



MOTT JORDAN

HOSPICE CARE

Sharing the Passage Out

By Ray Gwyn Smith

In this Eden snuggled between mountains and the bay, where the weather is benign and the politics civil, far from the worlds of famine and infectious epidemic war, it is hard to remember we will die. If we jog West Cliff, take spirulina, talk about our feelings, fasten our seatbelts and use condoms, we believe that somehow we will be absolved.

To fall terminally ill before skateboarding old age is somehow to have failed in life's Olympics, to be suspect of violating some law of well-being—too much work or lack of purpose, too much sex or blocked passion. We scan each other's life-styles for pitfalls to avoid: booze, cigarettes, sugar, MSG. But however avant-garde or diligent our offerings to the gods, nothing can grant us immunity. In this age of mega-vites, creative visualization and TM, people of all ages are still dying for reasons beyond their control.

Not long ago, death was a natural presence in our lives. Living on the land we had lots of children, knowing not all would survive. Grandparents shared our homes, grew frail and passed on. But when we moved to the cities death was removed from the flow of life. Hidden from view behind the walls of institutions it became a strange and dreadful nightmare.

Most people who died in this country in the last decade spent their last days in a medical situation, their bodies attached to machines, their basic needs met by strangers too overworked to listen to their fears. If they were lucky, family and friends came to visit. But most likely they were too afraid of

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their own inevitable death to admit this was more than a bad episode from which they would soon recover.

Our dying does not have to be so desolate.

In the last five years the death and dying movement has helped refamiliarize us with death, and the hospice concept of home care has done much to relieve the insufferable abandonment, pain and despair we have come to associate with dying.

Home from the hospital for the last time, a person facing death is no longer reduced to "the leukemia patient in 106," but is related to as a whole person whose need to share frustrations, laughter and tears are as relevant as the needs of their failing body. In the quiet and privacy of home, supported by people they love and who love them, they are able to face letting go of life unhindered by interruptive schedules and medical procedures. The focus is no longer on avoiding death but on the quality of the life they have left. A hospice home care team of visiting nurses, volunteers and a consulting physician

work with family and friends on an egalitarian basis to ease the dying person's passage.

Sally Blumenthal, who has been caring for the dying for more than 10 years, radiates a remarkable vitality and warmth.

"People ask me, 'How can you do what you do? Isn't it depressing?' But it's the most rewarding, life-affirming thing I've ever done," she says.

People facing death have no time to waste on what is irrelevant. Each moment becomes precious and the questioning of what is really important can give life new meaning. Some say ironically that now they know they are dying they have never felt so alive. Sally talks of the closeness she experienced with a 40-year-old woman she cared for.

"She had melanoma and she'd had so much surgery her body was all distorted and her head was blown up like a moon. The way her husband coped was by staying away from home. We'd have slumber parties and

be like kids giggling in the night. We had so much fun: there was an opening, an honesty. No junk. No game playing. It was just what was happening now . . .

"I've learned that the biggest thing in life is joy," she says, "and when it comes down to it, the rest doesn't matter."

Coming down to it is a lot of what dying is all about. We spend our whole lives polishing our identity, but facing death our manufactured self-image is rendered obsolete and we are given the chance to see who we really are beyond the pretense. An impeccable resume, a great profile, the new Porsche in the driveway, don't mean a thing when you are too weak to get to the bathroom without help.

Perhaps the greatest asset in anyone helping a person who is dying is to be able to drop all preconceptions of what is expected and to be simply genuine, a caring person present and responsive to whatever needs arise.

"The first dying person I cared for confronted everything in me as a nurse," says Sally. "I'd want to do all the things nurses do but she didn't want any of that stuff. I'd want her to eat but she didn't want to eat because she knew she was dying. I'd never taken care of anyone who knew they were dying and wanted it to happen. She really made me question whether I was there for her or me."

It was Sally's experience of nursing dying children on the busy pediatric ward of a large L.A. hospital that moved her to join the Shanti Project, a San Francisco group which helps people to die at home. She now works for the Santa Cruz AIDS Project.

When Sally first met Tommy he was 34 years old and bedridden.

"Ordinarily he never would have liked me," she says. "He was real controlled and rigid and I was much too wild and woolly. But death makes strange partners. I'd come in and laugh and joke and bring my friends over."

"It was spring and there he was stuck in his bed because nothing worked anymore. He had this big window overlooking the park and he had a hummingbird feeder. The birds would come and I'd say to him, 'Tommy, if you could hitch a ride on a hummer where would you go? What would you see? He'd close his eyes and tell me where all the flowers were blooming, and what trees were in blossom. His whole body would relax and he'd be gone . . . We always said we'd keep in touch after he died, and whenever I see a hummingbird now I think of him.'

After experiencing such closeness with people who are dying, is it hard for Sally to let them go?

"I can deal with death because I don't see it as the enemy anymore," she says. "It's an opening, an expansion. Being with people when they are actually dying is the highest moment in my life. There is no fear, no judging or analyzing. It's just total feeling. It's the ultimate in silence and peace."

Sally describes the death of Margaret, with whom she developed a particularly meaningful relationship.

"I walked in the house that day and she was just different. She was glowing. I said, 'It's today!' And she said, 'I know.' I said, 'Do you want me to call anybody?' She said, 'No, just be here' . . . So I sat there holding her hand and I waited. Then her daughter walked in for lunch and took the other hand. We held her hands for two or three minutes and all of a sudden we both felt this soft, gentle whoosh."

"We just kind of watched her go. And here we were holding onto this empty shell. Nursing in a hospital I'd never seen a death like that because I was too busy pumping drugs and pounding chest. But I just got to be there with her when she left. We just sat there in awe and we cried and laughed. I never thought I'd be able to laugh the day someone close to me died."

A significant factor in such peaceful deaths is the liberal attitude of doctors cooperating with hospice towards prescription of medication, releasing many from the anguish of pain in the precious time they have left.

"Most people can have their pain under control and still be alert," explains Sally. "They don't have to be snowed under."

Ironically, rare resistance to administering pain-blasting narcotics comes not from the doctors but from the relatives of the dying person.

Visiting nurse Karen Peiffer tells of a situation that arose caring for a dying woman whose son was a policeman.

"He had a lot of conflict about having heavy drugs in the house. He kept asking if they were addictive. His mother was only going to be living another couple of weeks—who cared if she got addicted to morphine!"

Karen was able to help the man see how his prejudice was inappropriate under the circumstances. Subsequently his mother was released from pain enough to resolve some issues before she died.

Bringing issues to resolution is not always a simple matter when the dying person and/or family are locked in a conspiracy of avoidance. It sometimes takes the gentle intervention of an outsider like Karen to help break through the facade to an openness and honesty. Encouraging people to think of what remains unsaid and to say it without further hesitation can avoid emotional drama in the last hours of life when there is often not enough time or energy left to deal with old resentments, fears and doubts. The sooner old accounts are settled,

the sooner the tension will be released, making closeness possible.

This is, of course, a paradigm for life in general. Imagine how different our lives would be if we lived fully aware that death can come at any time. As Stephen Levine puts it in *Who Dies?*, "There is no other preparation for death except opening to the present. If you are here now, you'll be there then."

Because dying is the aspect of life least under our control, it is perhaps not surprising that when Elizabeth Kubler-Ross offered

selves beyond help in a world of make-believe. Karen Peiffer tells the story of one patient she could not reach.

"I was sitting with somebody who was on a respirator, who couldn't even breathe on their own and was almost dead. They were watching these evangelical ministers on TV, sending all their money in to these faith healers, buying their tapes. Their day-to-day existence was spent trying to be healed instead of dealing with the short time they had left. They never accepted what was really happening so I couldn't help them."



us the five-stage theory of dying we pounced on it as an absolute blueprint. In fact, real people seldom move sequentially through denial, anger, bargaining, depression and finally to acceptance, and Kubler-Ross has since regretted publishing the concept, for it has caused well-meaners to interfere with people dying their own unique deaths.

It has been said that how we face death is much the same as how we face life. Those of us who give ourselves fully to life, let go more lightly when the time comes. But some of us find ourselves facing our last days still longing for fulfillment we never found.

They stayed focused on hope for a miracle until the very end."

To force a person in denial to admit the harsh fact of their impending death would be brutally invasive. However, occasional gentle questions such as "Tell me what's going on with you?" can usually help the dying person talk about their feelings and open to the reality of what is happening.

Those who commit themselves to sharing the dying process with someone they love find themselves immeasurably deepened by the experience. Though natu-

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So much of our life had been postponed, so many dreams abandoned, so many opportunities not taken, so much love unexpressed, that we frantically cling to the remnants of a life barely lived. Those who have barricaded themselves against life, resisting change, will more than likely hide from death behind a wall of denial.

We all know the compulsion to run from the truth when it makes us vulnerable. Easier to create a pseudo-reality where we can retain a delusion of safety and control. Some are so desperately afraid of acknowledging that they are dying that they isolate them-

rally there are feelings of sadness and despair, sharing the struggle of coming to terms with death brings us to a new level of compassion and meaning in our own lives.

With the help of the Hospice Caring Project of Santa Cruz, Lori Williams, a local painter, cared for her mother at home through her last months.

"Cancer is the greatest teacher," she says. "The lessons my mother learned—about letting go, about loving, about forgiving—she probably wouldn't have learned otherwise. And one of her legacies is that as she was learning these things I learned them too."

Faye was, in Lori's words, "a vital dynamic woman in her prime" when she was first told she had cancer. She was a zoologist with plans for a camping trip to the desert, and the diagnosis abruptly changed everything. It was a year later on the drive home from the doctor's office that they fully realized she would never make it to her beloved Baja.

"My mother really went within herself. She was feeling all this intense anger, fear, regret and loss. I wanted to make it OK but I couldn't. I called our hospice worker and she said, 'Just be there for her. You don't have to give her any answers' . . . Hospice was like an anchor . . . OK you are going to die. We are not trying to prevent it. We are accepting this."

"And yet there was another part of me that was influenced by the overwhelming consensus that death is bad and that we must fight it. I came to realize that my fears weren't based on anything real. They were just a set of ideas about what death is—like death being black and silent, no me . . ."

"I was committed to being with my mother through whatever it took. When she'd be going through something heavy I'd go and sit with her. We'd go down into it together and go through it. It was sort of alchemy that went on . . ."

"It was amazing to see the difference in attitude between the time she was assuming she was going to live and the time she knew she was going to die. After she accepted it, she was a different person—the person she used to be when she was happy. She wasn't fighting anymore. She was filled with light, giving light."

The luminosity of someone accepting their imminent death is the glow that comes with the awareness that death is simply part of the flow of change which exemplifies life, as returning—like rain falling back into the ocean.

Sam Keene in *The Passionate Life* describes the experience, usually too profound for words: "A change in the psyche's identity takes place as one realizes that the self, like light, is simultaneously a particle and a wave . . . a vibratory event within the quantum world—a spirit."

Perhaps the greatest lesson to be learned from the dying is that the individualism endemic in our culture is delusional. We are not in fact separate independent entities but a system of interconnected beings sharing the planet. The rapidly growing interest in hospice care reflects the emergence of our natural human yearning for a sense of interdependency, of belonging, of community. We are hungry for the kind of love which unfolds only in an atmosphere of mutual responsibility and support.

Mother Teresa, awarded the Nobel Peace Prize in 1979 for her devoted work with the dying throughout the world, pointed to the deprivation particular to our society.

"Maybe in the United States we don't see the hungry, the hopeless, but there are people feeling unwanted, unloved . . . there are people who have forgotten what is human love, human touch . . . this is a very great poverty. We must understand that love must begin at home first . . . you must make your home and your family a place where love, peace, joy and unity reign . . . then you reveal this and give it to your neighbor."

Because caring for our dying with honesty and compassion unfailingly reunites us with our humanness, it is perhaps the most powerful and fundamental contribution we can personally make towards humanizing the world.

For further information regarding hospice care, call Hospice Caring Project, 688-7684, or Santa Cruz AIDS Project, 688-7641.

I would like to thank Christy Longaker, who teaches care of the dying seminars at Twin Lakes College, for her valuable knowledge and insight.