believe in God.

Even though research indicates that people value spiritual care and spiritual well-being, many of us may find it difficult to put our belief into practice during life's most difficult time.

When illness occurs, many people may want to feel a sense of purpose in their lives and may begin to reflect on their past and, in doing so, may find themselves asking difficult questions about life and its meaning.

After being diagnosed with Alzheimer's disease at 59 and knowing her life was coming to an end (she died at the age of 64), Pat Summitt who will be remembered for winning more women's basketball games than any other college coach, male or female, said, "God doesn't take things away to be cruel. He takes things away to make room for other things. He takes things away to lighten us. He takes things away so we can fly."

When the physical body becomes frail, our inner being can become stronger as our spirituality is awakened. Some people may experience a desire to resolve issues with family

and friends as they detach from this world and get ready for the next stage—whatever they believe that to be.

When someone says they feel overwhelmed or sad about dying, try not to dismiss such feelings, which are deeply important at this time.

You may want to suggest coping techniques such as relaxation, meditation, writing down thoughts and feelings, talking to a hospice chaplain, prayer, yoga, reading or listening to audio recordings of sacred books.

**"God doesn't take things away to be cruel. He takes things away to make room for other things. He takes things away to lighten us. He takes things away so we can fly."**

When someone reveals feelings about spiritual matters, you do not need to have an answer to these profound questions. Sit quietly and allow time for listening, thoughtfulness and stillness. Be aware of your own thoughts and feelings, as your emotions may come to the surface.

Trying to find a spiritual practice that feels right may cause someone to experience a range of new emotions, but it is during the wild and sometimes turbulent ride that a loved one may make new discoveries which can lead to a more joyful and meaningful life. ✕

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As a hospice volunteer, Beth Carlton has watched lives transformed through spiritual awakenings.



# 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, where we were joined by their brother, Frank.

"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?" Frank 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.'"



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 the weather, or about death.

#### When You Don't Know What To Say

What do you say to the dying?

Most of us 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. Should we talk about baseball or your chemotherapy?" 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 the end of life.

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.

June, 92, was living in a retirement home when her doctor found a tumor wrapped around her aorta. Given her age and poor general health, treatment was not advised.

Her son and daughter-in-law told June, "As you get sicker, we don't

want you to go into a hospital and be cared for by people who don't know you. We want you to die in our home. Between us and the kids, we'll manage. You've always been there for us, now we'll be there for you."

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 the author of *The Needs of the Dying* and co-author with Elisabeth Kubler-Ross of *Life Lessons* and *On Grief and Grieving*.



# 7 Ways *to celebrate 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.

## 1 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.





## 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.



## 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.



## 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.



## 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 Pennsylvania-based freelancer who specializes in writing about health care issues.

# Making Peace with *Our Biggest*







# Fear

By Dr. Ken Druck

Our fear of death begins when we're kids. Perhaps we had to face the mystifying idea of impermanence when a beloved pet, parent or grandparent died. The stark reality that this loved one was really gone—and gone forever, was both devastating and terrifying. From early childhood, when we're introduced to the concept of "futureless-ness"—that is, old age and eventually death, there are few things as difficult for us to deal with. Facing down the fear of dying requires great strength, humility and spiritual fortitude. But, as you will see, it's worth the effort.

Summoning the courage to quell our fears and come to terms with our mortality may be one of the most challenging things we ever do—but it may be one of the best things we can do to improve the quality of our lives. Freeing up the space in our minds and hearts where fear has resided and replacing it with newfound peace, courage and understanding is one of the greatest gifts we can give ourselves.

Here are several things that have helped me, and those I've had the honor and privilege of working with over the years, to make peace and even find joy as they near the end of their lives:

## 1. Treat Conquering Fear as a Process

Loosening the grip of death's terrifying, paralyzing and often, depressing hold on us comes with learning to calm our hearts and our thoughts, deepen our faith, bolster our courage, surrender our need for control, give a voice to our fear and reimagine the greater possibilities. The goal is not to obliterate our trepidation about dying or to never again be afraid. This may not even be attainable for most folks. We can, however, learn how to contain, channel and ease our fears. And this alone will be enough to lighten our hearts. ►

## 2. Allow Humble Unknowingness

We do not know with 100 percent certainty what happens when we die. Or where, if anywhere, we were before we were born. Unknowingness is a natural part of the human experience. We can try to fight it, pretending we know exactly what's going to happen when we pass, or we can remain humble, seek deeper understanding and keep the faith that there may be something greater in store for us when we pass from this life.

## 3. Don't Try to Outsmart, Outrun or Outmaneuver It

The fear of death resides in our DNA. We're programmed to live... and to do everything in our power to survive. Since the thought of dying can be overwhelming, we try to run and hide from it. Opening ourselves to the possibilities of life after death is natural. And so is conducting honest inquiries into the true nature of life and death.

Our capacity for true inner strength, faith, reflection and spiritual awakening is limited if the only thing we do is recite rituals and pray to be saved by a higher power. Assured a ticket to life everlasting in heaven, we cling to blind faith and forgo the opportunity to cultivate "organic" faith. The benefits of faith derived from courageously dealing with, rather than "spiritually bypassing," our fears make all the difference when it comes to making peace.

## 4. Embrace Uncertainty and Choose to Believe

That we undergo a transition from this life when we die is indisputable. There are "believers" and "nonbelievers" who claim to live with a clear sense of certainty about

exactly what that is. And then, there are people like me, who are uncertain about the true nature of life and death—but choose to place our bets anyway.

I choose to believe, for example, that when I die, I'll be reunited with my daughter Jenna, who died tragically while studying abroad at age 21. I remain hopeful and humble, vigilant and patient, in my uncertainty about the mysterious nature of death.

## 5. Believe That Love Does Live On

I have found some measure of peace, and my heart is calm most of the time. But there are times when I'm visited by fear, doubt and profound sorrow. Staring into the abyss, scared that I might be telling myself a story to stave off sorrow and fear... I find the idea of a great nothingness to be quite frightening. However, these occasional lapses into despair, when I feel defenseless, are offset by the times when I feel at peace.

Accepting life's terms, reconciling that we don't get to live forever and being eternally grateful for the blessing of having lived, gives me peace. So does being intimately connected to my daughter in the spiritual realm, bonded by an undying love. From the day of her death in 1996 to this very moment, I've experienced the love that never dies.

Telling Jenna that I love her—feeling her love, and even her presence, has soothed my heart and assured me that love is greater than death. And that love does go on. While my daughter's death has been a source of unspeakable pain in my life, it has also calmed my fears about death. Whatever and whenever that transition is,





I will hope to be joining her, my parents, grandparents and others I have loved someday. And that's OK.

### 6. Pay the Good Forward

When we make strides in reconciling the fact that we're here on lease, we can decide to live from gratitude and pay the good fortune, blessings, gifts and miracles we've been able to experience forward to our kids, grandkids and future generations.

Leaving a legacy of love is in direct contrast with living from fear, jealousy, bitterness and resentment. Those who fail to face down their fears of dying think nothing of taking it all down with them when they die. They become reckless and/or indifferent to the kind of future they're leaving behind for future generations. The peace afforded to those who choose to look beyond their own lifetime and pay the good in their lives forward allows them to let go when it's time. And to do so knowing they have left a legacy of love from which others will benefit.

And keep in mind, the following ideals of what I call "courageous living" can be of great help when facing down the fear of death:

- Stay humble, and find peace in your unknowingness. You're a part of something so big that it is unfathomable. The true nature of the universe—where life comes from and where it goes when you die—is an unfolding mystery. Just ask the stars.
- Cultivate a calm mind that allows naturally arising fears and doubts to come and go. Learning to breathe and release even your primordial fears is a form of surrender.

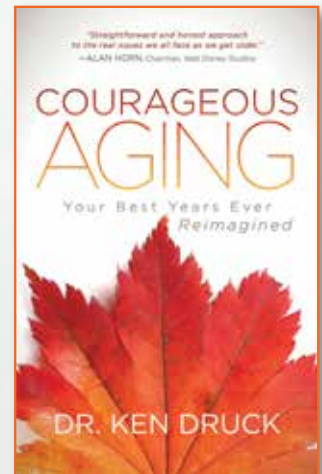
You can make peace with life itself as it really is.

- Keep the faith that whatever you believe in your heart is true—or what you wish to be true. It's okay to abide by a hoped-for narrative without knowing if it's entirely accurate or not.
- It's also just fine to have faith in a divine truth without apology or justification. Do so while respecting and honoring the rights of others who may have a different view.

### The Process of a Lifetime

Dealing with death occurs over the course of a lifetime. When it comes to accepting the inevitable, we are all works in progress and a certain amount of existential unrest is part of being human. The seasons, changes, losses, and transitions of life demand upgrades in our operating systems. Summoning courage, faith, understanding and humility requires great determination. Allowing for, and accepting, life's terms, as well as voicing our objections to the parts that are sad and scary, is all part of the journey. May you find peace. 🍁

Dr. Ken Druck's book *Courageous Aging: Your Best Years Ever Reimagined* offers practical and inspirational guidance on making peace with, and finding joy in, every stage and season of life.





# Sibling Rivalry... or Revelry?

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 massage, fresh fruit, a relaxing CD.
- Treat your sib 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 sib 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, California.



# The Best Plan *for You*

*Life often feels out of control for many of us, even when we are not facing life or death decisions.*

By Domenica Rafferty

**M**aking plans is our way of moving forward and making decisions that feel right. Making plans often alleviates fear or anxiety when facing major changes while allowing us to open up our creativity and imagination to experience life on our terms.

When confronted with our own mortality, some of us will attempt to “get our affairs in order” by meeting with our accountant, lawyer, clergy or funeral director and overlook one of the most comforting resources available during life’s most challenging time.

Hospice invites us to be involved in the planning of how we want to live during the limited time we may have left and how we want to die in comfort and dignity.

Many patients with life-limiting illnesses have used hospice to help manage symptoms so that the end of life can be a time of dignity and

comfort for patients, families and friends.

A popular misconception is that hospice is for the last few hours or days before death. Patients are eligible for hospice care if diagnosed with six months or less to live and can leave hospice care at any time.

Unfortunately, most people don’t receive hospice care until the final weeks or even days of life which causes many patients to not fully experience the care and quality of the hospice relationship.

Dr. Ira Byock, a leading palliative care physician and author of *Dying Well* and *The Best Care Possible*, emphasizes that “we can relieve the suffering of almost everyone that we care for if we have the time to prepare.”

Hospice staff are on call 24 hours a day to help patients in pain and can also train caregivers on how to administer emergency pain

medications that take effect before nurses arrive.

Hospice doctors, nurses, clergy, health aides and volunteers assist the patient with planning and implementing the best care possible for a person with a terminal illness.

For some people, such plans might include having extended visits with loved ones, visiting a favorite place, or organizing family photos.

For others, the most important thing might be to live out their days in peace and comfort in their home or a hospice facility.

Hospice aides can also relieve some of the burdens on family members during a patient’s final weeks and months by assisting in personal care, while hospice volunteers can provide caregivers with a few hours respite each week.

The preparedness of hospice offers the time to create the best plan for your life. ❖



A woman with dark hair, wearing a dark jacket and a grey scarf, looks directly at the camera. She is standing in a crowded city street with many other people walking in the background. The scene is brightly lit, suggesting a sunny day.

# How to Get Through — Not Over — Grief

By Deanna Upchurch

All of us have had a loss or will grieve the loss of someone we love in our lifetime. It is important to understand this grieving process and learn how to help ourselves and others cope on this journey.

## The commonality of grief

While every loss is as unique as each grieving individual, many people report feelings of losing control and hopelessness. Something as simple as recalling the scent of your loved one's favorite perfume can trigger a well of emotions. There are ups and downs, waves and spurts of grief. Grief is unpredictable.

What is the hardest part of grief? Even those surrounded by large families and an abundance of friends can often feel isolated and alone in their grief. Some relatives may be immersed in their own sense of loss, while others attempt to provide comfort by calling and delivering comfort food in the first weeks but may quickly fade away. Those who participate in counseling support groups, whether sporadically or long-term, find comfort in sharing their stories with others experiencing grief. The exchange of stories between grieving participants, coupled with the guidance of trained grief support counselors, provides comfort for those on the journey of loss. Gentle and non-judgmental self-care—such as yoga, meditation and mindfulness are activities that can help provide great comfort and insight to oneself during this process.

## What do I say?

"You're young; you'll get married again." "It was God's will." "He's in a better place now." These statements are examples of what not to say. Many people have a difficult time knowing what to say unless they've walked in grief themselves. If you're unsure of what to say or do, remember that less is more; offer a hug, be a good listener and don't try to fix things. Sharing a fond memory of the person's loved one or just saying, "I am so sorry, I am here for you," is often enough.

## Helping children and adolescents handle grief

Every individual, no matter their age, grieves in their own way. With shorter attention spans, children go back and forth between wanting to talk about it and wanting to move on to something less overwhelming. Be honest and use concrete language to avoid confusion. For example, saying, "We lost Grandma," can mislead children to think she can be found. As children move into adolescence, their understanding of death's permanence deepens.

While there is no right or wrong way to grieve, it all starts with self-care, and there is a variety of help available to guide people in their transformation from grief to healing. To learn about the grief support services available from HopeHealth, call (888) 528-9077 or visit [HopeHealthCo.org](http://HopeHealthCo.org). ❖

# Father's Day

*By Edward W. Martin, MD, MPH, FAAHPM*

**T**he medical student's question surprised me. Although the medical students and residents who rotated through hospice often commented, "Don't you find this depressing?" and asked me "How can you do this every day?" none had asked me to reflect on being a hospice doctor. When a student asked, "How does your work in hospice affect you personally?" I thought about the patients, families, and staff I had worked with during my 30 years in hospice and of the impact they had had on my life. When I think about that impact, my visit to Mr. Nowak years ago is a vivid memory.

It was rainy and somewhat cool for early June. The trees and grass were a deep green and the gardens I passed were just beginning to fill out. I had been called the day before to



request the assistance of hospice in allowing Mr. Nowak to return home to die. He had had a long battle with ALS and had remained at home with the help of his devoted wife and daughter. Earlier in the week he had been hospitalized and one night, in spite of his DNR order, was intubated as he developed respiratory failure. He made it clear to his family and physicians that he did not wish to live like that and requested that he be extubated. Mr. Nowak would need the assistance of hospice to have the tube removed and it would be done at home.

Heading up his street, I could see the wheelchair ramp at the front door long before I could identify the number on the house. Judy, the nurse from hospice, had already arrived, so we sat with Mr. Nowak's wife and daughter and heard the story of his battle with ALS. He had a prolonged struggle with the steady and progressive functional decline, to the point that he decided he wanted no further aggressive efforts to extend his survival. If it was his time to die, he was ready.

The ambulance transporting Mr. Nowak home had been delayed in the early rush hour traffic. We spent the time looking at pictures of celebrations and triumphs, chronicling his very full life. We heard the stories behind many of the pictures as his wife and daughter reminisced. The ambulance finally arrived and the mood in the house quickly changed. His family's anxiety was visibly evident as the ambulance crew wheeled the stretcher up the ramp. Mr. Nowak was home.

The crew left after assisting us in getting Mr. Nowak into his bed. After confirming that he wanted the tube removed we deflated the balloon, removed the endotracheal tube, and called his family into the room. He appeared to be comfortable, but his respiratory rate was slowing and it appeared clear that he was actively dying.

I was surprised when his daughter left the room, knowing that she wanted to be at his bedside when he died. She promptly returned, sat on the bed beside him, and opened a sealed envelope. She removed his Father's Day card and began to read her Father's Day message. She told him in great detail what a great father he had been, how she had always loved and admired him and how much he had meant to her. She thanked him for everything he had done for her and let him know what an important part of her life he had been. We were all weeping openly by the time she finished her Father's Day message.

Moments later he sighed slowly for the last time and died.

I had a long ride home that night, with plenty of time to think about how lucky I was that my father was living and in good health and how lucky I was to be working in hospice. None of my other work in medicine had been as consistently rewarding and gratifying. I did have to make one stop on the way home. I had a Father's Day card stamped and ready to go, but my "have a great day, see you soon" message seemed embarrassingly inadequate.



That night I wrote out my Father's Day card saying all the things I had left unsaid over the years, not just how much I loved him, but the things I wanted my father to know about the role he played in my life, my career choice, and my approach to patients. I had had a wonderful father and teacher and I wanted to be sure he knew it.

I explained this to the medical student who had asked the question. I assured him that hospice had had a very profound impact on me personally in so many ways, ways that I am not always conscious of. The most gratifying thing for me in medicine has been the relationships I have established with my patients and families, even if for a very brief time. ❧

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



took a lot of the burden away from us. To have help from people who understand and are compassionate and are there to work with you is a blessing.

Hope Hospice is a great organization, and the staff is awesome! ”

*Cheryl Hulslander  
Hope Hospice family member and caregiver*

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

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

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

