

A publication of Hospice of Central Pennsylvania
hospiceofcentralpa.org

Touching Lives™

Holding Hands. Holding Hearts.

**Living
Better,
Living
Longer**

Five Stages
of Life
Reconciliation

Why You Need
to Talk About It

Celebrating
the Journey

Simple Gifts
That Nurture
the Soul

Hospice
OF CENTRAL PENNSYLVANIA

When Time Together Matters Most

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Dear *Touching Lives* Reader,

Hospice of Central PA has been our community's leader in caring for those with a life limiting illness for over 30 years. We are an independent, not for profit, Medicare certified agency with a rich tradition of providing our services to all those in need, regardless of financial status. The generous support of many local foundations, organizations, and individuals allows us to enhance the scope of services we offer our patients and families. Today, in an era of large medical systems, corporate profits and complex treatment options, Hospice of Central PA continues to offer comfort and hope to those we serve by putting the needs of patients and families ahead of all else.

This issue of *Touching Lives* Magazine offers pertinent information for individuals and families who are in need of care as a result of a life-limiting illness. As you read through these pages you will find details about the services offered by Hospice of Central PA as well as articles that address some common issues and concerns.

We hope you find this magazine educational and helpful.

Karen Paris
CEO
Hospice of Central PA



To learn more about Hospice of Central PA, including how we can help, call us at **(717) 732-1000** or visit **HospiceofCentralPa.org**

For more information on volunteer opportunities or other ways to support us call **(717) 732-1000**

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Partial funding for Hospice of Central PA is made possible through support from the Carlisle Area Health and Wellness Foundation and United Ways of the Capitol Region and Carlisle and Cumberland County.



For Comfort and Hope

When Time Together Matters Most

How We Can Help

- ❁ Hospice care is not just for the last few days of life. In many cases, we provide services over several weeks or even months.
- ❁ Your private physician will help us to care for you or your loved one, but anyone can make a referral to hospice.
- ❁ Medicare and most insurance plans cover hospice care. However, when a patient has no insurance coverage, or when insurance benefits are exhausted, we provide our services free of charge.
- ❁ Medications and medical equipment related to the hospice diagnosis are provided as part of the hospice benefit.
- ❁ Hospice is not just for cancer patients. Our staff is trained to provide care for any type of life limiting illness including heart disease, ALS, Parkinson's, dementia, lung disease, Alzheimer's, and liver and kidney disease.
- ❁ We provide our services in many settings including private homes, our hospice residence, nursing homes, assisted living centers and in hospitals.
- ❁ Care is provided by a specially trained team of nurses, aides and social workers who visit according to the needs of each individual and family. Additional support is available from hospice chaplains, the patient's private physician, hospice physicians as well as massage and music therapists.

To find out more about how Hospice of Central PA can help or to request our services please call (717) 732-1000 or log onto www.hospiceofcentralpa.org. ❁



Advance Care Planning is an ongoing process that includes appointing a healthcare decision-maker, communicating and documenting medical care preferences and wishes, and addressing financial and estate related issues. The information on this page can help guide you and your family through the care planning process.

Understand your future health care options.

Learn as much as you can so you can make informed choices. Investigate services that are available in your area and how health care expenses will be paid.

Think about your choices in light of what is important to you.

Sometimes thinking about personal concerns and values, spiritual beliefs, or defining what makes life worth living can be as helpful as thinking about specific treatments and circumstances.

Share your end-of-life care decisions with your loved ones and doctors.

Talking about end-of-life issues can be awkward and initiating the conversation may be difficult but experts generally agree that having discussions 'before the crisis' is optimal.

Put your decisions in writing with these advance care planning documents

- A *Living Will* allows you to document your wishes for medical treatment if you are unable to communicate for yourself. Keep the original in a safe, but accessible, location and distribute copies to key family

Planning Ahead



"The future depends on what we do in the present"

Mahatma Gandhi



members and professionals including your physician and health care proxy.

- A *Medical Power of Attorney* (or healthcare proxy) allows you to appoint a person to make medical decisions on your behalf. Your agent can be a relative or a friend, but should be someone who knows you well and whom you trust to advocate on your behalf.
- A *Durable Power of Attorney* allows you to appoint an individual to manage financial matters if you are unable to do so yourself. It may be helpful to complete a financial inventory and have all of your important legal and insurance papers together in one place.
- A *Will* is a document that states how your money and possessions are to be distributed after death.

Reassess your decisions over time.

Care planning is an ongoing process and your views and wishes may change. It is important that you review these documents and your choices as your health or personal and family circumstances change throughout your life.

For more information

on advance care planning go to www.caringinfo.org.

For a free copy

of a living will entitled *Five Wishes*, please contact Hospice of Central PA at 717-732-1000. ☒

The Five Stages of Life Reconciliation

By David Kessler

Our 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

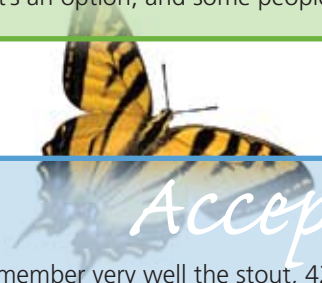
2 People have often said that facing a life-challenging illness has improved the quality of their lives. Specifically, it helped them take responsibility for their actions, thoughts, and lives. They know that they're not to blame for their diseases and that dying does not mean that they have somehow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



Forgiveness

3

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

4

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.

5

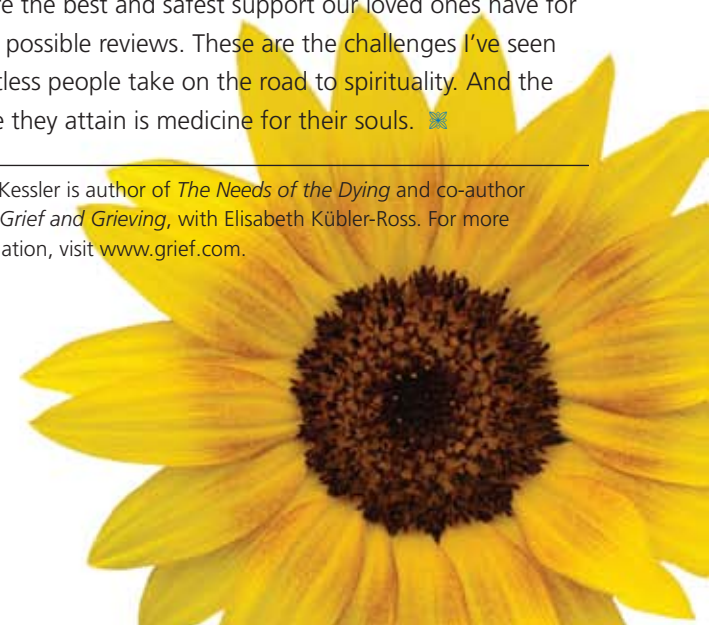
Gratitude

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. ✨

David Kessler is author of *The Needs of the Dying* and co-author of *On Grief and Grieving*, with Elisabeth Kübler-Ross. For more information, visit www.grief.com.



Why You Need to Talk About It

By Larry Beresford

❖ *What would Americans want if they knew they were nearing the end of life?*

Research conducted by the George Gallup Institute for the National Hospice Foundation found that people want to be free of pain and able to die at home, surrounded by their loved ones, with their dignity intact and their families protected from financial impoverishment by their care needs. This list of preferences tracks almost perfectly with what hospice care at its best is able to offer.

❖ *Are these care preferences realized when the time comes?*

In the most recent data from the Brown University Center for Gerontology and Health Care Research, only 23 percent of Americans die at home. Fully half of all American deaths (which totaled 2,448,017 from all causes in 2005) occur in the hospital, with 23 percent in nursing homes.

❖ *Why is there a disconnect between what people say they want and the care they actually receive at the end of life?*

A 1997 survey by the national advocacy coalition American Health Decisions found that Americans approach the thought of their own dying with a mixture of dread and procrastination—fearing a medically intrusive, mechanical pathway to death yet avoiding the kinds of conversations with family and health providers that could make their preferences known and honored. In fact, research has shown that Americans are more likely to discuss the emotionally charged topics of drug use and sex with their teenaged children than to talk about end-of-life care preferences with aging parents.

Living wills and other advance directives, which capture hopes and wishes for future medical crises in a legally recognized document, have been completed by only 40

percent of Americans. And experts say these documents are less likely to be effective if they aren't accompanied by frank discussions with physicians and with loved ones—especially those who would be making medical care decisions if the individual were to become incapacitated. Some physicians can be reluctant to give honest prognoses to their seriously ill patients.

❖ *If physicians are sometimes reluctant to give a terminal prognosis, and if patients are unwilling to think about or talk about end-of-life care options and preferences, do many patients choose hospice care?*

Yes, last year 1.4 million people with life-threatening illnesses received care from America's hospices, according to the National Hospice and Palliative Care Organization. In 2007, 39 percent of all deaths in the United States were under the care of a hospice, up from 35 percent the year before. Thus, while fears and resistance to a hospice referral may be common, many people are able to overcome these hurdles at a time when hospice can help them realize an end-of-life experience that more closely resembles what Americans say they would want. ❖

Larry Beresford is an Oakland, California-based medical journalist, hospice volunteer, and author of *The Hospice Handbook*.



Celebrating the Journey

By Maggie Callanan, RN

After 25 years of being a hospice nurse, I'm still in awe of the raw courage it must take to open the door to someone like me for the first time. Everything I represent must be frightening. Nobody ever wants to acknowledge that dying is a given.

But I ring doorbells over and over because I *know* I can make this journey more comfortable, less frightening, and more meaningful. My goal is to take this tragedy and “reframe” it into a final and positive opportunity.

What do I mean by “reframing”? It's like taking a picture, changing the mat color, adding a new frame, and repositioning it on a different wall so it has a different look, feel, and effect on the room. The picture itself hasn't changed, but the way we look at it now is different... so it *feels* like it's changed. It may look more positive now.

So, how do you take a loss and make it look and feel like a final, powerful, even wonderful life opportunity to be shared? After trust and physical comfort are achieved, “reframing” is the answer.

There is no one right way. Some people look for spiritual meaning in their illness; others find solace in inspirational readings, while there are those who may write their stories for others dealing with illness and loss.

My way is more direct and concrete. I sit with the caregiver and sometimes the patient. Using a long piece of paper, we make three vertical columns titled FIXABLE, MEMORY MAKING, and NOT FIXABLE.

The first column is FIXABLE. This would include aspects of the illness like pain, nausea, constipation, avoiding skin breakdowns, sleep disturbances, depression, anxiety, fear, isolation, caregiver stress, and exhaustion. These are all problems that hospice is trained to improve or eliminate. It is logical to give these issues our fullest attention and energy to increase the quality of life for the patient and family.

The middle but most important column is MEMORY MAKING. This column will embody the hopes and dreams yet unrealized. “What haven't you done that you always wanted to do?” “Whom would you like to see?” “Where would you like to go?” “How can we help accomplish your wishes?”



The last column is NOT FIXABLE. These are situations and symptoms that cannot be fixed but could possibly be controlled or made manageable as they increase over time, issues like continued progression of the illness, increasing weakness, decreasing appetite, increasing sleepiness, increasing time in bed, and emotional detachment from the less important aspects of day-to-day living.

It is important for the patient and family to recognize those issues that are not fixable so they will give them less focus and attention. Rerouting their attention and energy to the fixable issues becomes the more beneficial priority.

However, constant monitoring by clinicians of the “not fixable” can often forecast changes ahead and suggest appropriate interventions or adjustments that will make these not fixable difficulties more manageable.

Once this column is filled out, we fold the sheet so this last column is now facing the back of the paper. The clinicians will work on this column very diligently. But the patient’s and family’s attention are now directed to the first two columns, where their efforts will reap rewards.

Many of my former patients and caregivers chose to reframe their terminal illness and use this important time as their final opportunity to live every moment as richly as possible until death came, rather than die every moment until the end. The following are some great examples.

A dying young mother used her time taking family photos that captured memories made with her young children and placing the photos into beautiful, individual albums called “Mommy and Me”—personalized memory treasures for each child.

The dying wish of one gentleman was to attend the reunion of the Battle of Normandy in France. Although severe issues of pain initially made this plan seem impossible, with the help of the hospice team, the comfort provided by a morphine pump, and the sheer determination of this patient and his family, this amazing



dream was shared together and continues to be a treasured memory for this family.

The brain tumor that had already stolen David’s eyesight, caused transient deafness, and rendered him bedfast did not thwart his drive to finish writing his book, with the daily help of his family. He completed it and died knowing it had just been accepted for publication.

Sound unusual? Not as much as you would think. Many people choose to live quiet but remarkable lives. By reframing, they use this final opportunity in remarkable ways and, by so doing, leave remarkable memories.

It’s a choice. But why choose a legacy of anything less? ❖

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

Living Better,

By Ira Byock, MD



Living Longer

One day in early winter of 2007, a *New York Times* reporter interviewed me for a story she was writing about the reasons people were referred for hospice so very late in their illnesses. We talked about the Medicare law and insurance policies that impose needless financial barriers and make doctors worry about referring patients who might survive longer than six months.

I told the journalist that there was no clinical or ethical rationale for forcing people to choose between treatments for disease and comprehensive care for their comfort and quality of life.

She asked me what I thought about humorist Art Buchwald's book about his hospice experience, which had become a best seller, and his surprising longevity. I explained that Buchwald's experience was not rare and mentioned that I recalled several

patients who survived because of our care. "Really? Can you think of anyone I might be able to talk to?" the reporter asked, obviously intrigued. I said I would get back to her.

Buchwald, whose *Washington Post* column was syndicated in hundreds of newspapers nationally, became a poster boy for the life-extending effects of hospice care when he wrote *Too Soon to Say Goodbye*, his account of thriving when he was supposed to be dying. He had been hospitalized with peripheral vascular disease and kidney failure, and decided to focus on quality rather than quantity of time. But instead of dying, he began to get stronger.

His book is a moving, honest, and insightful reflection on illness, love, friendship, depression and joy, and life and death. Buchwald writes, "I am known in the hospice as 'The Man

Who Would Not Die,'" adding, "But in case you're wondering, I'm having a swell time—the best time of my life."

Let's face it: the very words "hospice" and "palliative care" tend to scare people. Although people who are struggling with cancer, heart, lung, or liver disease would clearly benefit from the services that hospice and palliative care provide, for some, the terms carry fearful symbolic power, even superstition.

Recently, I introduced myself as "Dr. Byock, from the Palliative Care Service," to a man who was hospitalized for advanced heart failure. He responded in defiance, "I'm not that far gone!" The same week, another patient responded to my suggestion that hospice would be helpful in caring for her and supporting her family at home, by plaintively asking, "Is there really no hope?"

Unfortunately, many people think accepting hospice or palliative care means you have to give up on living and embrace your dying. No wonder they don't want it.

This is a critical challenge, because ill people and their families may resist, delay, or refuse this care without knowing what they are missing. Recent research into the impact of hospice care on length of life reveals just how pressing this problem is.

Researcher Stephen Connor and his colleagues studied Medicare data for people who had died of one of five categories of cancer or congestive heart failure. They found that people who had received hospice care lived an average of twenty-nine days longer. People with advanced heart failure or cancers of the lung, colon, or pancreas survived significantly longer with hospice than without it.

As I decided which hospice success story to share with the *New York Times* reporter, I thought of Mitchell Zimble, a 74-year-old man who was then dying of cancer.

Mitchell's cancer had begun in his prostate but had spread throughout his abdomen and liver, and was wreaking havoc on his body. His oncologist told me that he thought Mitchell had just a few weeks to live and asked our Palliative Care Service to get involved to help control his symptoms and support him and his family.

Mickey, as he preferred to be called, had been hospitalized for over a week and told me he felt miserable. Gnawing pain in his groin and around his liver, nausea, and rampant diarrhea were sapping his strength and will to live. He told me he knew he was dying. He just wanted to feel less awful.

We started by listening to his and his wife's description of his symptoms and their concerns. Mickey's wife, Sandy, was at his bedside day and night, and beside herself with worry. She felt overwhelmed with the many details of his treatments. And her anxiety was proving contagious to the many friends and relatives who loved them both.

We assured them we would do everything we could to make things at least a little better. I said, "Even though we cannot expect a cure and recognize that Mickey's life is limited, there will always be things we can do to improve his comfort and quality of life."

Unfortunately, many people think accepting hospice or palliative care means you have to give up on living and embrace your dying. No wonder they don't want it.

We switched him from long-acting morphine pills to a transdermal pain patch, which delivered medicine through his skin directly to his bloodstream, bypassing his already upset stomach. We discovered that his diarrhea was due to "*C. diff*," an all-too-common infection among hospitalized patients with weakened resistance, and started him on IV antibiotics.

Within a day, Mickey felt a little bit better. I told him that after spending over an hour reviewing his medical records, I knew a lot about his diagnoses, scans, blood tests, and treatments but almost nothing about him as a person. He told me he was born and grew up in the Boston area. He and Sandy met during his last year of college and were married just after he graduated. Sandy proudly explained that he was a born entrepreneur who took his father's scrap metal company and made it a supplier of raw materials to major American industries. He had recently retired, and the couple split their time between their retirement home in rural Vermont and a condominium in Florida. They had hoped to spend their retirement years playing tennis and golf and enjoying their children and grandchildren.



With meticulous attention to his many medical problems, Mickey became more comfortable, and Sandy grew confident in her ability to manage his care at home. Five days after we met him, we began discharge planning in earnest. I explained that hospice offered the best home care and support for Sandy. I assured them that we were only a phone call away and we would see him whenever he returned for appointments with his oncologist.

We arranged for his hospice nurse to meet the Zimbles in the hospital two days before discharge and again at home the same day he was discharged. I called their home two days later. Sandy said that, to her surprise, things were going very well. Mickey's pain was much better. He was eating a bit more at meals and had developed a taste for chocolate covered raisins. She asked if she should worry about that, but I thought it was a good source of extra calories and iron.

Hospice care for the Zimbles included visits by his hospice nurse—at first, three times a week—as well as visits by the hospice physician, social worker, and physical therapist. If it sounds like a lot, you're right. This was intensive care. But it worked.

Over a period of weeks, Mickey gained weight—and became stronger. He took walks and carried around a putter as a cane. He started reading the newspaper again and took up Sudoku. Within two months, he was walking a mile and a half every day and had progressed from putting practice on his lawn to nine holes of golf. He dropped out of hospice, simply because he didn't need the services.

In August, when I saw them in the cancer center's infusion suite, Mickey looked well. Sandy told me, "Hospice care gave me my Mickey back." Mickey nodded and smiled but said he credited the chocolate covered raisins. His oncologist felt he was strong enough to restart chemotherapy. For several months, it worked to shrink his tumors. Mickey was able to enjoy the summer and fall that he had not expected to see. As winter approached, the Zimbles decided to spend it at their second home in Florida. In conjunction

with Mickey's oncologist, we spoke with his doctor in Florida and transferred the test results and care plans.

The *New York Times* reporter never was able to talk with Mickey. Every time she called, he was either running an errand or playing golf, but she was able to talk with Sandy. Sandy recalled a doctor in Florida who reviewed Mickey's records and told him, "On paper you should be dead, but you look great." On February 10, 2007, the *New York Times* story featuring the Zimbles was titled "There Is Life After Hospice, and Even Golf in Florida for Some."



When the cancer again progressed, it was clear that further treatment would not be in his best interest. Mickey was again cared for by a hospice program in Florida during his last days. Both he and Art Buchwald outlived all expectations of their doctors, apparently because of intensive care that was focused on their comfort and quality of life. It is not really surprising that by reducing

people's pain and other symptoms, planning their treatments, and preventing foreseeable problems, some people end up living longer. At the very least, doing so makes their lives and their families' lives a little easier.

Art Buchwald made his living as an astute social commentator. He concludes the first chapter of *Too Soon to Say Goodbye* by observing that "Dying is not hard. Getting paid by Medicare is."

It is time for Medicare and insurance companies to relax regulations that restrict access to hospice, and expand support for palliative care. Instead of resisting hospice and palliative care, people are wise to insist on this care for themselves and those they love.

As a doctor in this field, I have long been fond of saying that hospice and palliative care add life to people's days. It is now clear that they can also add days to people's lives. ❧

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

Simple Gifts

That Nurture the Soul

By Matthew P. Binkewicz

Spirituality expresses the most profound aspects of our lives. As human beings, our journey of life is marked by certain rites and passages that define us as individuals sharing our experiences, celebrating our triumphs, and seeking solace in times of need.

When we stand face to face with a terminal illness, we search for answers to life's most intimate and profound questions. Our relationship with the Divine, life's meaning and purpose, fear, and uncertainty seem to consume our thoughts and energy.

Good spiritual care focuses attention on the moments in our lives when faith seeks meaning in our pain and suffering. There are ways that each of us can provide spiritual care to those who are on the final journey in this life. The simple gifts that all of us possess—the gift of presence, the gift of silence, and the gift of stillness—are essential for good spiritual care.

The gift of presence, the mere act of being near to someone who is dying, sends a message to a person that he or she matters. Regardless of their social or economic standing, when you take time to sit in the presence of other human beings, you acknowledge them for their real worth. They matter because they are fellow travelers who now journey toward uncharted territory, and you have made the effort to be with them. By your presence, you have declared they have dignity and are fully human, regardless of their outward appearance or physical condition.

The second gift you can offer is silence. Silence gives a dying person the opportunity to speak without fear or apprehension. Silence nurtures the soul, which in turn offers a calming presence over the entire being. When a terminally ill person is at peace, his or her loved ones are at peace. It is in moments of silence that we can learn to live and love in ways unattainable amid the noise of our busy lives. Silence speaks volumes.

Stillness, the third gift, provides a channel by which the soul communicates with the Divine. When we quiet ourselves both internally as well as externally, we allow the power from within to commune with the Power behind our existence. Stillness is a discipline that gives a dying person the opportunity to acknowledge what has happened, to experience the present, and to accept what may come.

The Shaker hymn "Simple Gifts" captures the essence of spiritual care in the lyrics: "'Tis a gift to be simple, 'tis a gift to be free." Patients and their families yearn for the simple gifts that free them from fear and uncertainty as end of life approaches. Let each of us be bearers of these simple gifts and provide the best spiritual care as we journey with those facing a terminal illness. ❧

Matthew P. Binkewicz is a hospice chaplain, educator, and author of *Peaceful Journey: A Hospice Chaplain's Guide to End of Life* and *Spiritual Care Companion*. You may contact him at matthew@matthewpbinkewicz.com.

presence

silence

stillness

Making Wishes Come True

By Stephen P. Kiernan

Sally had advanced brain cancer, but she was less worried about the prognosis than she was about being cogent enough to say proper goodbyes. With the help of energetic hospice volunteers and nurses whose compassion included a ready sense of humor, Sally's family threw her a living wake. It was a huge party: toasts, tears, laughter, even a rock and roll band. "Everyone is here," she told her children and grandchildren. "I feel so loved. This is going to make everything else so much easier."

Hospice is primarily about delivering good medical care to people in the last phase of their lives. But the true benefit of hospice is the nonmedical opportunities it makes possible.

At the end of a long struggle with HIV, all Tom wanted to eat was chocolate ice cream. Even when he could no longer appreciate the flavor, it cooled his parched mouth. One day a hospice social worker was just entering his room with a fresh bowl when Tom's brother Pete arrived. They had been estranged for years, and it was an awkward moment. Tom told the social worker he did not have the energy to feed himself right then. She offered the bowl to Pete, who took it with some unease but then sat and began spooning ice cream into his brother's mouth. And in baby steps, they began to converse.

When the social worker returned later to get the bowl, Tom held it out to her. "I thought you didn't have any energy," she said.

"Pete and I have a tough history," Tom answered with a wry smile. "He's going to need some positive memories after I'm gone."

The familiar definition of healing is cure of a disease. Hospice demonstrates that healing has many other meanings.

Eighty-two-year-old Gracie was a devout Catholic whose six adult children had all left the church. Hospice arranged for a priest to come and say the rosary with Gracie. He happened to arrive when the whole family and a hospice

nurse were gathered in her room. As he began praying aloud, the children one by one inched toward the door. Just as the eldest left the room, Gracie had a fit of difficult breathing. Everyone rushed back to her side. Her breath soon calmed, and the priest resumed his prayers. Again the children tiptoed away. Again Gracie coughed and gasped; her breathing eased only after everyone had returned. After the third episode, the nurse whispered to the family, "She wants you to stay."

The children laughed and remained in the room, and Gracie's prayers were answered.

Farewell parties, mended relationships, prayers answered—this is what hospice does best. ✕

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



Create a Caregivers Community

By Margaret O. Kirk

Last winter, Susan Einbender wanted to help coordinate meal deliveries for a dear friend whose husband had been diagnosed with a terminal illness.

As she hit the “send” button on her computer, blasting an e-mail to everyone in her address book, Einbender instantly dreaded the constant influx and overlapping of electronic responses, a situation she had experienced when her sister was ill and friends rallied to help. One of the first responses, however, proved to be a godsend. “You may want to check out this Web site,” a friend wrote. “It’s called Lotsa Helping Hands.”

Lotsa Helping Hands (www.lotsahelpinghands.com) is an online, private group calendar that’s specifically designed to organize individuals who want to help loved ones in need. As Einbender soon realized, the free, Web-based calendar and message board system helped her coordinate meal deliveries, monitor schedule changes, provide medical updates, and post special notes of thanks from her friends and her family.

After inviting concerned friends to join the online community, Einbender watched as they quickly used the Lotsa Helping Hands calendar to decide on menus and drop-off times, and even when to skip a delivery if leftovers were plentiful.

“I couldn’t believe that someone had created something so perfectly matched to what our needs were,” said Einbender, an early intervention educator at the Pennsylvania School for the Deaf in Philadelphia, Pennsylvania, where she lives with her husband and two children. “There was nothing I would have liked to have had that I couldn’t find on the site.”

Einbender’s experience is exactly what Lotsa Helping Hands co-founder Hal Chapel enjoys hearing. Chapel and co-founder Barry Katz created the concept in 2005 in Sudbury, Massachusetts, after experiencing firsthand how friends wanted to help in response to a medical crisis in Katz’s family. With Chapel’s background in starting high-tech companies, the two men immediately turned to the Internet as a way to provide a service “when friends and family need help.”

Chapel decided early on that the system would be “easy to use. It doesn’t require computer training.” Einbender agreed. “I barely get by with my limited computer skills!” she said. “And I found it incredibly easy.”

According to Chapel, there are now more than 12,000 individual online communities on Lotsa Helping Hands, communities that do whatever it takes for “life to run smoothly during times of medical crisis, end-of-life caring, or family caregiver exhaustion.”

“I grew up in a household where my parents were caregivers for their parents,” said Chapel. “I didn’t know that you did anything but take care of people, and I saw a lot of the stress and the burden that people went through.”

Chapel points out that Lotsa Helping Hands is also an information resource for caregivers and provides partnerships with more than thirty professional organizations, like the Alzheimer’s Association, Living Beyond Breast Cancer, and the Well Spouse Association.

“People in the community want to find some way to support the people they care about,” said Chapel. “With Lotsa Helping Hands, they can.” ✕



Hospice

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Bereavement and Support Programs

photo ©2005 L.M. Sweger

Hospice of Central PA offers grief and bereavement support in many forms, including individual visits, educational programs, phone contacts, social programs and support groups. All of our bereavement programs are free of charge and open to anyone, regardless of whether your loved one was cared for by our agency.

Regularly scheduled programs are listed below. Call (717) 732-1000 or (717) 241-0014 for program dates, times and locations.

Passages

A general support group for adults who have lost a significant person in their lives. This group is offered in both our Harrisburg and Carlisle offices.

Harmony

This group is open to widows and widowers who have experienced the death of a spouse at an early point in the life cycle. This group addresses general grief issues, as well as concerns related to children, being single again, role changes and transitions at work. Babysitting may be available.

Transitions

This is a group for individuals who are grieving two or more years after the loss of a loved one.

Generations

This group addresses issues that arise in adult children who are grieving the loss of a parent(s). The goal of this group is to ease adults through the transition that occurs after the loss of a parent.

Ladies Luncheons

A monthly luncheon designed for women who have experienced the death of a spouse. Locations vary throughout the area and include restaurants in Carlisle as well as the East and West Shores.

Men's Breakfast

This monthly breakfast is designed for men who have experienced the loss of a spouse. Locations vary from East to West Shore.

Growing Through Grief

This 6 week series offers education and support to individuals who have experienced the death of a loved one. This series is offered multiple times throughout the year in various locations.

Newly Bereaved Series

This is a three week series offering education and support for adults who have experienced the loss of a loved one within the last 1-3 months. This series is offered multiple times throughout the year. ❄

The Carolyn Croxton Slane Residence

The Carolyn Croxton Slane Residence provides 24 hour hospice care to individuals who are unable to remain at home. We can offer residential hospice services when personal choices or complex medical needs make other care options and settings impossible or undesirable.

The Residence is operated by Hospice of Central PA and offers:

- Individualized care and attention
- A warm home-like setting
- 24 hour hospice care
- 6 private bedrooms
- Indoor and outdoor living areas for patients and families
- 24 hour visitation

Situated on several private wooded acres in Susquehanna Township, the Residence is easily accessible from Hershey and the East and West Shores.

To learn more about The Carolyn Croxton Slane Residence, call (717) 732-1000 or 1-866-779-7374 or visit our website: www.hospiceofcentralpa.org.



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Carolyn Croxton Slane Residence



Save the Date

Saturday April 24, 2010

Please Join

Hospice
OF CENTRAL PENNSYLVANIA

At the Sheraton Harrisburg Hershey
For a very special evening with

Jeff Zaslow,

co-author of the international bestseller

The Last Lecture

Lessons from the final lecture
of Carnegie Mellon Professor
Randy Pausch

also

Author of the NY Times Bestseller

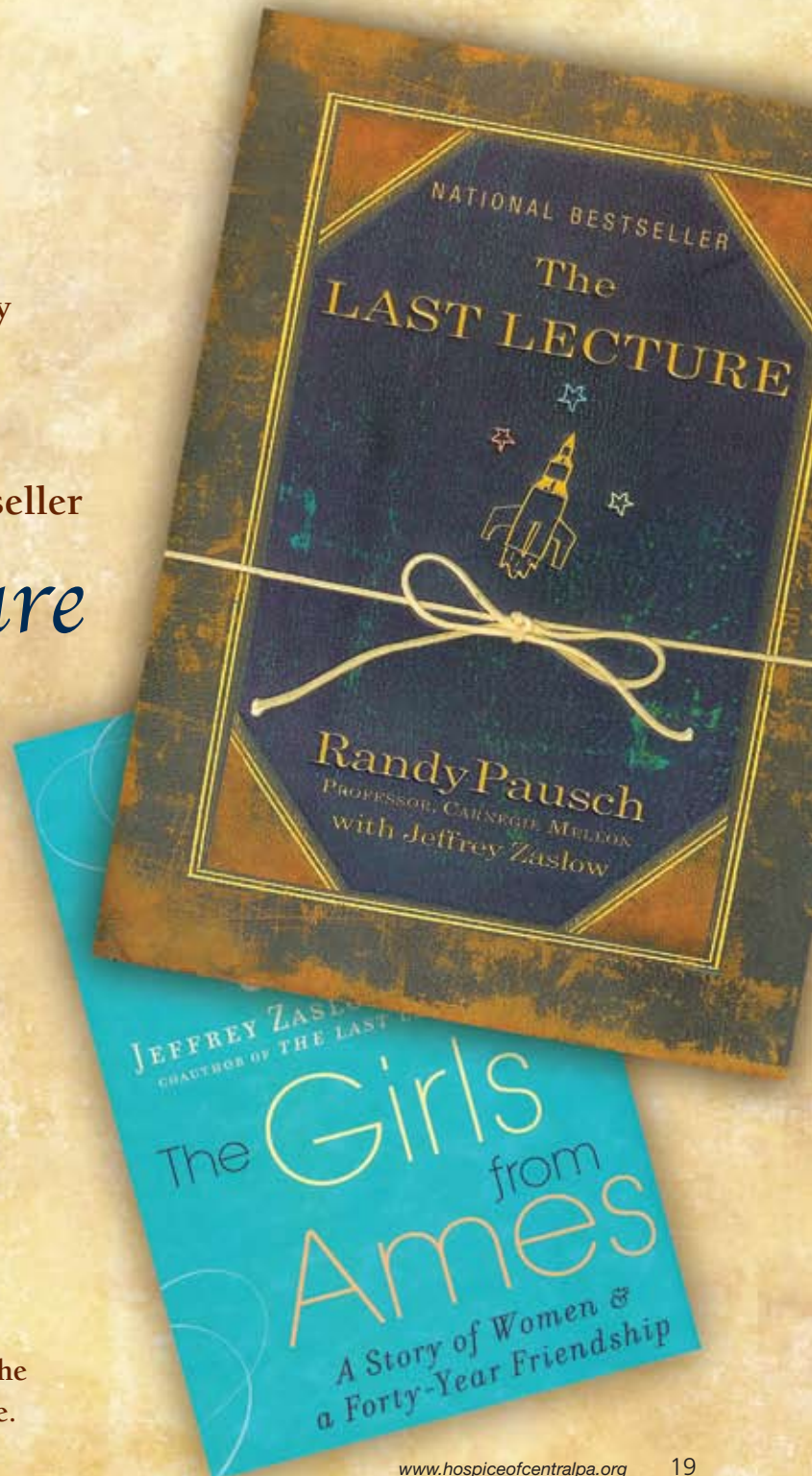
The Girls from Ames

A story of women
and extraordinary friendship

Seating is limited

For more information or tickets
for this gala event please call
(717) 732-1000

Proceeds from this event help to support the
Carolyn Croxton Slane Hospice Residence.



When Time Together
Matters Most



There is only one

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