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Hope for the Journey: Meaningful Support for the Terminally Ill

by Kathy Kalina, RN, CRNH

The Burden of Suffering

Suffering strikes us as fundamentally wrong. How many times have we heard, "No one should have to suffer"? In a perfect world, there would be no suffering. (That would be heaven.) In this world, to eliminate suffering we would have to eliminate breathing. It's an unfortunate, unavoidable part of every life.

Dr. Eric Cassell defines suffering as "the state of severe distress that threatens the intactness of the person." Coming to terms with all the losses that accompany a terminal illness and facing the end of worldly existence is the essence of suffering: a burden to carry and a wall to break through. It calls for soul-wrenching interior work to emerge whole on the other side of the experience. This work is instinctive; it doesn't need to be taught. It can be avoided, but it can't be denied. Our natural longing for wholeness serves as the motivation to do the work, which includes the following:

Surfacing Meaning "Why do I have to suffer this way? Why does God allow this? Is there a God? What kind of God?" The search for meaning leads us to question everything. "What is the point of my life? Where have I succeeded? Where have I failed? What is the meaning of life in general?" This is deep, dark work for a deep, dark time. It is lonely, 3 a.m. business. Even people with strong religious beliefs must put a personal spin on their faith, and internalize it in a new way. This is very private work that is only shared with intimates or a carefully chosen stranger, if at all.

Reconciliation Granting and accepting forgiveness in important relationships can be formidable work, especially if the hurts are brutal. When reconciliation is one-sided, when the other party is unwilling or unable to reciprocate, it's primarily an internal process. Asking forgiveness of God seems to come easier, but believing and accepting God's forgiveness can be a monumental task without a confessor.

And many people, in the secret recesses of their hearts, have a need to forgive God for the tragedies in their lives. From what I've seen, reconciliation, with other human beings and with God, is an absolute prerequisite for a peaceful death.

Acceptance of Humanity / Mortality A final illness shatters our illusions of self-sufficiency and control. Mourning the loss of health involves facing our dependence on others. Denial is usually part of the process, because the full force of the truth is too much to digest all at once. The journey to recovered wholeness involves finding a new sense of personal worth in "being" instead of "doing," defining the self in new ways, and finding a place of comfort within chaos as the old "perfect" life is turned upside down.

Surrender Accepting what cannot be changed, relinquishing control of the uncontrollable, is crucial work. Struggling and straining to be free of the suffering, we risk being consumed by it. The key is handing over the burden to God, where it belongs, and accepting the peace that this world cannot give. It seems to take a lot of practice, surrendering bits and pieces of the uncontrollable, before a person can make a final act of abandonment, a leap of faith, at the moment of death. One young man told me in his last hours, "I feel as if I'm standing at the end of a diving board, about to dive backwards into ... I don't know what." When you consider the volume and depth of interior work involved in completing a life, our meager efforts to help seem so insignificant. But I've seen what an extraordinary difference even one person can make in the life of a suffering person.

A woman very close to death asked me that question over and over, and it still rings in my ears. No matter how I responded, she didn't seem satisfied. Finally I realized what she was really asking.

"I was sent home to die. I don't know how to go about it. What am I supposed to do?"

She was asking me how to behave on "death row."

"You die on one day," a hospice chaplain told me. "During one moment of one day. All the rest is living." So what can we do to help our terminally ill brothers and sisters live fully, to the very last?

I didn't have a clue when I first found myself in the daily company of the terminally ill. Becoming a hospice nurse brought me face to face with mortality in general, and mine in particular. I've never felt so vulnerable. It seemed I had nothing of value to offer.

At first I hid behind nursing skill and professional demeanor, but that proved to be a flimsy shield. After all, the most aggressive medical treatment had failed these patients. There was no need of high-tech "bells and whistles." As for professional demeanor, it doesn't go very far with people who have a limited time left on the planet.

My supervisor insisted that I spend one hour at each visit, and an hour seemed endless. So I just wasted time with them: listened to their stories, laughed at their jokes and let them laugh at mine. And I cried with them, too.

I stumbled along in the dark for months, not quite sure what needful help I was providing or omitting. Then I began to notice what made the difference between living every day, and dying inch by inch. Over time, I came to see a connection between quality of life and hope.

Fostering Hope

The words "hope" and "terminal illness" don't seem to belong in the same sentence. But hope is exactly what's needed to stay engaged in living while shouldering the burden of an uncertain future. The opposite of hope is despair, and despair is a living hell. For the terminally ill, the absence of hope leads to the "death row" mentality, a place where suicide seems to make perfect sense.

Hope is an incredible, personal gift. It is a spiritual virtue. You can't give it to someone, and you can't take it away. But you can encourage even the smallest spark of hope and help it to serve its purpose: providing the courage to face each new day. We can foster an

environment where hope can grow and thrive in a number of ways:

Physical comfort It's very difficult to hold any hope for the future when pain and discomfort scream for attention. Hospice and palliative care professionals know how to manage pain and other distressing symptoms. Physical comfort takes top priority, and we should settle for nothing less.

Authentic presence Living in the shadow of a final illness can be incredibly lonely. We should never wait for terminally ill persons or their families to request visits from representatives of the Church. They should not carry the burden of staying connected. Occasional phone calls and regular visits speak volumes, even if the offers of assistance are declined.

The most well-intentioned among us can produce perfectly reasonable excuses to avoid the company of the terminally ill. The real reason is fear and a sense of helplessness. We don't like to face our own mortality. We're afraid of saying or doing the wrong thing, or having nothing of value to offer. Our own fears can paralyze us into benign neglect.

Early in my hospice career, as I struggled with my own inadequacy and the sense that I was "just wasting time" on my visits, a quote from Sister Wendy Beckett changed my attitude: "Actions fueled by prayer have the radiance of prayer." When I came to believe that, everything changed.

Spending time with the terminally ill is love in action. It's body language that says, "You are important. You are valued. You are worthy of my time." And that time is a mutual blessing. All the masks and games and trivial relationships fall away during a terminal illness. The authentic person shines through, and our own false self becomes quite transparent.

Promoting normalcy One of the first things that happens to the person with a life-threatening illness is the loss of a normal life.

"Patienthood" means relinquishing daily routine. Time revolves around doctor appointments, tests and treatments. The rest of the time is spent talking and thinking about them. Eventually, in a terminal illness, medical intervention runs its course, and the patient is sent home to live out his life. The old routine is gone. It's very common to get stuck in an in-between place.

When I think of the difference "normal" can make, I think of Lucille. When her doctor said, "You have six months to live," she went home, gathered up all her clothes and all her shoes and gave them away. Eighteen months later she said, "I'd like to go somewhere; maybe get out of this house for a bit. But I don't have any clothes and I don't have any shoes. And it would be so wasteful to buy new ones. I'm dying, you know."

The cowboy who wears his boots long after walking is possible, the always well-groomed lady who insists on make-up and manicures, or the football fan who continues to dress in the home team's apparel generally have a better quality of life than those who submit to the anonymity of the dreaded patient gown.

In his book, *Intoxicated By My Illness*, Anatole Broyard said, "I think that only by insisting on your personal style can you keep from falling out of love with yourself, as the illness attempts to diminish or disfigure you." Recognizing and celebrating people's individuality can help them to re-claim their lives. We need to avoid putting on our "visiting the afflicted" face. Anything we do to treat them normally is a blessing.

I learned this lesson from a fellow hospice nurse. She made friends with a resident who assumed the role of official greeter and hospitality minister at a nursing home as she went about her rounds. The resident always opened the door for her, then flirted and joked as he escorted her to the elevator. One day she went to admit him to the hospice program. She followed her usual routine: explaining the services, taking his history, and getting his signature on the appropriate forms. Toward the end of the visit he asked, "Lisa, what's wrong? Have I done something to offend you?" She responded with a

stunned denial. He said, "Well, something's changed. You're not joking with me today."

She had been treating him like a patient! And what did that mean? If the difference was so noticeable, she needed to re-examine her approach to all her patients.

If we are representing the Church, visiting the terminally ill may involve the sacrament of reconciliation and the Eucharist. Afterward, I urge you to step out of your ministerial role and spend some time connecting, one person to another. Long ago I made a rule for myself: Stay five minutes after I'm ready to leave. Over and over, those last five minutes have proved to be the most fruitful.

Creative, confident problem-solving In a final illness, the rules change. People's trust in their body diminishes or evaporates. Losing the ability to do the simplest tasks can deal a crushing blow to hope. The terminally ill person needs an advocate who can look at the situation with fresh eyes. Making phone calls and getting necessary help can make an enormous difference in daily life. Every loss of function is a little death, and must be grieved. During those times it's important to say, with our actions if not our words, "I'll hope for you, until you can hope for yourself again."

Surfacing fruitfulness One of the greatest sources of suffering during a grave illness is being the recipient of care. It's common to feel burdensome and useless. But every human being is capable of teaching, learning and growing to the very end of life. And every person has non-material gifts that will go to the grave if they aren't shared. I've personally been the recipient of fail-safe tips for playing the stock market, words to dance hall songs and instruction in the finer points of bull-riding. I may never have need for any of it, but it was an honor to sit at the feet of masters, and a delight to see hope ignited before my very eyes. These treasures can be purchased with the only currency that matters: our attention.

Suffering is incredibly self-centered work, and anything that calls the

suffering person out of that center, to extend care to others, should be encouraged. I have a beautiful picture in my mind of a tiny, arthritic woman all alone in the barest of rooms, furiously crocheting a baby blanket for our hospice chaplain. "That girl's forty years old, having her first baby," she explained. "She deserves a blanket, at least!" She groaned from the effort, but I'd never seen such an angelic smile on her face.

Very often, the life of the spirit flourishes as the life of the body declines. Consider making prayer requests of the terminally ill, sharing as much detail as you can about the needs of individuals in your community. I remember one bedfast patient who suffered from depression. A lay minister spontaneously asked her to pray for a young mother experiencing a high risk pregnancy. She took her mission quite seriously, and anxiously waited for the latest news about her charge. Her hope resurrected and she outlived the doctor's projections by several months as she served as spiritual midwife for a new human being.

Light-heartedness / Humor There is nothing so hopeful as laughter. Every person has a sense of humor, and tapping into that can build a connection faster than anything else. Suffering people are tender all over, and humor is risky, but worth the risk. Occasionally my jokes have been poorly received, but each time I just asked forgiveness and permission for a fresh start.

It helps to bring the outside in, sharing bits of your day. Just letting the ill person know that you're a little light-hearted will open the door. Humor breaks down barriers, allows a safety valve for anger and frustration, and gives a sense of control over uncontrollable situations.

It worked for Fred. Feisty and 96 years old, he'd just been brought at the nursing home against his will when Glenda, his hospice nurse, arrived on the scene. "Do you have any children?" he demanded of her. "Let me give you a tip. When you get old, and they all come to see you at the same time, run for your life. They're gonna put you in a home!"

In an obvious effort to tug at his children's heart-strings, he begged Glenda to take him home with her. She said, "I couldn't possibly take you home. Everyone at my house has to work."

"Oh, I can work," he said. "I'm a hard worker!"

It became a routine. Each visit, Fred would beg Glenda to take him home with her, and Glenda would come up with reasons it wouldn't work. One day he told her about working for the Chevrolet dealership in his younger days. Glenda gasped and said, "That settles it for good. You can't come home with me because we're not compatible. You're a Chevrolet man and I'm a Ford girl." Fred took Glenda's hands and said with soap opera intensity, "But darlin'... I could learn to love a Ford!"

Laughter is the great equalizer. Sharing a joke levels the playing field and invites true relationship, a dance of giving and receiving. When we laugh, we experience joy, and celebrate this moment, right now, regardless of how chaotic the life situation may be. It's a wonderful mitzvah, or mutual blessing.

Confronting Our Own Fears I'm convinced that what makes us afraid, what makes us embarrassed, what makes us want to run from the room is not only the presence of the suffering person, but also our own "issues." It helps to revisit the story of our own lives, especially the part about our own sufferings and those of loved ones, and our previous experiences with death. If there is unresolved grief, it will surely cast a shadow over the present situation.

Standing by our brothers and sisters who experience intense suffering is the simplest and most difficult thing we can ever do. It's simple because all we have to do is show up. It's difficult because our natural instinct is to run for our lives. Of all the people who loved Jesus, there were few willing to stand at the foot of the cross. Our powerlessness is excruciating at such times. We can easily believe we're just not strong enough to bear it. But what I've learned from "foot of the cross" experiences is this: it doesn't take strong hearts to do this difficult

work; it builds strong hearts. And grace abounds.

"If There's Anything I Can Do ..."

We are the body of Christ. Our role in the life of the terminally ill may be pastor, lay minister, family member or friend, and carrying out those roles is important and meaningful. In addition, we all have unique, individual gifts to offer. There's no need to ask the suffering person for direction. We know what to do. It takes prayer, courage and determination to stay engaged in the daily relay of care for our suffering brothers and sisters. Like everything else we do in the service of such a generous God, our efforts will produce fruit in abundance.

Then blessed are they who never turn away
and blessed are those who stood quietly in the rain.
Theirs shall be the harvest; for them the fruits

Rainer Maria Rilke

from The Book of Hours

Kathy Kalina, RN, CRNH, is the author of two books, *Midwife for Souls: Spiritual Care for the Dying and Living the Final Season*.

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