Being with the Dying

What does the faith leader bring to the dying person and his/her family that’s different—maybe even unique? (Unique to your faith, denomination and person)

1. A reminder of the presence of the Mystery (e.g., God, higher power)
2. The ability to identify and water the seeds of happiness.
3. The awareness of and facility in working with the myriad decisions facing the dying and their family members.
4. An ability to explore and offer insight into the meaning of one’s life and one’s spiritual experiences, including dying.
5. The conduit to our culture’s rituals around dying
6. The ability/assignment to just be in the presence of suffering
7. A willingness to enter into the unknown/to be a safe anchorage in a tumultuous sea
8. An ease/facility with the symbolic and experiential (to acknowledge, without suspicion, the special awareness the dying often acquire).
9. Facilitate the critical end-of-life tasks: saying I love you, Thank you, Forgive me, etc.

How can the faith leader be/feel present for the dying? (Being, not doing, which is hard to get our hands around. Involves opening our hearts to whatever is unfolding)

1. Do your own death work.
2. Confront your own demons around death and dying.
3. Have an ongoing "talking partner" (someone with whom to process this work and the feelings it engenders).
4. Rely on your faith and be familiar with your faith’s tenets re: dying, refusal and withdrawal of treatments (including nutrition and hydration), pain management.
5. Feel safe in knowing that your comfort level will grow and be aware of what you will gain/receive/learn on this path
6. Use the Braille method — feel your way through.
7. Remember spiritual care is relational.
8. Make a space for yourself at the table. (Become part of the team supporting the patient and family.

What can the faith leader “do” while being present?

1. LISTEN -- Listening for Cues and Themes.
2. Show up (be fully present).
3. Be a spiritual & religious presence.
4. Be a non-judgmental presence.
5. Have an inviting demeanor.
6. Resist the urge to impose your own agenda.
7. Be a conduit to faith and the spiritual.
8. Be a calming, open model to the family and caregivers.
Every night before putting on his pajamas, Dad emptied the coins from his pockets. The special ones he placed in an album, but most went into a jar to be saved.

So how could the hospital bill for the final days of this frugal man -- with carefully prepared end-of-life instructions -- add up to $323,000 in just 10 days? That’s the price of a home for a struggling family. Enough to put a future doctor through medical school. Hundreds of prenatal visits. Thousands of vaccinations.

My father’s story -- the final days of a frail 88-year-old with advancing dementia at the end of a long and rewarding life -- poses a modern dilemma: Just because it’s possible to prolong a life, should we?

It’s a story of people doing their best in a system that’s built to save our loved ones. And it’s a reminder of the impossibility, during a crisis, to assess costs and benefits that aren’t at all obvious.

This was the lesson of my father’s passing: It is easy to get quick access to world-class treatment. It’s much harder to reject it.

"If we look at what's coming down the road in technology," said 81-year-old bioethicist Daniel Callahan of the Hastings Center, "we have to realize that this endless fight against aging can’t go on.

"What medicine provides is more and more ways to keep people going," he said. "An extra few days, or a month -- it is very, very hard for doctors and families to give that up."

First, two important facts: Stanford Hospital provided great care, and it lost money on my dad. Of his final bill, Medicare only paid $67,800. Like other hospitals, Stanford only collects what its contract with Medicare specifies. Therefore, Stanford wrote off the rest of the expenses, and will recover the money over time through other patients’ private insurance and fundraising. While Stanford doesn’t make a profit, it needs to break even.

This background helps explain why Americans spent nearly $2.6 trillion on health care in 2010 -- or about $8,400 per person, the federal government reported this month. That’s almost double the $1.37 trillion in spending in 2000. As baby boomers age, the climbing cost of health care poses a threat to the nation’s long-term solvency.

"The costs are rising at an unsustainable rate," said Virginia Hood, president of the American College of Physicians, which this month issued guidelines urging more cost-conscious care.

"It’s 17.6 percent of our GDP (gross domestic product) -- twice that of any other country," she said. "Yet we don’t provide care to the same number of people as do other countries, and our health is not as good."

And we don’t spend health care dollars equally. Five percent of Americans accounted for half the total. About one-fourth of Medicare spending goes to pay for the care of people in their last year of life -- generally, in a hospital. The average end-of-life hospital stay is 12 days; of those, seven days are spent in an intensive care unit, according to data from the Dartmouth Atlas of Health Care.

Death used to be a family affair. Increasingly, it’s institutional.

Who’s driving big health care spending? People like my dad.
A plan for death

That bill for $323,658 would have angered Dad because he did all the right things. Determined to avoid suffering and costly heroics, he had drawn up "do not resuscitate" and "desire for a natural death" orders.

Kenneth Harris Krieger was a man who sought to give to society, not take. He was a successful engineer with an MBA, a devoted husband and father, an usher at church on Sunday mornings. He grew up during the Depression as the son of a judge. At 19, when war broke out, he was sent to work on the Manhattan Project. Later he traveled to five continents, built Heathkit radios, tutored me through chemistry and perfected a powerful tennis serve. I adored him.

Thanks to modern medicine, he lived decades longer than his father.

But Alzheimer’s crippled his mind. And his hearing had faded. Frustrated by his inability to hear, comprehend, or speak, he turned silent. There were moments of contentment, but every day he seemed more remote, sad and uncomfortable. He asked for my mom, dead for five years. He hid his wallet and accused caregivers of theft. One night he tried to escape through a window. His back ached. His heart was arrhythmic. And his bones had grown brittle.

When he tripped and broke his hip three months earlier, surgery was traumatic -- he couldn’t understand why he hurt, where he was, or how to heal. Increasingly, he just slept.

Should we have quit?

The medical nightmare started, as they so often do, incrementally. On a lovely Saturday, under a cobalt blue sky, we shared a happy day of gardening. He couldn’t remember how to rake, but helped by picking up each leaf by hand. I showed him how to wind a garden hose. He became drowsy after lunch, so I drove him back to his assisted care facility.

He wasn’t feeling well that Sunday, and he couldn’t say why. Caregivers didn’t find a fever. I made a doctor’s appointment, then massaged his back until he slept. The doctor prescribed antibiotics.

By Tuesday he was shaking, dehydrated and speaking gibberish. Fear was in his eyes. I raced him to Stanford’s emergency room. The diagnosis: septicemia. Bacteria were rushing into his bloodstream, causing shock. At 88, his immune system was weak. His veins were leaking, causing his blood pressure to crash. He needed fluids, antibiotics and a tube to help failing lungs. It was the last time I saw him conscious, the last time I saw his open eyes.

Doctors and nurses in the emergency room jumped into action. The final bill attests to their effort: ER charges ($18,589), catheter to monitor oxygen ($2,125), other catheters ($5,400), chest X-ray ($1,076), and much more.

Should we have quit then? Suddenly, that "do not resuscitate" order seemed unclear; its black-and-white legal language didn’t really apply. He needed a ventilator to help him breathe long enough for antibiotics to work. Dad’s acute infection seemed treatable. Doctors said there was a decent chance we could turn it around. We’d likely know within a day, they said.

'Who was I to summon his death?'

I was adrift in a sea of conflicting emotions. Even if we saved him, dementia would continue its march. Some other illness, at some later time, would claim him. But he deserved a chance. And in the hospital I felt secure, no longer terrified and helpless. Diagnosis and cure: That’s the fuel that drives the clinical engines of places like Stanford.
This was a man who gave me life. Who was I to summon his death?

Proceed, I said. It’s a risk worth taking.

So Dad was moved into the ICU, and I got a bedside cot. Daily charge for the ICU: $25,643. There were glimpses of hope; his blood pressure was stabilizing. He held my hand again.

But there was still infection -- where was the source? The search began, with X-rays, Doppler exams and other powerful tools.

Such advances in medical technologies save lives. And they are some of the most powerful forces behind the nation’s soaring health care costs. The more tools advance, the longer ill people are kept alive. Each new innovation raises patients’ and their loved ones’ expectations - - and costs.

Yet by Friday, Dad still wasn’t strengthening. I noticed something new -- every time nurses moved him, he winced in pain. Over the hours, we saw why: The infection was in his leg, creating black necrotic patches. This was no routine bacteria. After repeated blood cultures, X-rays and another day in the ICU, we finally had a diagnosis: necrotizing fasciitis, a rare and deadly flesh-eating infection.

Now was it time to stop?

A new Pfizer drug, Linezolid ($1,936), held out hope. A synthetic antibiotic, it targets bacteria resistant to other antibiotics. And it can protect against bacteria-induced toxic shock.

Increased use of medicines is another big driver of costs. The cost represents years of research, and patent protection. And demand is increasing: From 1999 to 2009, the number of prescriptions purchased in the United States grew 39 percent, while the population rose 9 percent.

Exhausted, I felt lost. By some measures, Dad was improving, thanks to aggressive care in the ICU, yet his climbing white blood count suggested a turn for the worse. And he hadn’t regained consciousness. Had the initial crisis been too catastrophic?

One last powerful tool

The infectious disease team deployed a powerful, $48,000 weapon: immunoglobulin. Part of a new class of therapeutics called "biologics," immunoglobulin infuses antibodies into patients who can’t make their own. It’s expensive because it’s hard to produce. Each liter of donated plasma yields 4 grams of product, and takes 200 days to make.

Yet even that didn’t help.

Now should we quit?

If Dad recovered, what awaited us? Unwittingly, with the best of intentions, we were violating his desire for "a natural death." Was this escalating price -- emotional, physical and financial - - worth it?

Only surgery could turn around this galloping infection, doctors said. Antibiotics weren’t enough. I heard the phrases "wound care," "possible amputation" and "skin grafts."

Every year, increasing numbers of old and sick people undergo surgery. That’s because we’ve become so good at it. Improved techniques mean doctors can operate on patients who would have been ineligible in the recent past.

It can be a blessing, prolonging lives. But the cost of elder care can be higher -- and the outcome less certain.

But could an 88-year-old with weak bones, an irregular heartbeat and dementia
survive? And if he survived, then what? When all the specialists left, I summoned my strength and stopped the attending physician: Please, tell me what’s ahead of us.

"It’s not black-and-white; it’s gray," he said, choosing his words carefully. "A long and bumpy recovery, with no guarantee of success."

**Complicated forecast**

It’s difficult to predict a patient’s prognosis, said Norman Rizk, Stanford’s interim chief medical officer. A national database, APACHE, offers a general prediction of mortality, based on age and other factors, he said. But it can’t forecast a patient’s future.

The issues of cost and allocation of care are societal challenges still to be tackled, he said.

"It’s very complex," he said. "We all recognize the tension between these personal situations and the public good -- the challenge of ‘distributive justice,’" or the fair sharing of a limited resource.

"In Congress, and on the campaign trail, some groups believe that life is sacred and we can always support it, forever. Thirty percent of the general public believes that God can bring miracles to bear when patients are hopelessly ill.

"And doctors want to be able to make things better and sometimes overestimate the utility of what they do. They want to be hopeful," he said. And in a crisis, families don’t want to hear the price of care, he added. They may sue if they feel care was wrongly denied.

"There are very powerful incentives for physicians not to pay a lot of attention to cost."

Feeling alone, I phoned Dad’s surviving family and friends. Their wisdom: Let him go. He is suffering without purpose.

There are far worse things than death.

Now, finally, it was time to stop.

Dad was moved out of the ICU. Over the next four days, his breathing turned shallow, but he slept deeply, sedated by painkillers. A nurse woke me at 3 a.m. Two young doctors rushed in and asked his cooling, pulseless body: "Mr. Krieger, can you hear me?" A chaplain came, with prayers.

Then it was just the two of us, in blessed silence. No more expert opinions, beeping monitors or hissing respirators. No more tests. No more tubes.

I kissed him goodbye, packed my bag and walked into the cool night air.

Modern medicine had carried Dad’s body beyond what it could bear. Even the best life is finite.
As a divinity school student, I had just started working as a student chaplain at a cancer hospital when my professor asked me about my work. I was 26 years old and still learning what a chaplain did.

"I talk to the patients," I told him.
"You talk to patients? And tell me, what do people who are sick and dying talk to the student chaplain about?" he asked.
I had never considered the question before. "Well," I responded slowly, "Mostly we talk about their families."
"Do you talk about God?"
"Umm, not usually."
"Or their religion?"
"Not so much."
"The meaning of their lives?"
"Sometimes."
"And prayer? Do you lead them in prayer? Or ritual?"

I felt derision creeping into the professor's voice. "So you just visit people and talk about their families?"

"Well, they talk. I mostly listen."
"Huh." He leaned back in his chair.

A week later, in the middle of a lecture in this professor's packed class, he started to tell a story about a student he once met who was a chaplain intern at a hospital.

"And I asked her, 'What exactly do you do as a chaplain?' And she replied, 'Well, I talk to people about their families.'" He paused for effect. "And that was this student's understanding of faith! That was as deep as this person's spiritual life went! Talking about other people's families!"

The students laughed at the shallowness of the silly student. The professor was on a roll.

"And I thought to myself," he continued, "that if I was ever sick in the hospital, if I was ever dying, that the last person I would ever want to see is some Harvard Divinity School student chaplain wanting to talk to me about my family."

My body went numb with shame. At the time I thought that maybe, if I was a better chaplain, I would know how to talk to people about big spiritual questions. Maybe if
dying people met with a good, experienced chaplain they would talk about God, I thought.

Today, 13 years later, I am a hospice chaplain. I visit people who are dying – in their homes, in hospitals, in nursing homes. And if you were to ask me the same question – What do people who are sick and dying talk about with the chaplain? – I, without hesitation or uncertainty, would give you the same answer. Mostly, they talk about their families: about their mothers and fathers, their sons and daughters.

They talk about the love they felt, and the love they gave. Often they talk about love they did not receive, or the love they did not know how to offer, the love they withheld, or maybe never felt for the ones they should have loved unconditionally.

They talk about how they learned what love is, and what it is not. And sometimes, when they are actively dying, fluid gurgling in their throats, they reach their hands out to things I cannot see and they call out to their parents: Mama, Daddy, Mother.

What I did not understand when I was a student then, and what I would explain to that professor now, is that people talk to the chaplain about their families because that is how we talk about God. That is how we talk about the meaning of our lives. That is how we talk about the big spiritual questions of human existence.

We don’t live our lives in our heads, in theology and theories. We live our lives in our families: the families we are born into, the families we create, the families we make through the people we choose as friends. This is where we create our lives, this is where we find meaning, this is where our purpose becomes clear.

Family is where we first experience love and where we first give it. It’s probably the first place we’ve been hurt by someone we love, and hopefully the place we learn that love can overcome even the most painful rejection.

This crucible of love is where we start to ask those big spiritual questions, and ultimately where they end.

I have seen such expressions of love: A husband gently washing his wife’s face with a cool washcloth, cupping the back of her bald head in his hand to get to the nape of her neck, because she is too weak to lift it from the pillow. A daughter spooning pudding into the mouth of her mother, a woman who has not recognized her for years.

A wife arranging the pillow under the head of her husband’s no-longer-breathing body as she helps the undertaker lift him onto the waiting stretcher.

We don’t learn the meaning of our lives by discussing it. It’s not to be found in books or lecture halls or even churches or synagogues or mosques. It’s discovered through these actions of love.

If God is love, and we believe that to be true, then we learn about God when we learn about love. The first, and usually the last, classroom of love is the family. Sometimes that love is not only imperfect, it seems to be missing entirely. Monstrous things can happen in families. Too often, more often than I want to believe possible, patients tell me what it feels like when the person you love beats you or rapes you. They tell me what it feels like to know that you are utterly unwanted by your parents. They tell me what it feels like to be the target of someone’s rage. They tell me what it feels like
to know that you abandoned your children, or that your drinking destroyed your family, or that you failed to care for those who needed you.

Even in these cases, I am amazed at the strength of the human soul. People who did not know love in their families know that they should have been loved. They somehow know what was missing, and what they deserved as children and adults. When the love is imperfect, or a family is destructive, something else can be learned: forgiveness. The spiritual work of being human is learning how to love and how to forgive.

We don't have to use words of theology to talk about God; people who are close to death almost never do. We should learn from those who are dying that the best way to teach our children about God is by loving each other wholly and forgiving each other fully - just as each of us longs to be loved and forgiven by our mothers and fathers, sons and daughters.

The opinions expressed in this commentary are solely those of Kerry Egan.
Acknowledge Suffering
By Ram Dass

One of the things that makes relationships so difficult is the way in which we protect ourselves from suffering — from our own and from each other’s. Because when you love someone you don’t want to lay your suffering on them and your fears. Also you are afraid if you open your heart too far their suffering will overwhelm you. Because when you look at the world, you just see suffering everywhere.

If you scratched the surface of every person in this room, you will find that there is some suffering. Some people who are walking around here smiling at each other and sitting down and having wonderful, gentle conversations, inside have very deep pain and deep fear. But they have learned so well how to mask it from each other. The culture reinforces that saying, *don’t bring your pain to me. I only want your happiness. I’ll put up with a little of it but not much of it because you will scare me.*

Now just as I said before, if you are going to be able to deal with seeing someone else’s beauty, you have to be able to acknowledge your own beauty. In a similar way if you are going to able to be available for someone else’s suffering you have to be able to acknowledge your own suffering and be able to understand the nature of suffering in such a way that you have converted the quality of suffering in yourself.

Gurdjieff, the Russian philosopher, said there is nothing that can be attained spiritually without suffering in life. But at the same time, if you are going to proceed on the journey you must sacrifice suffering. You hear the dual nature of it. You have to have suffered because the suffering is what burns through you and deepens the compassion and opens the door. Suffering brings you closer to the mystery. At the same moment if you hold on to the suffering and grab at it and sort of wallow in it or cling to it, it stops the journey.

There is an understanding of suffering such that you don’t invite suffering into your life but when it comes you work with it and transform it. The extreme of it is the Christian monk who is saying, “God, God give me more pain. Give me more suffering because I want to get closer to you.” And Maharaj ji saying, “Do you like suffering or joy,” and saying, “I love suffering – it brings me so close to God.”

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We are all going to die but don’t know when. Life is precious. These truths are traditionally contemplated to motivate a spiritual seeker to persist, with patience and trust, during the work of uncovering and then embracing the resistance that seemingly separates us from each other and our true selves. Our woundedness then is no longer overwhelming.

I’ve been a meditation teacher for almost forty years and am able to calm my mind, open my heart, rest in Presence, merge with the Beloved. The extraordinary events of my life - love, death, survival, tend to deepen my practice. Yet again and again in the ordinary activities of daily life, the scores of emails and telephone calls and little tasks that appear each day, I lose myself and forget to live what I know to be true. How can you and I each find the motivation to put into practice that which we know, that which in other moments our hearts have embraced?

Recently I needed to have a new publicity photograph taken. The shot I’ve been using is over 5 years old, my last passport photo, not much feeling or personality showing. So two friends took about 40 pictures of me. My job was to select the one or two shots that would be used in promotions for upcoming events.

Examining these pictures with a critical eye was an unsettling experience, not because of the wrinkles in my face, the obvious wear and tear that life had so honestly imparted, but rather because in most of the pictures I look like somebody who was busy having his photo taken. Only in a few was somebody really there, looking out, knowing that he would die but not knowing when.

I’ve been around a lot of death in my life. I’ve often seen death arrive unexpectedly. Despite knowing this possibility I still treasured some unexamined assumption that at least I will be alive for the next few hours, that I will be able to finish writing this sentence, that when someone is taking my photograph there will be time to take another shot if the image isn’t sufficiently enchanting. I realize I was lost in the illusion of immortality once again, missing the preciousness of the moment in which the shutter snapped.

A few days ago a friend told me she regretted all the time she had wasted in her life, time in which she had not been fully alive. But perhaps in those moments anxiety
and fear were unbearable. Distracting herself had been her only possible response; she had not been ready to look nakedly and directly at the truth of the moment. Yet the suffering of all those distracted moments brought her to the awakening of her regret. In truth, not a moment had been wasted. Can we have compassion for that part of ourselves that so often has turned away from the preciousness of life, from our humanity?

Many of the people I know who found the deepest spiritual realization have been motivated by a profound crisis earlier in their lives, often even resulting in a breakdown. For those of us on a more gradual path, finding ongoing motivation in the preciousness of life and the certainty of death seems to me essential. Do I really know that I am going to die, that I am dying? Can I be humble enough to go back before the beginning of practice and be touched by the preciousness of life? I work with those facing death not just because I want to help people, but because I want to know in the core of my being that I am going to die, possibly even in this next moment, and hence be fully alive right now.

When I accept my mortality I feel particularly vulnerable, raw, exposed. If I directly feel this moment might be my last moment, then my relationship with the notion of self is radically transformed. Receiving spiritual truths at only an intellectual level is far too easy and comforting. If we see nakedly the fragility of life, see that everything is dying each moment, how can we not love and care for other beings and for ourselves? Then, as zen master Dogen puts it, we live with passion and intensity as if our hair were on fire. Walt Whitman said, "Sometimes touching another human being is almost more than I can bear." If I know that you and I might die in the next moment, how can our touching be less than almost unbearable?

—Dale Borglum
Executive Director

Before you begin to pray,
decide you are ready to die
in that very prayer.
There are some people so intense in their worship,
who give up so much of their strength to prayer,
that if not for a miracle they would die
after uttering only two or three words.
It is only through God’s great kindness
that such people live,
that their soul does not leave them
if they are joined to Him in prayer.

Your Word is Fire
The Hasidic Masters on Contemplative Prayer
ed. and translated by Arthur Green & Barry Holtz