

DEATH AS A HEALING PROCESS

A talk I gave August 8, 1992 to some 200 persons. Sponsored by the Office of Elderly Affairs, County of Kauai. These persons were all care-givers.

You know the mind is an amazing thing: it starts working the minute you are born and only stops when you get up to make a speech.

Some time ago, the president of a large insurance company invited me to give a talk on the subject of death and dying. He asked me for a topic and without much hesitation I said, how about "Death as a Healing Process". There was a long silence and when he finally spoke, he said, "Wow, when I think of death, I always think of a great loss, a big tragedy. So when you said, "death as a healing process", for a moment you lost me." And I replied, "you weren't lost, you just need direction."

Then, I told him this story. It's a story about a traveler who was convinced that he was on the wrong road. So he came to a halt in a village. Calling one of the villagers to the car window, he said, "Friend, I need help, I'm lost." The villager looked at him for a moment, "Do you know where you are", he asked. "Yes", the traveler replied and named his destination. The villager looked away for a moment, "You ain't lost", he said at last, "you just need directions."

Emotionally speaking, many of us are in the position of the traveler, in relation to death. We know where we are: fearful sometimes, grieved, filled with sense of loss. And we know where we want to be--at peace, liberated from our fears and anxiety. Like the traveler, we are not permanently lost. We need a sense of direction.

I want to share with you a sense of direction which may enable all of us to experience death as a healing process.

Five points

I'm going to cover five points:

1. To experience death as the important key to self-understanding
2. In dying, time is experienced as Now, the present, instead of past/future.
3. Dying teaches us how to accept with gratitude things that are being done to us the dying. But most important, dying teaches us how to wait.
4. Death/dying creates a special community-- a community that heals.
5. Finally, dying creates in us a special knowing: that love is stronger than death.

The first point: death as the key to self-understanding.

Many of us will experience dying as a very important key to self-understanding. Death will reveal to many of us the person we can really become, for:

- death can put us in touch with our deepest feelings
- it can help us concentrate on what is most important and essential in our lives
- it can help us find meaning in life.

I think of a very successful business executive who went to see a doctor because he had a difficult time breathing. After many tests, he was told that cancer had spread throughout his whole body. And when he asked the doctor, "what are my chances..." the doctor replied "anywhere from 3-6 months."

When he invited me to work with him, he had already:

- give up his business
- his two sons had left the mainland colleges to be with him
- his daughter was experiencing great confusion
- and his wife had relinquished all her community services.

One evening, he invited me to have dinner with the family. There was much laughter and joy. After dinner, we went into the living room and there, the great illumination took place. This is what happened. The father went to each of his children, called them by name and told each one of them, "I love you."

This person-to-person declaration of love enabled each of his children to be free:

- free to be themselves
- free to express their deepest feelings for each other
- free to become the family they were meant to be.

You remember Lee Atwater whose mean-spirited tactics helped put George Bush in the White House? He was responsible for the creation of Willie Horton, the black prisoner. Lee Atwater linked Willie Horton to the image of Dukakis's philosophy of being soft and liberal on crime. Shortly before his death, he considered his win-at-any-cost political philosophy.

He wrote: "Long before I was struck with cancer, I felt something stirring in American society. It was a sense among the people of the country--Republicans and Democrats alike--that something was missing from their lives--something crucial. But I wasn't exactly sure what it was. My illness helped me to see what was missing in society is what was missing in me: a little heart, a lot of brotherhood.

"The 80s were about acquiring--acquiring wealth, power, prestige. I know. I acquired more wealth, power, and prestige than most. But you can acquire all you want and still feel empty. What power wouldn't I trade for a little more time with my family? What price wouldn't I pay for an evening with friends? It took a deadly illness to put me eye to eye with that truth, but it is a truth that the country, caught up in its ruthless ambitions and moral decay, can learn on my dime. I don't know who will lead us through the 90s, but they must be made to speak to this spiritual vacuum at the heart of American society, this tumor of the soul.

"I've come a long way since the day I told George Bush that his "kinder, gentler" theme was a nice thought but it wouldn't win us any votes. I used to say that the president might be kinder and gentler, but I wasn't going to be. How wrong I was. There is nothing more important in life than human beings, nothing sweeter than the human touch."

The second point: the Now--the Present

Dying and death becomes a healing process because death transforms our experience of time. We think that past and future really exists. We live our life as though it truly exists. But for a dying person, what is important is not the past with all its joys, its achievements, its regrets--nor is it the future with all its promises and fulfillments. What is real, what is important is the Now--the present. I am dying now.

We all carry around in us an image of ourselves that we create and then struggle to maintain. To carry around an image of ourselves is a great burden, causing a strain or tension between what we actually are in the moment and the image we're trying to project.

Once there were two monks travelling and saw a woman in distress. She had no means of crossing a stream. So the first monk approaches her, and with her consent carries her and wades across the stream. He releases her and continues on his way. But the second monk began to harass his friend. "You know, in our way of life, we are not allowed to touch a woman. You violated one of our rules." Throughout the day, the second monk kept harassing his friend. Finally, the first monk turned to his friend and said, "I released the woman early this morning. Why are you still carrying her."

Dying helps us to live in the moment. When I live in the moment, something remarkable happens. Suddenly, I realize that there's nothing to be, nothing to do, nothing to have. There's nothing special to be, nothing special to do, nothing special to have. Having nothing—we've got nothing to lose. When we have nothing, we can be anything. For one thing, we can let go of our self-image.

I have found a very interesting phenomenon about dying persons. When they can be anything, they usually want to share their sense of humor. There's this story of Norman Cousin. When he was in the hospital, his wife used to bring all kinds of food, especially the apple juice Mr. Cousin relished. In this hospital, there was a nurse who was one of those "we-nurse"—always saying, "How are we doing today". When she gave him the urinal cup, she would say, "We shall fill it up now." And Mr. Cousin would say, "you do it first". One day he filled the urinal cup with his favorite apple juice. When the nurse came to pick it up, she held it up and said, "it has an unusual color today." Whereupon, Mr. Cousin, took the cup and drank it saying, "Maybe the second time around it can become clearer."

When John was gravely ill, a friend visited him and said, "John, you look well, your appearance is good." John smiled weakly. "Ah, Ted", he replied, "it's not my appearance that concerns me now, but rather my disappearance."

When we live in the moment, we can begin to see the humor in our lives.

The third point: Accept with gratitude what others do for us
You remember the business executive who looked at each of his children and said, "I love you". Well, Robert, that was his name—had an enormous problem, even as he was dying. This is how he stated his problem:

"All my life, I have lived to do things for people, for business, for my community. And now, here I am, unable to do anything for myself, for others. I can't even go to the bathroom without some help. Please help me to understand my situation in a new way."

In our world, there is this strong desire:

- to accomplish something
- to be successful
- to gain some sort of achievements.

But note what accomplishing something leads to: we become our success.
We not only desire to be and to do many creative things. But we often make the results of our work the criteria of our self-esteem. We become our successes. In short, we are worthwhile because we have successes. In this success-oriented world, our lives become more and more dominated by superlatives. We brag about the highest building, fastest runner, most home runs. And the result? We become like the husband who climbed the highest mountain, fought the fiercest tiger, swam the roughest sea—all to impress his wife. When he arrived home from his conquests, he found a note at home. It was from his wife. She wrote, "I'm leaving you—you've never at home."

What Robert learned.

He accepted the fact that he had become the one to whom things are being done. He is being fed; he is being drugged; he is being told what to do. Things are being done to him over which he has no control. He is now the recipient of other people's initiatives.

Robert had finally learned how to receive. So one day, he said to me, "I can now allow things to be done to me—people can bathe me, change my clothes, feed me...with gratitude."

He had finally learned to receive, to be open to others--with gratitude and grace.

There was a second learning which for Robert was the greater learning. He learned how to wait. Waiting is not a very popular attitude. Waiting is not something that people think about with great sympathy. In fact, most people consider waiting a waste of time. Perhaps this is because the culture in which we live is basically saying: "Get going. Do something. Don't just sit there and wait."

What did Robert learn in his waiting?

That death is a significant part of life. That dying is the last experience of life itself. I told Robert of Lord Peterson, when his doctor told him he was dying, replied, "Die, my dear doctor. That's the last thing I shall do."

I also told Robert about a graffiti found in Southern California: "Death's the greatest kick of all, that's why they save it till last."

So Robert made the decisive decision to accept death--to choose to die. The moment he chose to die, his waiting had a sense of promise. In the words of Henri Nouwen, "his decision had become a seed he had planted. And now in his waiting he was eagerly waiting to see the seed turn into a flower. He knew now that something hidden will be manifested." "Unless a grain falls on the ground and dies, it remains only a single grain, but if it dies, it yields a rich harvest." (John 12:24).

The fourth point: a special community

Those who take their death and make of it a healing process create a special community. Notice what happens in this community:

- conflicts never last long
- tension are talked out
- disagreements resolve.

Because of the dying:

- there is always someone at home
- moments of silence and quiet
- always words of affection, gentleness and tenderness
- patience and endurance
- smiles and tears visible to all
- space for mutual forgiveness and healing.

In this community:

- we do not seek competition, conflicts, individual stardom
- there is no refugee camps, overcrowded prisons
- no violence, no crimes
- no people sleeping in the streets.

We are a community of people who are simply being present to each other.

Conclusion: befriend death

In conclusion I want to say this: in order to let death become a healing process, we must first of all befriend death; let death become a friend.

We are inclined to avoid deny, suppress the painful side of life, a tendency that always leads to physical, mental or spiritual disaster. I have a deep sense that if we could really befriend death, we would be a free people. So many of our doubts and hesitations, insecurities, are bound up with our deep-seated fear of death. Our lives would be significantly different if we could relate to death as a familiar guest instead of a threatenig stranger.

But how do we befriend death?

Beside the four points I shared with you, let me lift up the final and perhaps the most important way of befriending death: it is love—deep human love is stronger than death.

Every death means parting, separation, isolation. Love overcomes separation and creates participation. When two persons are bounded by love, there is community—a place of acceptance and joy.

Love is stronger than death. It creates something new out of the destruction caused by death. It bears everything and overcomes everything. It is at work where the power of death is strong—in the frail body of a person stricken by terminal illness.

Love does not seek to abolish death. Rather, love dares to accept death into its own bosom. Love willingly enters the grave and witness to its power of resurrection.

Love rescues life from death. It rescues each of us, for love is stronger than death.

M.Scott Peck, M.D.
Denial of the Soul

THE LEARNING OF DYING

In the last chapter I put forth the two reasons I am critical of euthanasia. One is distinctly theological and relates to all suicide in general. It is that, as our Creator and Nurturer, God is as much a stakeholder in our lives as we ourselves are. As creatures with free will, we have the power to kill ourselves. Whether we have the ethical or moral right to do so is a different matter entirely. Through the act of suicide one sets the timing of one's death without reference to the Life-Giver. It is a denial of God and God's relationship with the soul.

The other reason I am critical is psychological as well as theological and pertains specifically to euthanasia as I have defined it. We have an enormous amount to learn from the process of dying a natural death. To kill oneself in order to avoid the existential suffering of aging and dying is to shortchange oneself of that learning. It is also, I believe, to shortchange the God who designed us for such learning. In the previous chapter my treatment of this subject was superficial. The purpose of this chapter will be to go deeper.

The Stages of Death and Dying

Elisabeth Kübler-Ross, M.D., was the first scientist who ever dared to sit down repeatedly with people who were dying and ask them what they were feeling about it. From this experience she wrote the classic work *On Death and Dying* (New York: Macmillan, 1969). In it she said that upon receiving the diagnosis of a terminal illness, patients tend to go through the following emotional stages in this order:

Denial
 Anger
 Bargaining
 Depression
 Acceptance

In the first stage, denial, they say, "The lab must have gotten my tests mixed up with somebody else's. It can't be me; it can't be happening to me." But that doesn't work for very long. So they get angry. They get angry at the doctors, angry at the nurses, angry at the hospital, angry at their relatives, angry at God. When anger doesn't get them anywhere, they start to bargain, saying, "Maybe if I go back to church and start praying again, my cancer will go away." Or "Maybe if I start being nicer to my children for a change, my kidneys will improve." When bargaining doesn't get results, they begin to realize they're really going to die. At that point they become depressed.

If the dying person can hang in there and do what some of us therapists refer to as "the work of depression," then he or she can emerge at the other end of that depression and enter the fifth stage—acceptance.

Like any book of extraordinary significance, Kübler-Ross's systematization of these stages has been criticized and in the process clarified. Critics have pointed out that stages may be skipped; the stages may be circular and repetitive rather than linear; patients may regress; a person may be in more than one stage at the same time;

the system is not a formula and should not be used formulistically. All these criticisms are valid. Nonetheless, the system is fundamentally sound and, when not applied formulistically, extremely useful.

Kübler-Ross described the fifth stage, acceptance—if it is reached—as one of great philosophic calm and spiritual light. That is almost an understatement.

As a psychiatrist I have had the good fortune to see several patients in the stage of acceptance, a lovely experience. I have been with two different dying men, who were not my patients, at dinner parties in their homes, an even more dramatic experience.

One man, close to seventy, had cancer of the bladder for which he'd just undergone an unsuccessful course of chemotherapy. He was extremely cachectic, or wasted. He also happened to be completely deaf from a different disorder, but he was adept at lip-reading. Because of a fungal infection of his esophagus due to his severely compromised immune system, he was unable to eat solid food. While the rest of us ate, he had to drink a ghastly looking nutritional mixture. That dinner was his last social occasion beyond the family, and he died three weeks after that night.

The other man, in his early forties, had suffered for over a decade from ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease). By the time of our dinner he'd become completely paralyzed below the neck. He had to be fed with a spoon while seated in his wheelchair. He was, of course, incontinent and required total nursing care from the other members of his religious community. He was to die within six months.

Because I'd known beforehand how terribly ill these men were, I'd dreaded those two dinner parties. I had no reason. Although the men were very different in personality, my experiences with the two of them were extraordinarily similar. Each, early in the evening, volunteered succinct and realistic information about his illness and impending death. Their intent was clearly to put me at ease. They succeeded. I have never seen two people who were so alert, so conscious of what was happening, so totally with it and *present*. Both

sparkled; they were filled with light, and their light seemed to embrace the entire company assembled. While the dates were not special, both dinners seemed like celebrations. The mood was one of serene hilarity. I have never enjoyed any social occasion more than those two evenings.

The final stage, acceptance, is very real and beautiful to behold, but most people do not die in that fifth stage. Most die still denying or angry or bargaining or depressed. The depression, when they hit it, is so painful that they do not know they can work through it, so they retreat back into the earlier stages, particularly denial. My distinct impression, although I have no scientific statistics to support it, is that the majority of people die even gradual deaths still denying the fact that they are dying.

How can this be? How can an intelligent adult be given a fatal diagnosis, watch himself deteriorate despite the best medical treatment, see the deterioration become ever more rapid, and still deny that he is dying? There is indeed something absurd, even deranged about this denial. Nonetheless, it is normative behavior. And if we are to understand why it is the norm rather than the exception we must not underestimate either the power of denial or the terror of death.

The power of denial is a direct reflection of the power of the human will. Given our freedom, we may choose to submit our will to a Higher Power—be it God, truth, love, or even reality. But if our will is not truly submitted, we are free to think and believe whatever we *want*. The facts be damned. It is actually easier to deny reality than submit to it. Not right, but easier.

For the most part, we do not want to die. As I've suggested, the will to live is built into every cell of our bodies. It is also built into our consciousness. Being alive is all that we know. Death is naturally terrifying. Despite any belief we may have in an afterlife, we still tend to worry that death may be nonexistence or worse.

Plumbing the depths of my own terror of dying I have discovered a strange fantasy that's even more terrifying than the prospect

of my nonexistence. It is the prospect of existing amid nothingness, in the void. In this fantasy I continue to exist after death, in the sense of being conscious, only I don't exist anywhere. I am conscious of being nothing in the midst of nothing . . . in the midst of utter emptiness. The analogy is that of a space traveler who has accidentally become unhooked from his ship and is helplessly floating in dark outer space, utterly alone, yet somehow alive and aware that he is doomed to be that way for eternity. Rationally, it is a fantasy that begs many questions. But it is terrifying, and a number of perfectly rational people have confessed sharing it with me.

Our terror of nonexistence is so monumental that Ernest Becker, in *The Denial of Death* (New York: Free Press, 1973), ascribed most human evil to the attempt to avoid the full consciousness of our mortality. Becker was not concerning himself, as we are, with those suffering a diagnosed terminal illness; he was speaking of the physically healthy. If his thesis is correct—if the denial of death is the root psychological cause of human evil—then think of the pressure to deny a fatal illness upon someone who is actually in the final stages, who is in the very midst of dying!

No matter how great the pressure, no matter how understandable and normal the denial of death is, it is not healthy. Nowhere have I seen this point made more compellingly than in the book *Midstream: The Story of a Mother's Death and a Daughter's Renewal* by LeAnne Schreiber (New York: Viking Penguin, 1990). It can be used as a case study of denial. It is perhaps so compelling because the author did not intend it to be such. She was simply witnessing the facts of her mother's dying and her own involvement in the process.

Her mother, around the age of seventy, developed cancer of the pancreas. She survived slightly more than a year from the time of diagnosis, probably as a result of a positive effect of radiation treatment, and she died more as a result of metastases than of the primary tumor. In the early stages, the emotional and physical pain-relief treatment she received from the medical establishment was highly flawed. But what made the book's account so grim for me was the patient's persistent denial that she was dying up until the very moment she was dead.

Just one of the powerfully realistic details of this case study is the matter of religion. The mother was a lifelong Catholic, overtly religious and involved for many decades in the activities of the church. The daughter was, and has apparently remained, overtly secular. At one point the mother and daughter together attended a healing service at the church, where the mother was prayed over. At best, this seemed like bargaining behavior. Her Catholicism gave the patient no apparent solace whatsoever. I was left with the distinct impression that she was more a cultural Catholic than a real one and that despite her superficial religiosity, she was, as is so often the case, fundamentally as secular-minded as her daughter. Any discussion of religion was apparently avoided between them, perhaps because it seemed irrelevant to the lives (and deaths) of mother and daughter.

Ms. Schreiber gently tried to penetrate her mother's denial, but her mother would have none of it. This is typical of many dying people. Efforts to pierce through denial are usually ineffective, and the more vigorously one pursues them, the more likely one is to fail. Persistence can even border on cruelty. The best approach is to give patients as many opportunities as possible to talk about dying—to welcome discussion of the subject without insisting upon it. Otherwise we should be respectful of the patient's need to deny.

Often, however, it is the family members and medical professionals who, because of their own denial, fail to welcome a discussion of dying. This is another way in which Ms. Schreiber's book is accurate. She demonstrates that her father was as much in denial as her mother. When those close to the patient are unwilling to discuss the subject of dying, they encourage rather than discourage the patient's denial, in this case placing her in a position of isolation where she can't talk about her deepest feelings even if she wants to.

Denial thus virtually ensures that no meaningful communication can take place. Ms. Schreiber's brother, a physician, was aware from the start that his mother was dying but, supposedly because of the demands of his practice in a different region of the country, kept his distance from her. He maintained his distance even during his many phone calls by hiding behind medical jargon and never expressing personal feelings. So the author, throughout the year, had no one to

whom she could really talk—which is why, I suspect, she later wrote the book.

At the conclusion of Chapter 3 about emotional pain I commented briefly on the phenomenon of redemptive suffering. I noted there the many reports I have heard of “good deaths” and the characteristics such deaths had in common. Most notable was the lack of denial on the part of the dying person and the completeness of his or her communication with friends and family. Good-byes were said with love. Frequently children and parents reconciled. Often the whole family came together in a deeper way than ever before. My reporters consistently described it as a privilege to participate in these deaths. To their surprise the experience was not dreadful but redemptive and uplifting.

For Ms. Schreiber, however, watching her mother die was not uplifting because family members could not talk to each other about the most important things. Despite the upbeat subtitle about “renewal,” I personally found *Midstream* to be a profoundly sad book. I could discern in it absolutely nothing redemptive about the mother’s death or dying, no evidence that Ms. Schreiber’s mother learned anything of significance during that last year of her life. I spotted no sign that her soul developed or grew.

Denial arrests the learning process. You cannot learn anything from your dying if you cannot even face the fact that you are dying. Hers was a natural death but not necessarily a good one.

The Kübler-Ross Stages and Learning

Although Dr. Kübler-Ross didn’t quite realize it at the time she wrote *On Death and Dying*, she had outlined stages that we go through anytime we make a significant psychospiritual growth step at any point during our lives.

Let’s imagine, for example, that there is a serious flaw in my personality and that my friends start criticizing me for the manifestations of this flaw. What’s my first reaction? I say, “She must have just gotten out on the wrong side of the bed this morning.” Or, “He

must really be angry at his wife. Doesn’t have anything to do with me.” *Denial.*

If they keep on criticizing me, then I say: “What gives them the right to stick their noses in my business? They don’t know what it’s like to be in my shoes. Why don’t they mind their own damn business!” I may even tell them that. *Anger.*

But if they love me enough to keep on criticizing me, then I begin to think: “Gee, I really haven’t told them lately what a good job they’re doing.” And I go around giving them lots of pats on the back, smiling at them a lot, hoping this will shut them up. *Bargaining.*

But if they truly do love me enough to keep on criticizing, then maybe I get to the point where I think, “Could they be right? Could there possibly be something wrong with the great Scott Peck?” And if I answer yes, then that leads to *depression*. But if I can hang in there with that depressing notion that maybe there really is something wrong with me and start to wonder what it might be, if I contemplate it and analyze it and isolate it and identify it, then I can go about the process of killing it and purifying myself of it. Having fully completed the *work* of depression, I will then emerge at the other end as a new man, a resurrected human being, a better person. *Acceptance.*

None of this is really new. I am fond of quoting Seneca, who said almost two thousand years ago: “Throughout the whole of life one must continue to learn how to live and, what will amaze you even more, dear friends, throughout life one must continue to learn how to die.” Of course, we have the choice not to learn anything about the art of living and dying. But if we choose to be deep learners and co-creators of our souls we will suffer little deaths all the time. In *The Road Less Traveled* (pp. 67–69) and other works I recounted how at the age of thirty-nine I went through all the stages of death and dying in the course of a single evening.

One night I decided to spend some free time building a happier and closer relationship with my daughter, who was fourteen at the time. For several weeks she had been urging me to play chess with

her, so I suggested a game and she eagerly accepted. We settled down to an even, challenging match. It was a school night, however, and at nine o'clock my daughter asked if I could hurry my moves because she needed to get to bed; she had to get up at six in the morning. I knew her to be rigidly disciplined in her sleeping habits, and it seemed to me that she ought to be able to give up some of this rigidity. I told her, "Come on, you can go to bed a little later for once. You shouldn't start games that you can't finish. We're having fun."

We played for another fifteen minutes, during which time she became visibly discomfited. Finally she pleaded, "Please, Daddy, please hurry your moves."

"No, goddammit," I replied. "Chess is a serious game. If you're going to play it well, you're going to play it slowly. If you don't want to play it seriously, you might as well not play it at all."

And so, with her feeling miserable, we continued for another ten minutes, until suddenly my daughter burst into tears, yelled that she conceded the stupid game, and ran weeping up the stairs.

My first reaction was one of denial. Nothing was seriously wrong. My daughter was just in a fragile mood. Perhaps it was her period or something. Certainly it had nothing to do with me. But that attempt at denial didn't really work. The fact was that the evening had turned out exactly opposite from what I had intended. So my next reaction was to become angry. I became angry at my daughter for her rigidity and the fact that she couldn't give up a little sleep time to work on our relationship. It was her fault. But anger didn't work either. The fact is that I too was rigid in my sleeping habits. So I thought I might run upstairs, knock on her door, and say, "I'm sorry, honey. Please forgive me for being rigid. Have a good night's sleep." Yet I had some sense at this point that I was bargaining. That would be a cheap apology. Finally it began to dawn on me that I had seriously goofed. I had started the evening wanting to have a happy time with my daughter. Ninety minutes later she was in tears and so angry at me she could hardly speak. What had gone wrong? I became depressed.

Fortunately, albeit reluctantly, I was able to hang in there and do

the work of depression. I began to face the fact that I had botched up the evening by allowing my desire to win a chess game to become more important than my desire to build a relationship with my daughter.

I was depressed in earnest then. How had I gotten so out of balance? Gradually I began to accept that my desire to win was too great and that I needed to give up some of this desire. Yet even this little giving up seemed impossible. All my life my desire to win has served me in good stead, for I had won many things. How was it possible to play chess without wanting to win? I had never been comfortable doing things unenthusiastically. How could I conceivably play chess enthusiastically but not seriously? Yet somehow I had to change, for I knew that my competitiveness and seriousness were part of a behavior pattern that was alienating my children from me and would continue to do so, causing other episodes of tears and bitterness, if I could not modify this pattern.

Since I have given up part of my desire to win at games, that little depression is long over. I used my desire to win at parenting to kill my desire to win at games. When I was a child my desire to win at games had served me well. As a parent I recognized that it got in my way. I had to give it up. I do not miss it, even though I thought I would.

I have told the story of that chess game often because it is the clearest example I know of how an individual can move rapidly through the stages of death and dying in dealing with a situation not of physical dying but of everyday life—and do so in the precise order that Kübler-Ross first outlined for those stages. But, as I mentioned that is not always their order. In fact, more often than not, a minor depression will descend on me suddenly, without warning and without my having discernibly experienced the preliminary stage of denial, anger, or bargaining. So let me tell a story of such a depression of mine, a story I have not told before.

Twenty years ago I was co-leading a weekly evening therapy group of some ten patients. Only fifteen minutes into the session

was clobbered by a feeling of depression so severe that I could neither think nor talk. It went on and on. Finally one of the patients asked, "What's wrong with you, Scotty? You haven't said a word. It's like you're not here."

"I'm not," I somehow managed to stammer. "I've suddenly become depressed. I have no idea why. I'm totally out of it. I can't even listen. I'm sorry. You'll have to go on working without me."

Physically I stayed present in the room, but emotionally I remained definitively not present until the two-hour session concluded. The group did continue its work. I was most grateful for the presence of my co-therapist. When the group disbanded, he asked me if he could do anything to help. "No, thanks," I told him. "I expect I'll have it figured out by morning. If not, I'll give you a call."

Not until I was in my car driving home through the night was I able to think clearly again. Knowing that depressions were usually kicked off by helpless rage, I began to wonder what had happened early in the evening's session to make me so angry. The answer came instantly: it was Bianca, one of the patients in the group; I was furious at her.

Bianca was a thirty-five-year-old woman who was not only a group member but also an individual therapy patient of mine. I had been seeing her for a year. Initially she had reminded me of a three-year-old: petulant, whining, and perpetually provocative. She blamed her husband for everything. Over the preceding four months, however, she had made great progress and had been acting her age—until that evening. The moment the group session began, Bianca had resumed her blaming and whining with a vengeance. It was as if she had regressed back to age three overnight, and I was enraged at her for it.

I knew it was common for such patients to regress temporarily in relatively early phases of therapy. Consequently I immediately realized there was something grossly inappropriate about the intensity of my anger at Bianca. So I sat on that anger, helplessly unable to express it. I was wise not to explode at her. The result, however, was my sudden and incapacitating depression.

By the time I reached home I had figured this much out. But my

curiosity as well as my lingering depression propelled me to dig deeper. For some reason what should at most have been mild annoyance with Bianca had instead been inappropriate, almost explosive rage. Why? The answer again came quickly. There are times in the professional life of a psychotherapist when all of his patients seem to be getting better and he begins to think he has a golden touch. Then there are very different periods when nobody seems to be making any improvement, causing him to seriously question his competence as a healer. So it had been for me recently. Not one of my patients seemed to be progressing . . . except Bianca. Over the past month I had frequently consoled myself by thinking, "Well, at least Bianca is moving ahead like wildfire." Only now she wasn't—she was moving backwards.

I wondered if perhaps it would be appropriate for me to consider gradually giving up the practice of psychotherapy if things continued to go sour. I didn't know. What I did know, however, was that it was *not* appropriate for me to base the entirety of my professional self-esteem on a single patient, to become enraged because such a patient had let me down, or even to feel let down by any patient's behavior. It was not fair to Bianca. For that matter, it wasn't fair to me. I would not allow myself to fall into that trap again. Like it or not, I was going to have to learn to give up at least some of my need for self-esteem. When I retired that night I was no longer depressed. I had completed the work of depression—or at least the work of that particular depression.

When someone completes the work of depression, the story invariably has a happy ending. I began the next session by apologizing to the group for my depression the previous week. I explained its dynamics and what I had learned from it. I further apologized to Bianca for using her to bolster my self-esteem. Bianca, it turned out, was profoundly moved by the importance of her progress to me. She acknowledged her regression and doubted it would happen again. Indeed, the incident marked the beginning of another major psychospiritual growth spurt on her part. As for the other members of the group, they were actually pleased that their therapist was human enough to become depressed himself, smart enough to work

it out, and brave enough to confess all the details. They proclaimed me to be a role model and, in the weeks that followed, seemed to use me as such.

Repeatedly I have used a phrase that is not in general parlance: "the work of depression." Most succinctly it is the work of existential suffering required for the healing of a depression. Since it is work of a psychospiritual sort and no one likes to suffer, most will try to avoid it by retreating from it. In doing so, they learn nothing and there can be no healing. But if they can hang in there with their depression long enough to deal with it thoroughly, they can work it through and emerge at the other end happier and wiser than they ever were before.

The work of depression is so critical to the betterment of individuals—and, as we shall soon see, to the betterment of society as a whole—that it deserves discussion in greater depth. The work can best be analyzed by dividing it into its four sequential phases.

The first phase is realizing that you are depressed and not running away from the fact. This is not as simple as it sounds. Just as people can deny that they are obviously dying, so they can also deny that they are seriously depressed. Perhaps half of the seriously depressed patients who come to psychiatrists do so with other complaints: insomnia, loss of libido, vague pains, restlessness, anxiety, marital problems, and so forth. Even to their friends they will look depressed, and the psychiatrist's first task will be to help her patient become aware that he is depressed.

Someone may also not be aware that he is depressed because the depression is relatively mild, gradual in onset, and complex in causation. During the summer of 1979 one of the early fans of *The Road Less Traveled*, a clergyman, came to visit me for several days. On his departure he commented, "I like you, Scotty, and I've enjoyed meeting you, but you're different from what I expected. On the basis of your book, I'd anticipated that you'd be a joyful, light-hearted man. Instead you seem to me heavy, almost depressed."

"I'm not depressed," I replied, "at least not that I'm aware of. Everything's going well for me."

Indeed the man's assessment seemed so strange, so off the mark, that it stuck with me. It wasn't until two years later, when my book was well on its way to fame and I'd become a somewhat accomplished public speaker, that I realized he'd sized me up accurately. Reflecting back on his visit, I remembered that I was waging an uphill struggle at the time just to keep the book in print, that I was facing my first speaking engagement with terror, and that my marriage was at its lowest point ever.

My depression of that time resolved itself with the improving circumstances of my writing and speaking career without my having to work myself out of it. One cannot do the work of depression unless he is aware that he is depressed. Six years later I was to enter a two-year period when I was profoundly aware of being moderately and continually depressed. Not surprisingly this lengthy depression centered on the time I turned fifty. It could very much be looked at as a midlife crisis. Part of that crisis was a complex of problems with our marriage. I had to do a great amount of the work of depression before I—and we—came out the other side. I have recounted several stories of the resolution of a depression over the course of a few hours, but one does not resolve the problems of a twenty-five-year marriage during a single evening.

Having completed the first phase of the work of depression by acknowledging that you are, in fact, depressed, the second phase obvious: it is to ask yourself why. Why am I depressed? Obviously though the question might be, the answer usually isn't. For instance the feeling of depression is frequently a concomitant of viral illnesses. Influenza and mononucleosis are notorious in this regard but the phenomenon also occurs with lesser diseases. As a psychiatrist, I have been particularly bedeviled by this fact. Dozens of times I've felt mildly depressed and spent several hours wondering why before experiencing the onset of a low-grade fever and aching joints and coming to the realization: "I'm not really depressed; I've just got a little bug."

But that's a minor issue. The bigger issue arises when you've got an honest-to-God depression and day after day you ask yourself why, but you can't come up with an answer. If your depression persists in being inexplicable, it's time to get yourself off to a psychotherapist. The therapist will not be able to do the work of depression for you, but she can assist you in this phase of it. If you're willing to be honest, the gentle questioning of a therapist will commonly reveal quite quickly that you've got plenty of reason to be depressed.

But if you're a reasonably insightful person there's usually no necessity to pay for the services of a trained therapist to help you do what you're capable of doing for yourself. Remember my saying that a feeling of helpless anger—helpless rage—is almost invariably the cause of depression. Simply ask yourself, "What am I angry about?" For instance, as soon as I asked myself what it was about that group therapy session that had made me angry, I immediately realized I was furious at Bianca. It was a helpless anger, however, because I instinctively realized it was more my fault than hers.

My only warning in this regard is that depressions are often overdetermined—that is to say, they have more than one cause. Frequently it will not be something you are angry about but some things. The majority of my minor depressions are like this. I notice myself feeling depressed at two in the afternoon. Thinking about it I will realize that not one, not two, but five things have gone wrong that morning. Each thing in itself might constitute nothing more than a minor annoyance, but the last one will be like the proverbial straw that breaks the camel's back, and these incidents in combination have put me in a helplessly pissy mood.

Once you have discerned the thing or things you are angry about, you have discovered the cause of your problem and completed the second phase of the work of depression. The third phase is then to ask yourself, "What do I need to do to get rid of this helpless anger?" Occasionally this phase requires no work at all. For instance, if my depression is nothing more than the result of a buildup of minor frustrations, all I'll need to do is get a good night's

sleep and I'll be fine in the morning. In the almost immortal word of Scarlett O'Hara, "Tomorrow is another day."

But when we're talking about a significant depression, sleep—you can get it—isn't the answer. In fact, the work of depression now becomes more difficult, more laborious. For the answer to the question, "What do I have to do to get rid of this helpless anger?" is that I do have to get rid of something—something in *myself*. I have to give up a part of myself. In response to the failed chess game with my daughter, for example, I realized I needed to give up my excessive competitiveness. Similarly, my inappropriate rage at Bianca taught me that I needed to give up basing my self-esteem on my patients' progress or lack thereof.

What makes this phase of the work of depression so laborious is our instinctive resistance to giving up any part of ourselves. As soon as I've identified any part of myself that I need to give up, my first reaction will be: "I can't. It's impossible." How can one possibly not play chess competitively? How can one help but base his self-esteem upon the apparent results of his work? In Chapter 3 I spoke of how depressed people feel trapped, as if they were in a cage, but also how the bars of the cage are usually of their own making. The fact of the matter is that we can give up virtually anything if we want to back out enough. The problem is in the wanting. Many of us therapists have had the experience of our patients quitting the work of depression at this point and leaving our ministrations, preferring to stay depressed rather than relinquish a part of themselves, no matter how obviously self-destructive and unnecessary that part might be.

When I said we can give up virtually anything, I did not mean that we can or should give up anything that is constructive. We should not, for instance, give up our souls—although some people do. I am speaking of things of the ego, like an excessive competitiveness or need for self-esteem. The list of such "things of the ego" is almost endless: arrogance, unrealistic fantasies, a habit of sarcasm, and on and on. The list includes anything that isn't working for you anymore.

Once we have completed this third phase of the work of depression by identifying what it is that we need to give up and realiz-

that we *can* give it up, the fourth and final phase is to do it: give it up. Bump it off. Kill it. Excise it. Again, this is easier said than done. It does feel like death. Certainly it is a process of self (or ego) surgery and is usually motivated only by a sense of self-defeat. As I said earlier, the solution to certain problems is to accept that there is no solution.

So we are back to acceptance—the label Kübler-Ross used for the stage beyond depression, the place of spiritual peace we will reach if and when we complete the work of depression. Her focus was on the acceptance of death itself and the sense of self-defeat that must be worked through in coming to terms with the fact that death is one of those problems for which there is no solution—that we cannot beat it. Increasingly, as we specifically consider the issue of euthanasia, our focus is going to be on another kind of ego defeat that is central to the process of dying: learning how to give up control.

But make no mistake: the defeat of the ego is painful. I spoke of the work of depression as laborious; it is analogous to labor, as in the process of giving birth. The pain may start gradually, but in the later stages it can be excruciating. Yet the result is new life. Similarly, the work of depression is soul learning, and the result is a new life for the soul that is almost akin to resurrection.

I cannot overemphasize the importance of these stages of dying in the process of unlearning and new learning. Not only individuals but groups, as small as married couples and as large as nations, need to go through them. Consider, for instance, the behavior of the United States in Vietnam. When evidence first began to accumulate in 1963 and 1964 that our policies in Vietnam were not working, what was our nation's first reaction? Denial. Nothing was really wrong. All we needed was a few more special forces troops and a few more million dollars.

Then, in 1966 and 1967, as evidence continued to accumulate that our policies were not working and were obviously seriously flawed, what was the government's reaction? Anger. The day of the body count began. And My Lai. And torture. And bombing that

seemed to be aimed at turning North Vietnam into an American parking lot. Yet by 1969 and 1970, when we had massive evidence that our policies in Vietnam were a failure, our next response was to attempt to bargain our way out of the war. We stopped bombing here as a carrot and started bombing there as a stick, thinking that we could somehow bring North Vietnam to the table. But that strategy also failed.

Although some of us as individuals at the time went through a significant depression over Vietnam, our government led the majority of Americans to believe that somehow we had succeeded in bargaining our way out. The truth is that we did not bargain our way out of Vietnam. Consistently in the wrong from the start, we were defeated, as we deserved to be. We fled with over half a million men. Because as a nation we generally failed at the time to do the work of depression involved in coming to terms with our collective guilt, there was little evidence that we learned any lesson as a result. Only recently, twenty-five years after the fact, does it look as if we may have done some portion of the work of that depression by learning to relinquish a shred of our arrogant desire to control the world and come to some modicum of humility in our international relations.

As for the smallest of groups, married couples, I believe that most successful long-term marriages go through these stages of death and dying in the same order that Kübler-Ross outlined. Certainly this has been true of Lily's and my marriage. For the first five years we devoted much energy to denying the painful reality that we were no longer romantically in love with each other. As this denial collapsed, we spent most of the next ten years angry at each other for not being the soul mate of our dreams. It was a time of criticism. Endlessly we specified the flaws we saw in each other, then tried to heal these deficiencies. Over and again I attempted to convert Lily to my way of thinking, and she tried to convert me to hers. Unconverted, we then went through a period of negotiating boundaries and rules that would allow us to work peacefully around each other. This activity was akin to bargaining—"I'll do this if you'll do that," we were both saying—but it brought us no joy. By the twenty-year

mark both of us had become significantly depressed about the marriage. We were unsure that it could survive, indeed that it even should survive.

Yet, for reasons that seemed ephemeral at best, we hung in there in our depressing marriage for the next decade, and strange things started to happen. Gradually, almost without willing it, some of Lily's foibles began to amuse me. I slowly realized that each of her shortcomings was the flip side of a virtue that I very much admired and depended upon. Similarly, she observed that some of the things about me she used to curse were quite natural side effects of certain gifts of mine that she herself lacked. It slowly dawned on us that we meshed rather well. We became adept at consulting each other. What once had been cause for friction and rage now became a cause for celebration—celebration of our smooth interdependence. By the thirty-year mark our previously depressing marriage was mostly fun, and now, seven years later, when we are well embarked into retirement, it is a delight.

What I have been saying can be summed up by a generalization. In those marriages that successfully survive beyond twenty-five years, somewhere around the twenty-year mark the partners begin to learn how to *accept* each other. Isn't it amazing, I might add with a hint of irony, how rapidly we human beings learn?

Over the past fifteen years Lily and I and other leaders of the Foundation for Community Encouragement have taught approximately a thousand different groups, ranging in size from ten to four hundred members, throughout the world how to be learning communities. We have done this through two- to four-day experiential community-building workshops. The central aim of these workshops is to teach the group to do the work of depression. The period when the group is most deeply engaged in this work we refer to as "emptiness." During this phase the members of the group will empty themselves of whatever is standing in the way of their becoming an authentic community. Often someone will say about the process, "My God, this isn't what I expected. This feels like dying."

Major learning is always a bit like dying. To learn anything new of significance we must first unlearn that which is old and to which

we are accustomed. We must give up a part of ourselves that has become anachronistic, and this process of self-emptying may initially feel like annihilation or a descent into nothingness. It can be terrifying.

The terror that may be involved was never more dramatically illustrated than in Martin's "rebirth." Martin was a slightly hard and depressed-appearing sixty-year-old man whose workaholicism had made him extremely successful, even famous. During the stage of emptiness in a workshop he and his wife attended, and when the group was still attempting to deal with emptiness on the level of an intellectual concept, Martin suddenly began to tremble and shake. For a brief moment I thought he might be having a seizure. But then, almost as if he were in a trance, he began to moan: "I'm scared. I don't know what's happening to me. All this talk about emptiness. I don't know what it means. I feel I'm going to die. I'm terrified."

Several of us gathered around Martin, holding him for comfort, still uncertain whether he was in a physical or emotional crisis.

"It feels like dying," Martin continued to moan. "Emptiness. I don't know what emptiness is. All my life I've done things. You mean I don't have to do anything? I'm scared."

Martin's wife took his hand. "No, you don't have to do anything, Martin," she said.

"But I've always done things," Martin continued. "I don't know what it's like not to do anything. Emptiness. Is that what emptiness is? Giving up doing things? Could I really not do anything?"

"It's all right to do nothing, Martin," his wife responded. Martin stopped shaking. We held him for about five minutes. Then he let us know that his fear of emptiness, his terror of dying, had subsided. And within an hour his face began to radiate a soft serenity. He knew that he had been broken and had survived. He also knew that through his brokenness he had somehow helped the whole group toward community.

Many of the things the members of a group must empty themselves of to become a true community are almost human universals: expectations of what the experience will be like; prejudices; the

need to heal, convert, or otherwise "fix" each other; argumentativeness that precludes listening; a desire for formulas; passivity on the one hand and a tendency to dominate on the other; the need to control. I could go on and on. Other things that must be emptied may be exquisitely personal, like Martin's workaholism or someone's preoccupation with a family situation that has nothing to do with the group.

In the earlier phases of emptiness not only do individual members often feel depressed but the entire group will look depressed to an observer. The leaders can do little except encourage the group to hang in and go deeper. The experience is perhaps even more painful for the leaders than for the participants. As the group goes deeper into its work of depression, into emptiness, it can be excruciating for the leader to sit helplessly by watching a whole group go through its death throes.

But "die" these groups do, metaphorically, and then they come out the other side into true community. It is not unlike Kübler-Ross's final stage of acceptance, but it's even more powerful because it is a group phenomenon. Again, it is like a resurrection. The group's sorrow has been turned into joy.

An important term in theology for this work of depression, of giving up or relinquishment, is *kenosis*—the process of the self emptying itself of self. It is a word of great power.

In the not-so-good old days many monks and nuns and other religious folks practiced the discipline of self-mortification. The word is derived from the Latin *mors* ("death")—as are "mortality" and "mortician"—and meant for them the "discipline of daily dying." It was often overdone with hair shirts and the like. But its basic purpose—kenosis—is essential to maintaining our vitality as individuals or as a civilized society.

The purpose of kenosis, or self-emptying, is not to have an empty mind or soul, but to make room for the new and ever more vibrant. The image of the kenotic individual in Christianity is that of an empty vessel. To live in the world we must retain enough of our ego to serve as the walls of the vessel, to be any kind of container at all. Beyond that, however, it is possible to empty ourselves

sufficiently of ego that we can become truly Spirit-filled. The goal is not the obliteration of the soul but its expansion.

Dying individuals who complete the work of depression do arrive at acceptance. Groups who hang in there through the agonies of emptiness do arrive at true community. The learning is enormous, and the end result glorious. But I do not mean to whitewash the existential suffering involved. The relinquishments are gigantic.

The Kenosis of Dying

Just as most people deny their dying, so they also deny their aging. I know many in their sixties, even early seventies, who still think of themselves as middle-aged. Being who I am, I deny neither my aging nor my dying; instead I write about it.*

People are immensely different in many respects. They age, both physically and emotionally, at different rates. My father routinely played eighteen holes of golf until he was over eighty. At sixty I am generally doing well to get around nine, even with a cart and painkillers.

I am not middle-aged; I am old. What with flossing my teeth, doing abominable but lifesaving back exercises for the degenerative disease of my spine, using three types of eyedrops for my glaucoma, applying lotions and salves to my deteriorating skin, etc., etc., etc., it takes me well over an hour to get going in the morning and, with similar rituals, the same amount of time to prepare myself for bed in the evening. I don't sleep as soundly nowadays, so I must sleep longer. I have little physical stamina. Travel is exhausting. Concentration requires more effort. I write more slowly. Although I have not yet been given a specific fatal diagnosis, I don't have to be a wizard to realize that I am dying.

It also happens that, when I put my mind to it, I listen better. That's not a bad trade-off.

* Much of the material in this section is discussed in greater depth in my most autobiographical book, *In Search of Stones*, where whole chapters are devoted to dying and aging and related issues.

Being old now, I pay more attention these days to television ads addressed to the elderly. They generally infuriate me as much as those aimed at baby boomers, with their blatant use of sexual titillation. One such recent ad for an arthritis pain reliever depicted a woman supposedly in her sixties, though naturally she looked about forty, happily swinging her racquet on a tennis court. At its conclusion, a loud invisible voice joyfully proclaimed, "Live without limits!"

The notion that we can live without limits at any age is absurd. But what old age is more about than anything else is learning how to *accept* one's ever-increasing limits.

Acceptance is both a voluntary and an involuntary process. Each new limitation represents a loss, a little death. These losses are initially inflicted upon us involuntarily. It is not in our human nature to welcome limitations and losses any more than to welcome old age and dying in general. We grieve. The extent to which we are willing to do the work of grieving—the work of depression—is a voluntary matter, however. It is a matter of choice. The choice is not one that is generally encouraged in our pain-avoiding, death-and-old-age-denying culture that incessantly caters to our original sin and tells us to "live without limits."

No experience in my career as a psychiatrist was more painful than having to place several wealthy elderly patients in nursing homes against their will. They had lost the ability to add and subtract accurately and keep track of complex financial matters. Yet they refused to accept this limitation. When I visited them at home, at the request of their families, I found them surrounded by piles of balance sheets, unpaid bills, and checkbooks in disarray. They had been frantically working all day long and late into the evening to make sense of it all. My efforts to suggest that they could no longer make sense of it were to no avail. They had the wealth to hire competent and loving people to manage their affairs so that they could sit back and enjoy grandchildren, sunsets, and walks in the garden. But they would not give up control. So the control had to be wrested from them. They went to nursing homes not because of a

failure of bodily function but because of their failure to accept less stringent limitations. It was terribly sad.

I have more or less equated limits with losses. The losses of aging are so numerous that they could fill books and so huge that they are incomprehensible to the young. We need every skill at our command to cope with them. One such skill is gallows humor. A particularly male variant of it goes: "At forty I would have settled for a beautiful woman. At fifty-five I would have settled for a great meal. Now that I'm seventy I'd settle for a good bowel movement."

Again without whitewashing, let me note that some of these losses may eventually come, for at least a few, to be experienced as liberation. Take the "beautiful woman" bit. In my fifty-fifth year I experienced a relatively sudden and dramatic loss of libido. It was not total, but along with it my capacity to attain and sustain erections became distinctly iffy. Such a loss of sexual potency would have sent many men, despite their embarrassment, running to their physicians in panic. Not me. Since I was a traveling man at the time, not infrequently subject to the attentions of beautiful women, this diminution of testosterone coursing through my veins felt as if I'd gotten a monkey off my back. It did take a while to accept, but when the while was done it seemed to me more like a healing than a disease.

I focused on this matter of sexual potency because potency—power, whether for women or for men—is what's most at stake. By power I do not mean just political power, as we ordinarily think of it. The loss of such power may be one of the great losses of aging. Mandatory retirement, for instance, can be devastating, particularly to those who enjoyed political stature because of their jobs. But most do not have much in the way of political stature. By power, as in willpower, I mean the capacity to do more or less what we want to do: simple things like having sexual intercourse, playing a game of tennis, riding a bike, driving a car, going downtown for a meal, even getting out of bed to go to the bathroom. Power can be

equated with freedom, with choices and options and potentials, with at least a modicum of *control*.

I awoke this morning, for instance, with the potential (potency) of working on this book, writing on my yellow pad, and enjoying the view outside my rural office window whenever my attention wandered. There being no emergencies demanding that I do otherwise, I had the freedom to exercise this option, to choose the plan I most wanted. And so here I sit, in control. But what if my glaucoma were to get out of control and I were to become totally blind? Writing on my yellow pad would no longer be a potential choice. Enjoying the view would not be an option for me. Like my glaucoma, these pleasant, useful things—and many more—would be beyond my control.

Life whittles away at our sense of omnipotence almost from the start. You may recall that in Chapter 3 I spoke of how during our terrible twos we begin to get it rubbed in our faces that we are not kings and queens of the whole world. Despite this ongoing whittling, however, we tend to be remarkably tenacious in holding on to only mildly attenuated feelings of omnipotence. Indeed, in middle age we often feel more in control of our lives than ever before. But in old age the whittling speeds up. It can be so rapid that it seems violent, no longer a whittling away so much as a stripping away.

Aging need not all be agony, however. About five years ago, when I was just beginning to imagine retirement and the loss of power involved, I was encouraged by a *New Yorker* cartoon depicting a man approximately my age saying to his wife over the breakfast table, "I'm losing my grip on things, and it feels just wonderful." And, in fact, as I move ever deeper into retirement, my predominant emotion these days is one of relief.

But note this: I have it good. Lily also is in old age, and she too does not yet have a fatal diagnosis. We have each other to share our aches and pains with. Our marriage is better than at any time in its thirty-seven-year history. We also have plenty of money, a competent staff to support us, good friends, and trips to Europe. Ours is an unusually potent old age. Rejoicing over our enjoyment, I recently said, "These really are our golden years."

"Golden years, hell," Lily retorted. "They're our platinum years."

So I've been lucky, and it is important, I believe, for the reader to realize that my good fortune may color my assessment of these matters. Nonetheless, the stripping continues. There are ever more days when I would like to write or we would like to play nine holes but we can't because we've got doctors' appointments, and when we traipse off to Europe it is with ever more pills each trip. And we have escalated the frequency of these trips to get in as much as we can, precisely because we know our platinum years will not last much longer.

We know the stripping away of our options and our competence will soon become increasingly rapid and increasingly violent. What form will it take? Will we be like Victoria who, because of her stroke, couldn't dress herself anymore? Will we become incontinent where we don't even have control of our bowels and bladder? We cannot predict the details. What we can predict is that the day is not too far off when the stripping will be total, when it will be complete, and when, on this earth, we will have no choices left whatsoever.

Thus far I have been speaking of physical losses and limitations of the body. More painful to me over the years has been the loss of illusions. I have *really* had to go through the stages of death and dying and do the work of depression as I relinquished my treasured dreams, ideals, heroes, and fantasies.

Many such illusions are human universals. I can remember a professor telling us psychiatry residents when I was thirty, "Nobody can be truly mentally healthy or emotionally mature until he gives up the fantasy that he can cure his parents." I could connect with that in my work with patients, and I recall nodding sagely at the time. But it was to be a dozen years before I substantially relinquished that fantasy in relation to my own parents, and I even held on to shreds of it until they died.

As I said, I could connect with that fantasy in my work with patients, but I also learned early on the truth of the well-known

lightbulb joke: How many psychiatrists does it take to change a lightbulb? Answer: Just one, but only if the lightbulb wants to change. More slowly I learned some of the ambiguities involved. I knew even Jesus couldn't heal anyone who didn't want to be healed, but I believed I could successfully take on all who were "well motivated." All I had to do was to love them enough. Yet I underestimated their biology and ambivalence and overestimated their capacities and mine, including my capacity to be all things to all people. In fact, I never healed any of my patients. I was merely fortunate enough to have a few with whom the mix was sufficiently right for them to use me as a catalyst in healing themselves before I burned out on my omnipotent idealism.

I could go on at inappropriate length about all the illusions I have learned to relinquish. But I will focus on only one more that is ubiquitous in our society and particularly germane to the subject at hand: the illusion of cure. This illusion is brutally exposed by Maggie Ross in *Pillars of Flame* (San Francisco: Harper & Row, 1988), a book about kenosis. Healing does occur, yes, and sometimes it may seem like cure, but in reality it is a very different process. My recovery from an almost fatal bout of pneumonia at age forty-seven is an almost simplistic example. After seventeen days in the hospital on three different types of intravenous antibiotics, I was released to recuperate at home, and within another six weeks I was back on the lecture circuit. But I was not the same man, either psychologically or physically. Psychologically, I realized that I had almost died because I'd been behaving like an iron man, lecturing all day in one city, only to get on a plane that evening so I could lecture all the next day in another city. As part of my healing I was forced, for the first time in my life, to accept and firmly set limits on my previously overdepleting schedule. I also, for the first time in my life, suffered from asthma, clearly as a result of what the pneumonia had done to my bronchial passages. Today, when we go off to Europe, some parts of the mountain of medicines we take with us are for asthma—to treat the effects of the disease of which I supposedly was cured more than a dozen years before.

As I've said, around the typical age of fifty I went through some-

thing of a midlife crisis and "healing depression." Among the things that sustained me through that difficult period was a little paperback of humorous quotes and drawings entitled *Who Needs Midlife at Your Age?** One of its quotes was: "Middle age is when you keep thinking in another couple of weeks you'll be back to normal." Ah, yes, the illusion of cure, the denial of aging.

All these delusions—perhaps all our illusions—are illusions of power. Of control and potency. Now let me point out that they are also all illusions of the ego. The soul does not care about power in the world's sense. Incontinence is often perceived as the worst thing that can happen to a person: the final lack of control, an utterly humiliating, total loss of dignity. But it is the ego that is humiliated. The soul does not concern itself with such niceties or with that dignity which is so superficial. Indeed, being immortal and pure spirit, the soul does not worry the least about the body, even the body's death.

It is the nature of the ego to cling to power, to chase restlessly the illusion of security, to deny loss, to refuse to accept limitations. Then how does a human being ever empty herself of these things? And why? How and why we do sometimes voluntarily relinquish power, choose to give up treasured illusions, overcome denial, and reach acceptance?

This happens because the ego is sometimes smart. After a while we can grow tired of butting our heads up against a stone wall. We can be clever enough to recognize that our illusions are killing us and that relinquishing them is the path toward healing. We may realize that our ego is getting in our own way and finally come to Buddha's and Jesus' understanding that the ego is its own worst enemy.

At this point, if we ever reach it, we embark upon the journey of kenosis, "the process of the self emptying itself of self," of

* Jack Roberts, Dick Gunther, and Stan Gortikov, *Who Needs Midlife at Your Age? A Survival Guide for Men* (New York: Avon Books, 1983).

purification, of the ego bumping itself off. Some engage in this journey of kenosis only halfheartedly, in fits and starts. That is to be expected. It is something of a miracle that we come to be engaged in it at all. A few eventually take up the journey wholeheartedly and come to see in it the very meaning of their existence.

The kenotic path is hardly encouraged in our "live without limits" culture. Take this matter of relinquishing illusions. In our culture we say, "Poor Joe, he's disillusioned." What we ought to say is "Lucky Joe, he's been disillusioned!" Instead, we commiserate: "Now he sees things the way they really are, poor guy."

As if it would somehow be better for him to deny that he is rapidly dying of a fatal disease and therefore unable to say his good-byes, as if it would be better for him to think he could still manage his finances when he can't count anymore, as if it would be better for him to have a heart attack while trying to prove a virility that no longer exists, as if he shouldn't realize that the research he is doing is being used by his company to manufacture weapons of mass destruction . . . and on and on.

But if the publishing industry is any indicator, there are some at least faint early signs of cultural change. Since the publication of Kübler-Ross's book *On Death and Dying* there has been a slow increase in the number of books on the subject of the *learning* of dying. Moreover, their quality seems to be improving. Two recent ones strike me as particularly sound and compelling, in part because of their spiritual yet nonsectarian nature. *Living Our Dying: A Way to the Sacred in Everyday Life* (New York: Hyperion, 1996) by Joseph Sharp, a long-term AIDS survivor, is the broader of the two. *Dying Well: The Prospect for Growth at the End of Life* (New York: Putnam, 1997) by Ira Byock is more rooted in details, including the mechanics of hospice care. I highly recommend both books and will mention them again.

The most commonly dreaded diseases in our society are probably AIDS and cancer, which cause an inexorable, gradual death where the afflicted have much time to watch themselves slowly deteriorate and waste away. Most people—if they had to die at all—would hope for a sudden death without even the consciousness of their dying.

Yet I once heard it reported that Dr. Kübler-Ross actually hoped she would die from cancer so that she would have the time and consciousness to learn from dying. I believe she was expressing a desire to learn kenosis.

But make no mistake: kenosis does not come easily or naturally. I am virtually certain that I myself could not follow a kenotic path, accepting without denial the stripping away of illusions and competencies that death and dying demand, nor could I welcome this stripping, were it not for my spiritual belief system. I couldn't do it unless I believed in a God who wanted me stripped away so that She could have me totally naked without any of the deceptive clothing of my ego . . . unless I had a personal relationship with God so that, among other things, I could complain to Him about His violence and possessiveness . . . unless I was convinced that I had a soul whose highest destiny was utterly and voluntarily to belong to Him . . . unless I knew with certainty that my only true power resided in my soul, that every effective and healing accomplishment of mine had been Her accomplishment emanating out of my real being, my soul, which She created, and that every stupid and wicked thing I have done originated in my ego and its self-preservative mechanisms . . . and unless I realized my ego to be but a temporary necessity, that it chose to cooperate with God as best it could and that I was forgiven from the day of my birth.

CHAPTER FOURTEEN: THE ELDERLY

TOPICAL OUTLINE

1. An elderly woman in a retirement center and her experiences of loss.
2. The elderly, developmental tasks, and death.
3. Encounters with death in late adulthood.
4. Death-related attitudes among the elderly.
5. Coping with life-threatening illness and dying in late adulthood:
 - maintaining a sense of self
 - participating in decisions regarding one's life
 - being reassured that one's life still has value
 - receiving appropriate and adequate health care services
6. Coping with bereavement and grief in late adulthood:
 - illness, disability, and loss
 - the death of a spouse or other significant peer
 - the death of an adult child
 - the death of a grandchild or great-grandchild
 - loss of a pet
7. Suicide among the elderly.

OBJECTIVES

1. To identify developmental tasks in late adulthood.
2. To describe encounters with death among the elderly in contemporary American society.
3. To examine principal factors in death-related attitudes among the elderly.
4. To identify issues that confront the elderly who are coping with life-threatening illness and dying.
5. To identify issues that confront the elderly who are coping with various types of bereavement and grief.
6. To examine suicide among the elderly.

KEY TERMS

An adult child: an individual who is a young, middle-aged, or even "young-old" elderly person, but who is also the living child of an older parent.

Ageism: a term coined by Butler, which he defined as a "process of systematic stereotyping of and discrimination against people because they are old".

Bereavement overload: a phrase proposed by Kastenbaum to identify situations common in late adulthood in which the elderly do not have the time or other resources needed to grieve and mourn one significant loss effectively before another occurs.

A developmental perspective: a point of view that considers other events in terms of the human life cycle and its developmental tasks.

Developmental tasks: (see Chapter 12, under key terms)

Developmental tasks in late adulthood: conceptualized by Erikson as involving a tension between "ego integrity" vs. "despair"; the successful resolution of this polarity is said to lead to the virtues of "renunciation and wisdom".

Ego integrity: a term used by Erikson to describe the attainment of an inner sense of wholeness; described by others as "self-actualization" or "reconciliation".

Forgotten grievers: Cyulay's phrase for grandparents whose grief remains unnoticed in situations involving the fatal illness, death, or bereavement of a grandchild; a kind of disenfranchised grief originally appreciated in relationship to the grief of grandparents.

The "graying" of society: a term used to describe the aging of the population; reflects the fact that the elderly are a growing portion of the population.

Late adulthood: an era in the human life cycle which follows "middle age"; includes those who are 65 years of age or older. The boundaries of late adulthood have become less clear, first because retirement at age 65 is less and less a well-defined social marker, and, second, because the elderly are living longer in our society. Thus, some scholars have advocated distinctions within late adulthood, e.g., between the "young-old" and the "old-old".

Life review: a process described by Butler as involving introspection, heightened interiority, self-reflection, and reminiscence in the elderly, designed to resolve old conflicts and achieve a new sense of meaning as means to achieve integrity, account to oneself for one's past life, and prepare for death.

Maturity: a term which Erikson substituted for "senescence" to designate the concluding period in the human life cycle; now more commonly replaced by "late adulthood" to describe "the elderly".

Senescence: a term used by Erikson in his original schematization to designate the concluding period of the life cycle; etymologically, a word linked to "senile" and "senility," thus implying not just "growing old" but also the presence of pathological weaknesses or infirmities which need not (and should not) be associated with normal development and late adulthood.

Suicide among the elderly: the elderly in the United States have been notable in recent years for having the highest rate of suicide among all developmental cohorts; this behavior is often associated with depression; by contrast with suicide among adolescents, suicidal behavior among the elderly is often very deliberate vs. impulsive and more likely to lead to a completed suicide than to a "cry for help".

'This Is How A Child Dies'

by Frank Deford

Every year of Alex Deford's life was hard. But the eighth—her last—was hardest of all. While her friends were attending third grade, Alex was shuttling in and out of the hospital, forced to undergo painful "therapy" daily in a vain attempt to counteract the cystic fibrosis that was squeezing the air from her lungs and the life from her tiny body. Despite this, until the very end, she found the energy to protect her loved ones from the sadness that was consuming them. In this final excerpt from Alex: The Life of a Child, which is being published this week by The Viking Press, her father, a journalist, writes about Alex's last few months.

Alex finally got out of the hospital and was able, officially, to finish the second grade, but by now she was so far behind that we started having Marlayne Schaeffer, who had been Alex's dance teacher, come in and tutor her. Alex was, as ever, conscientious, but it was growing more difficult for her to sustain any effort.

"Sometimes," Marlayne remembers, "she was obviously just so tired, but other times I came to realize that she was only being gracious when she said that, that she was really just in great pain, but didn't want to burden me with that knowledge."

By now, even when Alex was not, for the moment, sick, we were on edge, poised, never far from trauma. Every day there was a crisis atmosphere, for she would so often plan something simple—to go see a movie, have a friend visit—and it would have to be canceled at the very last minute because she showed a high fever. Sometimes I thought that, no matter how many ways she could get sick, it would be a broken heart that would kill her. By now the emotional deprivations were growing as great as the physical.

As the summer wore on, the pain increased and Alex had to be denied so much that even her spirits began to flag. A few months before, she had initiated a conversation about the general subject of

illnesses, why some people get them and others don't. That was about as close as she had ever come to cursing her luck. But even then she hadn't approached the matter directly. Instead, the question she posed was, "What is the worst disease in the world?"

We discussed the matter for a while. On the one hand, I didn't want to give Alex's disease short shrift and make light of what she suffered; but on the other hand, neither did I want to make cystic fibrosis sound so bad that it would depress her. Finally we came to an agreement that the worst disease of all would be one that left you completely paralyzed. There had been a boy from South America in the Yale-New Haven Hospital who could hardly move anything but his eyelids, and he obviously had left a great impression on Alex. "Don't you think that would be the worst?" I asked.

She thought for a time, and nodded. But then, very quickly, she looked directly at me. "Then what's the second worst?" she asked.

I couldn't walk any more tightropes that day. "Well, what do you think, Princess?"

"Oh, I think I know," she said, and she only smiled at me for trying to be kind.

By summertime, though, Alex no longer felt she had to be evasive about such matters. She had more pain all the time and hated the nose prongs that she had to sleep with now so that she could get

CONTINUED

There on the lawn, closer to the house than ever I had seen one, was a huge, coal-black raven, the bird of death.

Bonus Book

more oxygen. It was obvious that she would soon have to go back to the hospital; in fact, we postponed it for a week or so in order to allow her to make the first day of third grade.

There was a point beyond which even Alex's goodwill was tested, and that was reached regularly now, especially when we did therapy. Obviously, no one is going to enjoy being turned this way and that while somebody pounds on you, but Alex was as good at accepting that as anyone you could imagine. When she did complain, it was more in the nature of any kid trying to get away with something, like Chris asking why he had to eat carrots or why he couldn't stay up later. So it was: Why do we have to do therapy now? Can't we skip this one? Let's finish it later. But really for the first time in any sustained way, that summer Alex began to complain about the very nature of the therapy. Soon, and almost every time, she was screaming at Carol or me: "You're hurting me, Mother!" "Please, Daddy, stop now, please, please. This hurts!"

But she was able to go to school that first day, and I was waiting at home when she got off the bus and began to struggle up the driveway. I ran out to meet her and, under the pretext of hugging her, picked her up and carried her the rest of the way in. Then we sat down and discussed all the things any parent would want to know about the first day of school: Where was your desk? How did you like your teacher? Did you meet any new friends? And Alex answered them all with excitement and enthusiasm. I doubted that she could possibly last out the school year, but here we were talking about a grade, about a spring that would surely never come for her.

And yet she wanted and planned to be a part of her third grade. "Daddy," she said, "do I really have to go in the hospital tomorrow? Please."

"Oh come on, Alex, you—"

"I won't argue about my therapy. I promise. Please, don't make me."

"You're not being fair, Alex. You know you really were supposed to go in a few days ago, and we kept you out just so you could go to school today."

"I have to go?"

"Yes, Princess, you have to. Don't get mad at me."

She nodded then, and came over and sat in my lap. "Can I tell you something then?"

"Sure."

"But I don't think you'll like it."

"Well, try me."

"Okay. I've stopped praying, Daddy. I mean, I've stopped praying for a cure... a cure for my disease."

I didn't protest. I just shook my head in understanding. "I can see why."

"You can?"

"Sure. You're always way down in the dumps whenever you have to go back in the hospital. It's tough for you now. I know. Is it okay with you if I keep on praying?"

She hugged me and said that was all right. We held each other for a long time then, and when I cried, I was quick to whisper to her that I was just so sad that she had to leave her school and go back into the hospital. Finally, when she pulled away from me, she said: "Daddy, do you remember that time we talked about the worst disease of all?"

"Yeah, I remember."

"It's cystic fibrosis, isn't it?"



One tear fell from all those in my eyes. So gently, so dearly, she reached up, and with an angel's touch, swept the tear from my face.

"Yeah, I guess it is," I said.

"I thought so," Alex said, and we both nodded and cried some more. "See, Daddy, I'd pray if I could see something, just something, but"—and just then she happened to glance down at her fingers. "Daddy, look at my fingers now. They're even worse." They were clubbed from lack of oxygen.

I took them and kissed them and held them so that she wouldn't have to see them and be reminded.

"You know Crissy?" she asked after a while.

"You mean the other little girl in the hospital with CF?"

"Yeah."

"Sure, I remember Crissy. She was nice."

"Do you think she'll be in the hospital this time too?"

"Oh, I just don't know, Alex."

"I think she probably will be," Alex said. "She's got this disease real bad too. Me and Crissy have it worse, don't we? She has real bad fingers too."

"Yeah, I know," I said. "Some kids with CF don't have it so bad. Some of them really just have problems with their stomachs."

Alex's eyes widened at that. I guess I never told her that before. "Oh, they're lucky, Daddy," she said. "They're lucky."

"Yeah," I said, agreeing that it sure was lucky just to be a little bit incurable.

"But I'll die," Alex said. It was the first time I had ever heard her say anything like that. And it was a statement, too. She had obviously worked this out so that she would be presenting the matter, not asking me about it.

"Well, sure," I said. I'd been prepared for this for a long time. "You'll die sometime. But I'll die too. If there's one thing we all do, it's die."

"But you'll be real old," she said.

"Not necessarily. I mean, I could die in an accident anytime."

Alex threw her arms around my neck. "Oh, my little Daddy, that would be so unfair."

"Unfair?" I said. *Unfair* is just what she said.

"You don't have a disease, Daddy. You shouldn't have to die till you're real old." And then she hugged me as hard as she could.

Alex already understood that her time was fading, and there was much she must do for herself. Just before her lung collapsed late in September, we had traveled to Baltimore to visit my parents and I celebrate my mother's birthday. It a grand family occasion, because my brother Mac, who is Alex's godfather, was also there with his family: his wife, Zehra, and their little son, Benjie. This was extra special, because Mac spent a great deal of time abroad. At the time he was a Foreign Service officer, and now he's with Merrill Lynch's international division.

He's been stationed in the far corners of the world: Jordan, Korea, Argentina, Vietnam; he met Zehra when he was posted to Jidda, Saudi Arabia. She's Turkish, and Alex was always especially taken by Zehra, exotic and sweet. And so on this trip Alex cornered Zehra while she was straightening up in a bedroom at my parents' house.

"Zehra," Alex said, "I want to ask you something."

"Yes, of course, what is it?"

"Is there a God?"

Zehra was, to say the least, staggered. Among other things, she's a Moslem, and the last thing she wanted was to start leading this little Christian astray. "Well, I think so," Zehra ventured.

"How do you know?" Alex asked.

"I don't know. I just feel sure there is talk to Him when I need Him."

"You do? How?"

"You know, Alex, praying."

"Oh," she said. "I do that too. Do you think He'd listen to me?"

"I think He listens to everybody."

Bonus Book

Zehra said, and nervously she started puttering about again. Alex sat down on the floor and watched her in silence. Zehra didn't understand that Alex had carefully selected her for these questions. She was both a good friend and family, and Alex liked her, so she could ask Zehra the questions she wouldn't dare ask Carol or me. After a while Alex spoke again. "Zehra?"

"Yes, sweetheart?"

"How do you die?"

Zehra stopped her cleaning up and turned to face Alex. She would deal directly, the best she could. "It's mostly just like going to sleep," Zehra said. "All of a sudden, though, you aren't in your own house. You're in God's house."

"Where's that?"

"That's in Heaven."

Alex thought about that for a while. "Are there toys there?"

"Oh yes, lots and lots."

"But it would be awfully lonely without your family, wouldn't it?" Alex said. There was no doubt from the way she said that, that it would be lonely because she would surely be going first.

"Oh, no, Alex, everyone will be there soon enough," Zehra said.

"You too?" Alex said. "Mac and Benjie? Grandmommy and Granddaddy?"

"Everybody. But before they do get there, you can always look out through a window in Heaven and see everyone down here that you love and you miss."

"You can?"

"Sure you can, Alex. Or otherwise it wouldn't be Heaven."

Alex thought about that for a moment, and then she got up and thanked Zehra and left her there to finish cleaning up.

The first time Alex's lung collapsed—a pneumothorax, it is called—she was given a large dosage of painkiller, and it really knocked her out; she slept for hours and was groggy many more. Thereafter, even though she was frightened of pain, she seemed more frightened that she might never wake up, and so she told the doctors only to give her a local.

We did not know it at the time, but this would be the last occasion when Alex would—could—have the tubes inserted to reinflate her lung. Carol and I and Alex feared that it would keep happening, again and again, the final cruel indignity, but what we did not know was that, after



Alex asked her aunt about Heaven. "Everyone will be there soon enough," her aunt said. "But before they do get there, you can always look out through a window in Heaven and see everyone down here that you love and miss."

this time, Tom Dolan, her wonderful doctor, doubted that her body could stand the trauma of another cut. There was so little left of her.

And so I carried Alex into her treatment room. By then she had prepared herself fairly well, but as soon as she saw that stark table where she was to lie and receive her shot and her incision, she stiffened, and she was the little girl again. "No, not yet! Not yet!" she cried, and she clung to me as tight as ever she had.

I remember noticing that both nurses turned away from us at that moment, because, for all they might see, day after day in a hospital, there was such an awful intimacy to Alex's gesture that they could not bear to intrude on us. I only held Alex and tried to comfort her more.

And, in time, when she had composed herself, she said: "All right. I'm ready now." And so she was.

So I started to lay her down where they would cut her open. And in that moment I could not hold back any longer; one tear fell from all those welling in my eyes. And

Alex saw it, saw my face as I bent to put her down. Softer but urgently, she cried out: "Wait!" We all thought she was only delaying the operation again, but instead, so gently, so dearly, she reached up, and with an angel's touch, swept the tear from my face.

I will never know such sweetness again in all my life.

"Oh, my little Daddy, I'm so sorry," is what she said.

One nurse turned and bowed her head and began to sob. The other could not even stay in the room. She ran off to compose herself. It was some time before we could get going again.

First, they put all this pumpkin-colored soap over where Alex was to be cut in the chest. I held her hand. Then they brought out the needle, a huge horse needle. I squeezed her hand, and she squeezed mine back, harder, harder, as they jammed it deeper into her. She cried. And then they started to cut her. Can you imagine what it is like to be with your child when they are cutting open her chest?

And all for nothing, too. I knew that. It wasn't really going to do any good. It wasn't going to save her. It might not

Bonus Book

even help her. All we knew for sure was that it would hurt her. But it had to be done. It had to be done, so I held my baby's hand, and the doctor cut through the orange goo as if she were a jack-o'-lantern being sliced up for Halloween, and then he brushed away the blood, stuck a tube in her, sat back and said, "Okay."

"It's over," I said.

Alex said: "Thank you, Daddy."

Later, Barbara Arends, her favorite nurse, told me: "Alex wasn't that specific about finding out what was happening to her until after the chest tubes." But at that point Alex seemed to grasp the utter hopelessness of her plight. And yet, how unfair it was, that as she could not live life like the rest of us, neither could she even talk of death to those closest to her. You see, in many ways she felt she had to protect us—her family—more than we her.

Alex knew. Barbara recalls episodes when Carol was especially upset and morose and Alex would then purposely act her worst, very fresh and bratty, so that her mother's emotions would be diverted and she would grow annoyed at Alex, rather than sad. One time Barbara remembers that Carol was fixing Alex's hair, fighting to hold back the tears as she made her dying child pretty. Alex suddenly started making such a nuisance of herself and Carol finally got so irritated that she said, "Alex, if you don't stop acting like this, I'm going to leave this room."

And Alex immediately did one more exasperating thing, which left Carol with no alternative but to storm off for a cup of coffee. As soon as she was gone, Barbara said: "Alex, that was horrible of you. You were really mean to your mother. You shouldn't be like that."

And Alex said: "Oh, Barbara, you don't understand. She was just being too sad, and that wasn't good for her. But if I told her that I didn't want her around, it would've hurt her. This was best for her. I'll be all right when she comes back."

A few days after that she was released from Yale-New Haven for the last time. It was Dec. 15, 1979, the day before my 41st birthday.

"There's no more I can do for her," Tom Dolan told me. "She knows that, too. Some kids, when they sense that, they give up on the doctor right away, but Alex hasn't. She's never blamed me for her disease. She's a wonderful child. I just pray for all of you that she lives some time past Christmas, because I've seen families where the child died over the holidays, and then every Christmas after that was ruined for them."

Always before, when she left the hospital, Alex would laugh and say something like this to Barbara: "Okay, I'll see you the next time they make me come back to this stupid old place." But this time, before Barbara knew what hit her, Alex said only, "Goodbye," and threw her arms around her. To Cyd Slotoroff (her good friend who played guitar for the kids) alone, the night before, in her room, Alex said, "Goodbye forever," and then, to a new nurse, one she liked but hadn't grown that close to, Alex was almost matter-of-fact. "I'm going home to die now," she said, "but don't you tell my Mommy or Daddy because it'll upset them."



By Christmas, Alex was so weak that her brother had to write a thank-you note to Santa for her.

To be honest, I really don't think that Alex believed in Santa Claus anymore. On the other hand, I also don't think she saw any sense in getting deeply involved in that issue. I think, when you're a child dying, it is quite enough worrying about God and all that, without making too much of a fuss over Santa Claus. Besides, Alex knew this was going to be her last Christmas, so why not keep the string intact? She let herself go on believing. And she wrote a letter asking for a puppy.

Chris and I went down to the pet store and bought the puppy, making arrangements to have it stay there until Christmas. Then, the last day before classes let out for vacation, Carol took Alex over to school. She was so excited at that. The whole Greens Farms Elementary School cheered her, and her own third-grade classmates surrounded her so that "we were squashing her," Aimee, one of her best friends, told me, and Mrs. Beasley had to cry out happily: "Come on now, back up from Alex. You don't want to hug all the health out of her." It was a happy, happy time, and Alex kept recounting those moments to me.

Of health, there was precious little left. Her face was drawn and pale, dominated by the blackness of her mouth and her eyes. Carol said to me, "It almost seems as if her whole face is eyes." Alex had to

sleep much of the time, and where once she had fought not to have to wear nose prongs, now she welcomed them. The additional oxygen and comfort they brought her. Increasingly, she had to sleep in what almost amounted to a sitting position, propped up on piles of pillows, leaning forward on Tink, her big cuddly round lamb. Apparently, this posture helped open up her chest for an iota more of air. "You see, Daddy, when you have CF, you must sit up like this or you get all scrooged up," Alex explained to me patiently, as if she were telling me how to play a game or put on a boot.

As always, Chris would start off the night sleeping next to her, but now, alternately, Carol or I would come in, move Chris back to his bed, and take his place next to Alex. Her breathing was so labored that it was actually difficult for me to sleep with all the commotion, and, listening, I was sure that it must hurt her just to breathe.

The worst was when suddenly she couldn't get any air at all, and she would shoot up in bed, crying, "Help me! Help me!" And it was all the more horrible that there wasn't really anything we could do when that happened. Mostly we would just run to her and console her.

"What can I do, darling?"

"Just hold me tight when I'm coughing."

It was four days before Christmas when Carol said, "I think we had better bring that puppy home today."

At first I didn't want to. I wanted to think that at least we could make every effort to have a Christmas as typical as possible, and also I thought of all those awful newspaper Wirephotos I had seen through the years, of Christmas trees set up in August and September for some child who would not live till Christmas. "Let's wait, please," I said. But I slept with Alex that night, and it was a frightening experience, so when I got up the next morning, first thing, I wrote her a note from Santa, explaining that the puppy was getting lonely at the North Pole, and he and Mrs. Claus and the elves and the reindeer—everybody—had discussed it, and they thought it would be a good idea to bring him down to Westport a few days early so that he could be with an especially good little girl.

It was all worth it. We named the little thing Buffalo, and even when we put him on her lap, and he rolled all around and nipped at her and made her cough from all the action, it seemed a fair price to pay. On Christmas Eve, Alex said she thought she ought to write Santa a thank-you note when he came back with the regular Christmas bounty. She left it down by the tree. It said: "Dear Santa, Thank you for the puppy. Here's some milk and cookies for you. Love, Alex xxxxxxxxooxxxxx"

Bonus Book

Alex usually wrote at greater length. Then I noticed these initials down at the bottom of the letter: "AD:cmd". Chris had written the note for her. She had grown too weak even to write out a few lines.

Once we were past the holidays we seemed to convince ourselves that death was, somehow, no longer imminent. Besides, I was trying to occupy myself some in order to—let's face it—escape. I was always more of a coward than Carol.

Our good friend Tina Crawford was a godsend. She spent more and more time with Alex those last days, spelling Carol when I was away. Tina has reassured me some, too. "Don't worry," she says, "Alex never would have died without you. I know it sounds crazy, but children pick their time to die."

Tina was wonderful in many ways, someone outside the family in whom Alex could confide. To the end, Alex protected her family, preferring to maintain a certain comforting fiction with us. Tina gave her the outlet she needed.

One night Tina volunteered to baby-sit for us so that I could get Carol out of the house, if only for a few hours. When she tucked Alex in, Tina asked her if she wanted to read or play a game, or maybe just snuggle and chat. Alex opted for the latter, and they lay there for a while, Alex leaning forward on Tink, trying to breathe better.

A few moments passed in dreamy silence, and then Alex heaved a sigh. Tina asked her what was up. "Oh, you know, Tina. I just keep getting weaker. I can't even sit through a game anymore. Nothing is getting better. It's hard when nothing ever gets better."

"I know."

"All I can do is think about things I used to do. Like when I could dance and play with my friends."

"Well, you do have a lot of nice things to think about," Tina said.

"When I was little, I was chubby. I really was. I was healthy looking. But now, as I get older, I just get skinnier. You know what I think, Tina?"

"What?"

"Sometimes I think soon there'll be nothing left of me, nothing at all, and then I'll just float away."

"Float away?" Tina asked.

"Yeah, like a leaf in the wind, or maybe a balloon—phffff. Maybe I'll just float off like a balloon. Just like that." And Alex sighed again. "You know what's really scary?"

"No, what?"

"When I can't breathe, Tina. When I just can't breathe at all. I'm sorry, but I get

all upset then, because I'm afraid I'll die and then I won't see my parents or Chris again. And you know what else is scary, Tina?"

"What's that?"

"Some people die a very painful death. They do."

"Yeah, I know, Alex, but many more people die a peaceful death, because the doctors can give them special medicines to make it easy."

"Oh yeah? I wasn't sure about that."

And Alex relaxed a little then. This was obviously something reassuring, something she had wanted to know. Why



"Sometimes I think soon there'll be nothing left of me, nothing at all, and then I'll just float away," Alex told a friend.

couldn't I have figured that out? But then, even if I had, how could I have gone up to my dying child and talked to her about ways of dying? So it was especially good that Tina could tell Alex these things.

It was my night to sleep in with Alex, but Carol suggested that all three of us stay in her bed. Alex loved that idea, and we all piled in together. She would have liked to have been in the middle, between her mother and father, but that wasn't possible, because she had to keep her nose prongs on all the time, and they were attached, on a fairly short tube, to the oxygen compressor that was placed next to her side of the bed. The compressor made a horrible kind of wheezing sound and it would kick out a thud at regular intervals. I hated that damn thing even as I had come to accept it as a part of Alex's room, her life, our house, our lives.

By now the compressor didn't even bother me when I slept in with Alex, but this night none of us slept much at all. The pain was worse for Alex, and the pills we gave her seemed of little value. "Help me! Help me!" she would cry, more and more, so finally, around 3:30, we called up Neil Lebhar, who was her pediatrician in

town, and he came right over and gave Alex a shot of morphine. She was still alert enough to worry that the shot would hurt her, but the blessed thing took effect quickly and put her right out. Peace for her, thank God.

I went back into our bedroom then so that we all might be more comfortable and get some sleep, and in fact it was past 7 before I awoke. I went downstairs to feed the dogs, and there—I shall never forget this sight—there on the lawn, closer to the house than ever I had seen one, was a huge, coal-black raven, the bird of death. I am not being dramatic. It was there. Out loud, to myself, I said: "So this is what the day your child dies looks like." It was only a normal sort of January day, crisp and clear, the ground brown and ugly without any snow cover.

Carol and I had decided against calling Chris back home during the night—he was sleeping at a friend's house down the street—but now, around 8, Alex began stirring, and we phoned and asked that Chris be brought back right away. He still wasn't certain what the situation was, though. "Do we have to take Alex back to the hospital, Daddy?" he asked me when he came back into the house.

I shook my head. "No, it's more than that."

"What is it?"

"Christian, I'm afraid Alex is going to die sometime today."

He shook his head at me in disbelief, and then fell into my arms and cried. Till then, he told me much later, he had never permitted himself to believe that this would ever really happen. And I had never had the courage or the chance to prepare him. I was going to go over all of it with him on Sunday, but here Alex was, dying on Saturday.

When he was better, I said, "Come on now, Alex wants to see you."

"Daddy, what do I say to her?"

"You don't have to talk about it. I know it's hard, but just be as casual as you can, and be as loving as you can."

"Does she know, Daddy?"

"I'm sure she does."

How she rejoiced when he came to her. "Oh, Chris, my Chris!" They chatted for a while, and then Alex saw how hard it was for him, and she suggested that he go play. She was right. I don't think it would have been good for a 10-year-old boy to have to endure staying hours in his dying sister's room. Carol and I just told him to play nearby, keep us posted, and to come back every hour or so to see his sister. It was better that way for Alex, too. It gave her a real treat whenever he popped back in. Somehow it even made things seem a little normal, when he would come in and tell her all the mundane boyish things he'd been doing for the past hour or so.

Alex would doze off now and then.

- Bonus Book -

Midway through the morning she asked me to go out and get her root beer. By the time I got back from the store, she had drifted off again. At one point I walked over and looked behind the oxygen compressor, that huge awful box going wheeze, wheeze, thump, wheeze. There was an hour tabulator in the back which registered how many hours the machine had been on. You were billed by the hour. I had to fill out a form and mail it in every month—it would be 1186.5 hours or 1238.2, or whatever. Now, when I looked, the total figures read 1306 and something.

Right away it came to me: 13s. Double 13s are coming up. The raven, now this. Alex will die when this machine reaches 1313 hours. I calculated that to be around 2:30 in the afternoon.

I don't want to die today," Alex said then. She wasn't being difficult. She knew she was going to die. She just said she didn't want to die today.

Carol said, "You know, Alex, when you die, you can see God and talk to Him, and you can tell Him all about us. And we will always be together, all four of us, because you'll keep an eye on us, and then we'll meet again in Heaven."

Alex took that all in, turning it over in her mind. She understood perfectly now, but still, right to the last, I suppose, she didn't want to absolutely, completely admit the whole truth.

And then, as the day wore on, as the last of her life got away from her, Alex spoke less and less of anything. She was often uncomfortable and occasionally there were moments of unbearable agony, but they were brief, thank God, and never again did she suffer sustained periods of great pain, as she had the night before. Still, increasingly, it was difficult for her to make the effort to talk, and so mostly now she only listened.

Carol took charge. She began to review Alex's life. I joined in. We never orchestrated this; we never plotted it. It just came naturally. After that, we only really talked with Alex of two things: her life, and what we could guess of death. It didn't seem to be the time for small talk, when your child was dying.

So we brought up as many people that Alex knew and loved as we could recall.



Carol told Alex that angels didn't have cystic fibrosis. Alex even had it on good authority that some angels wore tutus.

We talked of the things she had done with them, and of the joys she had given them, and they her. We talked of all the places she had been and all the wonderful things we had done together. We talked about her school and about her room and her house and the dogs Chaucer and Buffalo; and we even talked about the hospital and all her friends there. We talked about all the things Alex liked. What was her favorite song of all? She gave that some serious consideration and finally decided that it was *I Don't Wanna Play House*, by Tammy Wynette. I went downstairs and found it and put it on her record player. Then we talked about the Broadway shows she had seen, and Benny Hill, who made her laugh, and all the dancing that she loved. Well, what we talked about was love. Love, love, love, Alex. We kept saying it.

And then we talked some about Heav-

en, too, about God and souls and angels. Carol told Alex that angels didn't have cystic fibrosis, so they can dance and float among the clouds in Heaven, all day, every day, and Alex smiled and managed to say yes, she already knew that, that she even had it on good authority that some angels wore tutus.

"Tutus!" said Carol. "Why some angels wear tutus just like that shiny one you have with all the sequins."

"Really?" Alex managed to say.

"Oh, yeah. Angels can get whatever kinds of tutus they want."

Alex nodded, and then she smiled. "Mother?" she said.

"Yes?"

"What about wings?"

"Well, all angels have wings."

"I mean, will I get mine right away?"

"The first day," Carol said. "And then you can always be our guardian angel and watch over us."

And once more Alex smiled at us. But soon, again, those bursts of pain in her chest began to strike her, and she rose up from where she lay, her head on the floor, crying out to us. So often we had heard this, but now it seemed even more anguished, more shrill. Perhaps, I suppose, because she was afraid that this time the pain would also include death in the bad bargain.

Not long after that Alex became passive. When her brother came again around 2 o'clock, she forced her eyes open as soon as she heard him coming up the stairs, and that was when she said, for the last time: "I love you, Chris."

That slight effort, to turn and speak, cost her so much, though, that when, shortly afterward, she wanted another sip of root beer, she could ask for it only by turning her head toward the glass and signaling for it with her eyes. Carol held the straw to her lips, and Alex managed a sip. And, for thanks, one more smile. That was her last smile. She wasn't ever able to muster one again. Finally, the cystic fibrosis had even taken the smiles out of Alex. Now, every conceivable effort had to be given over to breathing. She was worn down, poor thing. Carol and I, her, first one of us, then the other, kept telling Alex about love. That constituted the conversation.

About 20 minutes past 2, the hour counter on the back of the oxygen compressor turned to 1313. About a half hour

later, Alex suddenly shot up. There was cry this time, no energy left for that, but instead, there was upon her little face such a shocked expression, her eyes so full and wide, that both Carol and I were sure that this must be the end.

I believe it was meant to be, too. But something held Alex with us for just a little more. She had never wanted to be left out of anything, and yet she was robbed of so much of life that I think she was at least determined, as much as possible, to see what it would be like when she died. She found out it was like this: She fell onto my chest, and Carol clutched her hands and told her how much we loved her and always would.

So that is how I die: in my father's arms, my mother holding my hands. That is how.

So Alex knew now. In time she lay back on Tink.

She just lay there, and I reached under her gown and rubbed her back. Oh God, the backbone stuck out so. You could hardly believe it, it was so far out. Skin and bones. That was all that cystic fibrosis had left of her now.

A few minutes passed. There was nothing Carol and I could tell each other, even with our eyes. We were quiet now. Suddenly, Alex bolted up again. I would have known, without any doubt, that this was death in all its power, but there had been the false alarm shortly before. Alex fell forward on my chest, her little body tumbling over my right leg, which was crooked up on the bed. Carol took her hands once again and, exactly as before, told her how much we loved her and what a wonderful person she was.

And this time, Alex raised up and away from me, but slowly, with purpose, not jerked by any pain or any forces but her own, until she was almost fully sitting up, somehow supporting herself, and she looked directly at us, her eyes shifting from her mother to her father, so that both of us felt them boring into us.

I'm sorry, but this is how a child dies.

I can see those eyes, this moment, still. I see them constantly. But I could never describe them properly for what they meant, what they told. They were just absolutely wide open, so that even in death a little light could come in, and what they seemed to say was: *Can you believe it, Daddy? Can you believe it, Mother? It's really happening. Right now. Right now, I die.*

Oh, and how they also seemed to call to with such unbelievable love.

And, at that, still just as open, they were also blank. The life had floated away, free. Alex's body stayed up for an instant or two more, but she was already up there with God. □



itself until life's only purpose seems to be, ironically enough, the further suport of medical devices." Hans Joans, "The Philosophy of Technology", Hastings Center Studies 9 (February 1979).

LONG-TERM CARE FACILITIES

Long-termcare facilities can be divided into several types:

First: there are board and care homes or shelter care facilities these are essentially residential facilities offering:

- a place to live
- obtain one's basic meals
- companionship

Second: is the intermediate care facility.

Care in such a facility is typically provided by nursing assistants or adies.

Third: there are skilled nursing care facilities in which care is provided by professional nurses.

HOSPICE PROGRAMS

Hospice programs are the newest social structure in our death system, one that has already become a major way of caring for those who are coping with dying.

Hospice programs engage professional persons, volunteers, and the public in complex intractions.

Today, hospice programs emphasize care for those who are in the fiaal stages of the journey of life.

Services are designed primarily to provide cae for those who are terminally ill.

The work of Dr. (and now also Dame) Cicely Saunders

She founded the St. Christoper's Hospice in southeast London in 1967.

She developed medications for the management of chronic pain in terminal illness.

The program came to Canada in 1975; in U.S. in 1974.

In 1982, a hospice benefit was apporved as a an aspect of Medicare reimbursement for health care.

Admission criterai required:

- a diagnosis of terminal lillness
- prognosis of less tan six months to live
- and the presence of a key caregiver in the home.

In 1990, more than 200,000 patients wre served by the Medicare hospice benefit.

When A Mother Dies

A YOUNG FAMILY REACHES
OUT TO A STRANGER AS THEIR
WORLD IS TORN APART.

WHEN THE PHONE RINGS ON WEDNESDAY AT TEN A.M., I pick it up as if it is just another ordinary phone call.

"Hello?"

"Hello. May I speak with Andrea?"

"This is Andrea," I tell a male voice that I don't recognize.

"Well, I don't know how to even start this conversation," he begins hesitantly. "My name is Jim and I guess I might as well just tell you that my wife Elaine is dying and Ondrea Levine gave me your name. She suggested that you might come up here and help us."

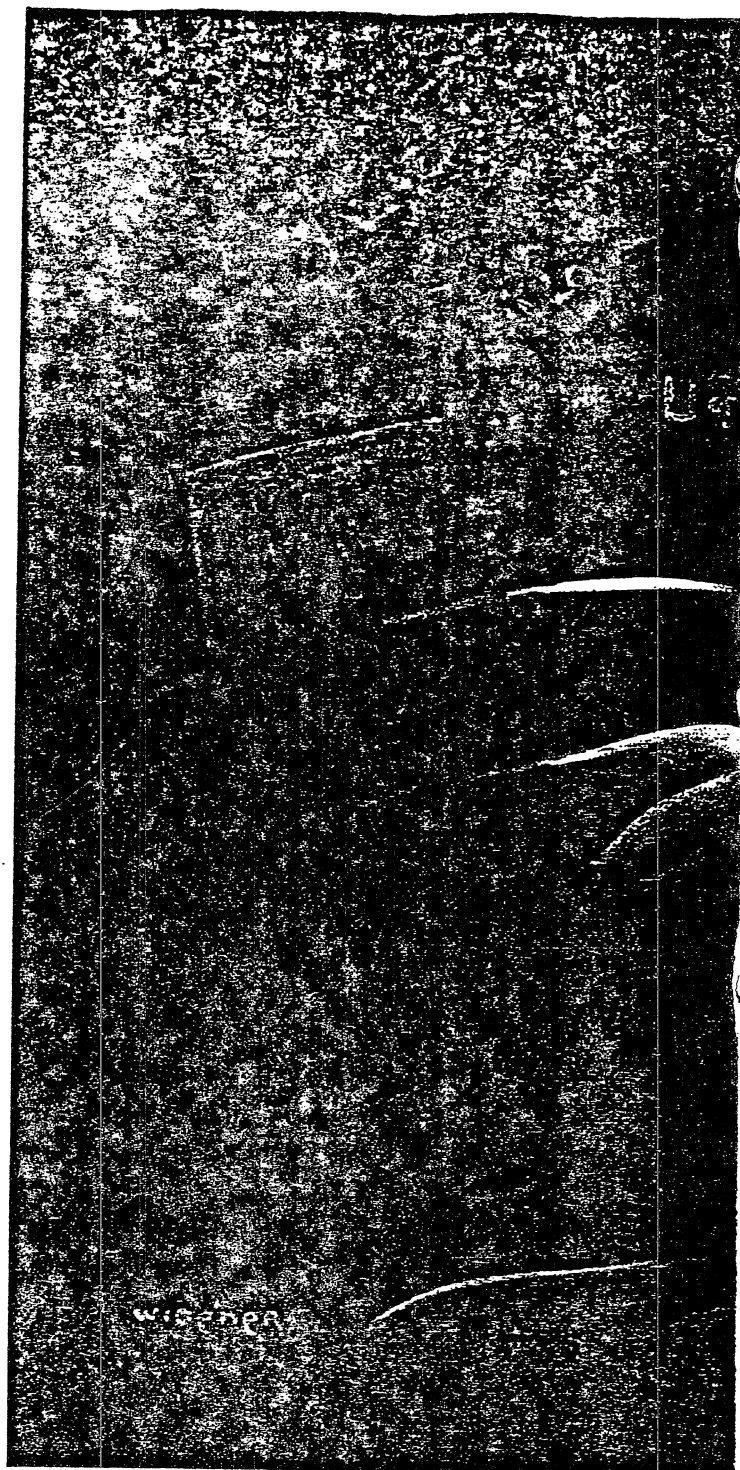
Although I have attended several Stephen and Ondrea Levine workshops on death and dying, and although they are aware of my hospice work, I am surprised to hear Ondrea's name. This is the first time that she has ever suggested that someone call me. Questions emerge in my mind. I ask them as they come up.

"Why do you want me there? What do you want from me? What are you looking for?"

"Spontaneous remission," he yells out to me and any eavesdropping angels that might be in earshot.

by Andrea Cagan

ILLUSTRATION BY TERRY WIDENER



I hear hoarse laughter from a woman's voice in the background. It is then that I realize that his wife Elaine will be dying very soon.

"Or prayers, or healing for our souls, or anything you can give us," he adds.

"We need it all," she says into the receiver. "We have three children."

Three days later, I am at the Los Angeles airport boarding a plane for Berkeley. I have taken a window seat. Unusual for me. I usually insist on the aisle. But today I feel protected in there, invisible, tucked closely against the wall where no one, not even the teen-age boy sitting next to me, will suspect that I am praying. Not for Elaine, or Jim, or the three children who are about to lose their forty-five-year-old mother. I am praying for myself, praying that I am not a case of mistaken identity for this family. Although I have been counseling and assisting the dying for

so want her to take the painkillers—they can no longer endure their *own* pain. But she will not be manipulated. She feels my presence and looks up at me. “I don’t even take aspirin,” she explains. I nod and she knows I am a safety zone. Her pain is all right with me. When the others see me, how open I am, how much space I have made for all that is there, they step aside with relief and quietly leave the room.

Once they have gone, I sit directly beside her on a small wooden stool. Jim sits on her other side. She raises her childish pink and blue flowered flannel nightgown to show me her naked belly. “I don’t want to take painkillers because I want to be present for my children,” she tells me imploringly. The beauty in her eyes so overwhelms me, it is hard to take my own from them to look at anything else. She gently draws my attention to her stomach, to her stretched-out bellybutton, by slowly

while she throws up thick, odorless, dark brown fluid. My mind tells me that it is disgusting, but my body does not react. I stay with her. I fast for the day; I cannot eat, not because I am repulsed, but because I am being filled up by Elaine’s energy, which is so much more powerful than food.

“Squiggle,” she directs me at one point. Jim looks at me bewildered, but I know exactly what she is asking me to do. I squiggle my fingers in the perfect spot on her back. Now and again, she needs to turn from one side to the other. The process is painful and slow; I move in rhythm with her, smoothly switching sides to continue the back rub. We repeat this dance many times without any words; it is choreography, I am the only one on her dance card.

Throughout the day, her children come and go. Helplessness pervades as eight-year-old Sarah tiptoes in and out to give her mother kisses. Twelve-year-old Mark, the middle child and the deepest in denial, flies in to report how he is doing on his latest video game. Finally there is Victor, the sixteen-year-old, who spews anger that his mother should be allowed to suffer so, yet equally hates it when she finally takes a tiny amount of morphine, because it slightly distorts her voice. If this is all he can have of her, he wants it all intact. Elaine’s mother enters the room from time to time, slightly irritating me with her ceaseless harping about giving her daughter a “little tiny suppository.” But I allow it all, not trying to change anyone or anything. It is because of this that the family accepts me, relieved that I am here, doing what they cannot do because of their deep emotional involvement.

Sometimes, Elaine asks me to read meditations to her while she closes her eyes to try to sleep. But sleep will not come. Sometimes, she asks me to read to her from my own book, which lies on the couch beside her.

At 4:30 in the afternoon, her exhaustion has peaked and I know that it is time for me to leave for the day. The women return to care for her, and I move in to kiss her good-bye. I deliberately miss her mouth and contact her cheek, feeling slightly guilty for my reason: The brown stuff that she vomited all day has stained her teeth. She looks at me and says, “I don’t know how anyone can do this alone.” Terror strains her face.

“It would be very difficult, but you don’t have to worry about that,” I tell her, looking at the three loving caretakers who have gathered around her. She relaxes. Jim drives me back to my motel, talking all the while, but calmer than he was in the morning.

“Control. It was always about control,” he says with a certain degree of contempt dangerously peeking out from behind the safety of the more accepted and dignified thing called grief. “Now, she’s in perfect control of her death and I am helpless. Same as it always was.”

As he drops me off, he once again repeats the words, “giving birth to her own soul.” I smile at him and he leaves. I walk inside my motel room and, exhausted, I collapse on the bed and sleep.

Jim arrives home at 5:25 P.M. At 5:30, with her husband at her side, Elaine dies—awake, fully conscious, and in perfect grace. The entire family dies with her.

THE NEXT MORNING MY SISTER JILL, WHO LIVES NEARBY, drives me back to the house. I don’t know that Elaine has died. I don’t even suspect it. But when we enter, I notice that something feels different. There is a stillness, as if everything has paused to take a breath.

Control. It was always about control,” Jim says with a certain degree of contempt. . . . “Now, she’s in perfect control of her death and I am helpless. Same as it always was.”

passing her own hands over the taut skin. With her eyes, she invites my hands to do the same.

I delicately make contact with her swollen belly and I think to myself, “There is cancer in there,” but instead of saying that aloud, different words emerge. I hear myself ask, “What are you giving birth to?” Tears fill Elaine’s eyes and she and Jim look at me expectantly. I realize that they want me to give them the answer.

We move Elaine carefully to the bed, and when she has settled down, tucked familiarly back into her husband’s embrace as she has done for twenty-seven years, I see them as two small children, waiting for me, the adult, to tell them a bedtime story, a real story—one that they desperately need to hear.

I open my mouth with no idea of what I am about to say. When I talk, I hear what I imagine to be the voice goddess’s speaking through me. “Your body has become too small to house your soul.” We all listen as it continues. “You have finished with this body. It is stretched beyond capacity. It is ready to go now. Your spirit wants to fly. You are giving birth to your own soul.”

Elaine nods quietly. Jim repeats my words out loud. “Giving birth to your own soul.” He is trying the concept on as if it were a newly bought article of clothing, seeing if he can stretch his mind to embrace it. He pushes his hands through the arm-holes and pulls the idea snugly around his broken heart. He smiles. “Yes. That’s it.” He repeats the words again, making sure, then he relaxes. It will do for now.

I spend the next six hours at Elaine’s side, massaging her back

Andrea Cagan, a poet and freelance journalist, is the author of Awakening the Healer Within (Simon & Schuster, 1990). She has a ten-year private healing practice in Los Angeles, where she assists people in developing their own healing potential.

WHEN A MOTHER DIES

[CONTINUED FROM PAGE 83]

keepsake, another record of the hugeness of this moment, more substance to define and give shape to the formlessness of a human body turned to ash.

Sarah sits quietly. Then she says, "I found out that my mother died yesterday when I got back from the park." She looks to me and then to her father for reassurance that she is permitted to speak about this. Satisfied with the openness of our listening, she continues. "When my mom died, I wanted to die, too. That's how I felt."

She allows me to stroke her long, sandy colored hair, and after a few moments she folds up the tear-stained letter and leaves. Jim exhales. We both become aware that the house is filling with people.

"You don't have to see anyone you don't want to see," I tell him. "You don't have to take care of anyone but yourself right now. Caretaking is over." I reach out to the bureau to grab the remnants of a used hypodermic needle and toss it into the wastebasket.

"Yeah. There's a lot to clean up and get rid of," he says.

Once I am downstairs, I recognize people from yesterday who have arrived. The dining room table, empty just an hour ago, is piled high with home-cooked food. I stroll around the house and through the back yard, observing the stricken faces of friends and family. As in the front yard, vivid wildflowers abound recklessly in the back garden. Flowers were obviously Elaine's passion, her balance, a perfect counterpoint to her need to control.

I settle into a chair on the back porch and watch people pass around me. I am not exactly unnoticed; I am simply serving no particular function for anyone at this time. So I take the opportunity to move my attention back inward to see how I am doing, what I am experiencing. As I review the events of the last day and a half, I am able to see what I have given to those around me. In this moment, I am able to truly perceive my capacity to give.

And yet, deep down beyond all that I have for others, I can still feel a void—an old, familiar emptiness that has been there for as long as I can remember. I can see now that the hole in my heart comes from my inability to receive what *others* give me. And I now know that my task is to develop that ability. Yesterday, Elaine had been demonstrating how to receive as she accepted all that her family, her friends, and even I, a complete stranger, were offering to her. She took all of it. I imagine how hard it must have been for her at

first and yet how beautiful it must have finally become, to be able to fully receive.

As I reflect on this, I realize that this is the most significant gift that this trip holds for me. This is the piece of my own puzzle that called me to Berkeley on three days' notice under the guise of helping a woman die. I need to die into my own heart, to see what is missing, and to orchestrate the rebirth of my own soul. And I can choose to do this now, and not wait like Elaine did, until I have no more choices and no more time.

As I bring myself back to the present, it seems that the light has softened and changed, yet I know that it is simply my own perception that has altered. I stand up and look around. I walk back into the house, thinking perhaps it is time for me to go. I walk toward the stairs with the intention of finding Jim to ask about a ride back to the motel, but before I can find him, I am stopped by Victor. He directs his grief-stricken eyes into mine and asks in a tone so quiet I can barely hear his shaken voice, "Can we talk now? Do you have time?"

"Of course, that's why I'm here," I reassure him. "Where can we go?"

He leads me upstairs, turns to the left, and opens the door to the inner sanctum of his life. I feel honored to be allowed to enter his sixteen-year-old world, the room that contains his things, his wall posters, his books and catalogues, his motherless future. I walk in respectfully yet boldly, knowing that any tentativeness on my part will destroy our ability to connect. He leads me up a ladder to a loft where we must duck to avoid hitting our heads on the ceiling. We sit on the bed and he opens the skylight window, allowing the air and light to fill the room. We both look up to the sky.

"Is it true that people can contact spirits?" he asks. "I always thought it was bullshit but now I need to know." He looks into my eyes, pleading for the truth. "I don't want to lose the connection."

I thank God that I am not a stranger to the spirit realms, that I have had my own direct experiences with what Victor needs, because to lie to him or lead him on at this time would be an unthinkable crime.

"Yes, you can contact her. You don't have to lose the connection. I can show you how."

He nods. "Let's do it."

I take out a quartz crystal from my pocket, one that I have brought for him as a gift. "We'll start out using this. Later, you won't need it. But you have to practice; it's like flexing a muscle. You must do this a lot, strengthen your ability to find

her. You may not feel very much at first, but believe me, she's here. You can talk to her as if she's right here in this room, just the way you did when she was alive."

I place the crystal in his hand and ask him to close his eyes. I lead him through a short relaxation process and then I call in Elaine's spirit. After a few moments, I suggest to Victor that he silently speak to his mother, that he let her know that he's alright. And then I wait. Five minutes go by, and when he opens his eyes, deep gratitude reflects in his face.

He nods his head; a tear rolls down his cheek and lands on the quilt beneath us. "There is hope," he says.

"It is up to you to keep the connection," I tell him.

"Will she go away?"

"No. But without your attention, you may not know she's here. You must keep the veil between the worlds thin and transparent so that you can feel her."

We exchange a loving glance. He leads me back down the ladder and as I step off the bottom rung, I can feel that my work is nearly done.

"I couldn't connect with your brother, Mark."

"No. He's not ready yet."

"Will you help him when he is, show him how to find his mother?"

"Yes."

Now I can go. I squeeze Victor's hand and walk back out into the house, ready to see Jim, ready to be on my way.

MORE THAN A MONTH HAS PASSED SINCE I left Berkeley. I have spoken with the family several times, and I even saw Jim once when he came south to scatter Elaine's ashes in the ocean at Laguna Beach. They are grieving, slowly recovering, and finding their center once again, redefining the family unit without the physical presence of wife and mother. It is an arduous task, but judging from the highly conscious way in which they dealt with Elaine's death, they have the tools necessary to move into the next phase with great love and support for each other.

Those of us who are fortunate enough to midwife the dying into a conscious passage come away with an unequalled appreciation and gratitude for life. This is the gift that I brought back with me to Los Angeles, and I pray that I may one day pass this gift on to some devoted soul who takes the time to sit beside me and give me final permission to graduate from this life. I put my hand to my lips, I kiss my fingers, and I extend them outward to you, Elaine. May you always know that you are in my heart.

DEATH OF A SPOUSE OR PEER

Bereavement and grief in pair relationships

In spousal relationships, when one member of a relationship dies the other experiences the loss

- not only of another person
- but also of a portion of his or her own identity.

Furthermore, death of a spouse or peer changes the world, the other, and the self for a bereaved adult.

Bereavement and grief associated with HIV infection and AIDS in adults

What a person with HIV infection faces:

- a life-threatening illness as well as its immediate situational and developmental implications
- its acute and chronic challenges
- and the social stigma often attached to this diagnosis.

Others face grief and bereavement that is complicated by similar psychosocial factors:

- a) The disease may have led to disclosure of hitherto unknown lifestyle choices that are difficult for survivors to accept.
- b) A person who was emotionally and existentially tied to the deceased (the man's homosexual mate, e.g.) may be shunned by the family of origin and not permitted to take part in providing care or in funeral ritual.

All of this is a classic pattern of rejection, stigmatization, and isolation associated with disenfranchised relationships, losses and grievers.

DEATH OF A PARENT OR GRANDPARENT

Death is increasingly associated with the elderly—a group that experienced more than 1.5 million of the 2.1 million deaths in the U.S. in 1990.

This means that most adults expect their parents and grandparents to precede them in death.

Nevertheless, when such deaths occur, they often are difficult experiences for survivors.

END OF CHAPTER 13

4. For many, early adolescence is a time of little sense of futurity and a high degree of egocentrism.

Thus, a key variable in adolescent attitudes toward death may be the level of maturity that the adolescent has achieved.

5. Summary: What emerges for many adolescents is a tendency to live in the moment and not to appreciate personal threats associated with death.

Thus, the key issue for adolescents may not be so much related to their capacity to think about death but to ways in which the significance of death-related concepts is or is not related to their personal lives.

The paradox here:

- adolescents must simultaneously move away from intensity of their lived experience so as to put their feelings into perspective
- and move toward applying apparently abstract concepts of death in ways that have personal reference and meaning.

ADOLESCENTS COPING WITH LIFE-THREATENING ILLNESS AND DYING

1. Because dying and adolescence are both transitional experiences, adolescents face a need to find meaning and purpose both in their lives and in their deaths.
2. Adolescents attach great importance to living in the present and being oriented toward the immediate future.
3. What dying adolescents need to maintain:
 - a sense of identity
 - to be treated with honesty; to pursue independence
 - to control what is happening to them
 - to have opportunities for privacy
 - to pursue an orientation to the future
 - and to experience love, comfort, reassurance and freedom from pain.

ADOLESCENTS COPING WITH BEREAVEMENT AND GRIEF

Contemporary adolescents have lots of experience with death/bereavement:

- One study of more than 1,000 high school juniors and seniors disclosed that 90% of those students had experienced the death of someone whom they loved.
- In nearly 40% of this sample, the loss involved the death of a friend or peer who was roughly their own age.
- In 20% of the sample, the students had actually witnessed a death.

Like all human beings adolescents respond by grieving

Their grief often manifests itself in confusion, crying, depression, feelings of emptiness and or loneliness, disturbances in patterns of sleep and eating, and exhaustion.

What is most important to note in bereaved adolescents:

- that their mourning processes are likely to conform to the characteristics of their distinctive developmental stage and thus may not exactly parallel those of adults.

Guidelines for Adults in Family and other Forms of Communication with Adolescents about Death

1. Take the lead in heightened awareness of an adolescent's concerns about death and in openness to discussing whatever he or she wishes to explore.
2. Listen actively and perceptively, with special attention to the feelings that appear to underlie what the adolescent is saying.
3. Accept the adolescent's feelings as real, important, and normal.
4. Use supportive responses that reflect acceptance and understanding of what the adolescent is trying to say.
5. Project a belief in the worth of the adolescent by resisting the temptation to solve his or her problems and by conveying an effort to help the adolescent find his or her own solutions.
6. Take time to enjoy the company of the adolescent and to provide frequent opportunities for talking together.

SUPPORT AND ASSISTANCE AFTER A DEATH

After a death, much can be done to help bereaved adolescents:

- can be helped to obtain accurate information about a loss and begin the process of interpreting and integrating that loss into their ongoing lives
- identify affective responses to a death
- express their feelings in safe and manageable ways
- and find their own ways of coping
- take active roles in funeral practices and commemorate losses in constructive ways
- and find ways to go on with healthy and productive living.

Two principles for counseling interventions with adolescents:

- (1) provide a safe environment in which the adolescent can explore difficulties
- (2) assist with the process of addressing the developmental and situational tasks that are often closely interrelated in adolescent bereavement.

END OF CHAPTER 12

ADOLESCENCE: DEVELOPMENTAL TASKS, BOUNDARIES, AND INTERPRETATIONS

Developmental Tasks in Adolescence

1. Erikson have described adolescence as an era particularly devoted to the establishment of a relatively stable sense of personal identity.

The characteristic virtue to be pursued is fidelity, or faithfulness to self, to ideals, and to others.

2. Other scholars propose a more detailed account of tasks and conflicts in normal adolescent development, organized around three maturational phases.

Table 12:1 Tasks and Conflicts for Adolescents by
Maturational Phase

<u>Phase I</u>	<u>Age</u>	11-14
	<u>Task</u>	Emotional separation from parents
	<u>Conflict</u>	Separation vs. reunion (abandonment vs. safety)
 Phase II	 <u>Age</u>	 14-17
	<u>Task</u>	Competency/mastery/control
	<u>Conflict</u>	Independence vs. dependence
 Phase III	 <u>Age:</u>	 17-21
	<u>Task</u>	Intimacy and commitment
	<u>Conflict</u>	Closeness vs. distance

Task/conflict of Phase I: work to emancipate oneself from the security and predictability of a child's family life.

Task/conflict of Phase II: to develop one's own competencies in the new arena of freedom.

Task/conflict of Phase III: to achieve a new synthesis of personal and social identity within which one can initiate new and renewed relationships.

Boundaries and Interpretations of Adolescence

Division between early and later adolescence:

Early: 12-16 years of age

-this group in the period that American society assigns to secondary education

Later: 17 to mid-20s.

-they are at the point when most young people in the U.S. enter college or the working world.

-society is willing to permit this group to obtain an automobile driver's license; volunteer for military service, drink alcoholic beverages and exercise the right to vote.

ENCOUNTERS WITH DEATH

Three leading causes of death (1990):

-accidents (rate = 43.9 per 100,000; the vast majority of which involved motor vehicles)

-homicide (rate = 19.9)

-suicide (rate = 13.2)

All of these are human-induced deaths; together they add up to approximately 77% of all deaths during the adolescent era.

Chapter 12 *Adolescents* 269

The Death of Dean Thomas 270

Adolescence: Developmental Tasks, Boundaries, and Interpretations 271

Developmental Tasks in Adolescence 271

Boundaries and Interpretations of Adolescence 272

Encounters with Death 273

Attitudes Toward Death 276

Adolescents Coping with Life-Threatening Illness and Dying 278

Adolescents Coping with Bereavement and Grief 279

Adolescents, Pregnancy, and Suicide 282

Helping Adolescents Cope with Death 285

Education and Prior Preparation 285

Support and Assistance After a Death 287

Summary 289

QUESTIONS FOR REVIEW AND DISCUSSION 290

SUGGESTED READINGS 290

CHAPTER TWELVE: ADOLESCENTS

TOPICAL OUTLINE

1. The death of an adolescent.
2. Developmental tasks for adolescents.
3. Encounters with death in adolescence.
4. Attitudes toward death in adolescence.
5. Coping with life-threatening illness and dying in adolescence.
6. Coping with bereavement and grief in adolescence.
7. Adolescents, pregnancy, and suicide.
8. Helping adolescents cope with death: education and prior preparation; support and assistance after a death.

OBJECTIVES

1. To identify developmental tasks in adolescence and issues in defining or interpreting that era in the human life span.
2. To describe encounters with death during adolescence in contemporary American society (death rates and leading causes of deaths among adolescents, plus other factors that influence death-related encounters in adolescence).
3. To examine principal factors in death-related attitudes in adolescents.
4. To identify issues that confront adolescents who are coping with life-threatening illness and dying.
5. To identify issues that confront adolescents who are coping with bereavement and grief.
6. To bring forward death-related issues associated with pregnancy and suicidal behavior that are distinctive of adolescence.
7. To suggest constructive ways in which adults can help adolescents cope with death.

subject studied by parapsychologists, who often divide it into two subtopics: ESP [extrasensory perception], or information obtained without use of the senses, and PK, [psychokinesis], or physical changes produced without bodily intervention. *There is by now clear evidence that such interaction can occur. I will cite a single example, chosen from many others that seem to me equally strong [emphasis added].*²²

The example Schmeidler cites is of a technique of studying psychokinesis using an instrument called a random number generator (RNG), which records events that physicists consider truly random:

In RNG research, a subject is asked to push a button on a machine so that the next recording will show a particular change (e.g., a faster rate of particle emission on some trials; a slower rate on others.). This is an impossible task for our bodies. Our sense cannot tell us what the next random event will be and our effectors cannot change it. . . .

Radin, May and Thomson . . . summarized the data of all published RNG research with binary targets from the time this method was introduced . . . to 1984. They found 75 reports, describing 332 experiments. When those experiments were evaluated as a whole, they showed success at rates astronomically higher than chance . . . I suggest to you that this demonstrates that some nonbodily part of ourselves can interact with an object in the external world.

This in itself tells us nothing about survival, but it and other evidence for ESP and PK seem to legitimize the concept that our self (whatever it is) includes something that has properties which our body does not have. This in turn seems to legitimize queries about the possibility of nonphysical existence after the body's death, and thus the survival concept.²³

Schmeidler then discusses the other lines of research that consider the survival hypothesis more directly "but do not give such clear-cut results."

Two of the methods study living persons. One is the near-death experience. . . . Of those who revive after being considered clinically dead, perhaps half report having had vivid experiences while apparently dead. The experiences they report tend to have a good deal in common but are far from a complete overlap. Perhaps most impressive are the occasional cases where a person revived describes accurately events that occurred in a distant place during the time of apparent death.

The second method with living persons tests those who claim to have out-of-body experiences, that is, experiences of being at a location distant from one's body. Some have accurately described events at that distant place. . . .

One method studies the dying. . . . Fairly often a dying person claims that a dead relative has come to help with the transition to an afterlife. . . .

Other methods study the dead. . . . Apparitions sometimes give information that is later found to be correct . . . At least one careful investigation has found that many messages gave correct and specific information known to no one who was present. And psychics and mediums, trying to obtain messages from a dead person, have often reported accurate information that was unknown to anyone present and (more rarely) that was known to no one alive until an attempt to check the message confirmed its correctness.

Each of these lines of evidence can be explained away by one or another counterhypothesis. The commonality among near-death experiences is explained as a combination of physiological change and wishful thinking. All the cases of accurate information are explained as extraordinary examples of effective ESP. . . . The explanations are ad hoc and seem forced; they often postulate more effective ESP than has otherwise been found. They are more intellectually satisfying than the survival interpretation, but whether they are more intellectually satisfying than the thesis of a spirit, separable from the body and surviving death, is still controversial.²⁴

The beauty of this summary of the literature on near-death experiences and the survival of death is its neutrality. Schmeidler states the case exactly as I have come to see it: the solid ESP and PK literature clearly suggest that a part of us can function outside ourselves; this in turn is consistent with, but does not demonstrate, the legitimacy of the literature on out-of-body experiences; and both literatures then support, but do not demonstrate, the possibility that near-death experiences are more than simply physiological hallucinations; and this in turn suggests, but does not demonstrate, a rationale for accurate information coming from departed souls.

A number of separate investigators, as Schmeidler suggests, have found that between 35% and 48% of people who come close to death have near-death experiences suggestive of an afterlife. Poll data by George Gallup have also supported these figures.²⁵

Karlis Osis and Erlendur Haraldsson did some of the pioneering scientific studies of near-death experiences of dying patients, reported in *At the Hour of*

Death. They studied over 1,000 death or near-death experiences of patients in the United States and northern India in order to achieve a cross-cultural comparison of these experiences from two very different cultures.

They found, first, that the psychological experiences that patients had that were suggestive of postmortem existence were of shorter duration than hallucinations concerned with this life—just as ESP phenomena in general are of shorter duration than imagery related to this world. Second, they found these deathbed visions were mainly of dead and religious figures (by a 4:1 ratio), while only a minority of hallucinations in the general population concern dead and religious people.

This finding is loud and clear: *When the dying see apparitions, they are nearly always experienced as messengers from a postmortem mode of existence.* Of the human figures seen in visions of the dying, the vast majority were deceased close relatives. This is in agreement with our hypothesis that close relatives would be the natural guides in transitions to an afterlife. Hallucinations of mental patients and drug-induced visions seldom portray close relatives. The pilot survey revealed the most dramatic characteristic of deathbed apparitions: the ostensible intent to take the patient away to the other world. *This was again found to be the dominantly stated purpose of the apparitions of the dying, as well as of come-back cases, in both American and Indian cultures.* . . .

In the pilot survey, it was noted that patients responded to the otherworldly apparitions in a most surprising manner. They wanted to “go”—that is, to die. Some even bitterly reproached those who resuscitated them. Again, we encountered cases of such resentment in both countries. Nearly all the American patients, and two-thirds of the Indian patients, were ready to go after having seen otherworldly apparitions with a take-away purpose. *Encounters with ostensible messengers from the other world seemed to be so gratifying that the value of this life was easily outweighed* [authors’ emphasis].²⁶

Patients who saw apparitions concerned with this world did not experience peace and serenity, while those who experienced “messenger” apparitions did. Patients who saw heaven or beautiful gardens reported strongly predominant feelings of peace, serenity, or religious feelings, while a small portion had negative experiences. Qualities of the scenes reported included brightness, intensity of colors, and great beauty. Some patients who saw no visions also became as serene and elated as those who saw messenger figures. And patients who were physiologically close to death had much more “complete” near-death

experiences than those who experienced themselves as coming psychologically close to death.

9

We found that mood elevation near death resembles those ESP cases where a person will respond with emotions appropriate to a distant event, even though he is not consciously aware of what happened there. . . . There were some cases where patients ceased to feel pain. According to our afterlife hypothesis, the mind or soul may disengage itself from awareness of bodily pain and discomfort, as if gradually separating from its physical frame.²⁷

The authors then review some of the alternative explanations of near-death imagery and experience. These include theories that the experiences are drug-induced; that they are related to brain disturbances caused by disease, injury, or uremic poisoning; that they are caused by lack of oxygen, or psychological factors associated with severe stress, or by cultural factors. In response, they argue that only a small minority of patients with these experiences had received hallucinogenic pain medications, and those that did had no greater frequency of afterlife visions than others. Brain disturbances in general either decreased or did not affect these experiences. Military research on oxygen deprivation, the authors state, does not support the anoxia hypothesis. And psychological factors, which can cause hallucinations, were not found to be related to phenomena associated with postmortem life.²⁸

Cultural background, on the other hand, does influence near-death experiences. Indian patients, for example, saw a predominance of elderly male messenger figures while Americans predominantly saw younger female figures. But:

The phenomena within each culture often do not conform with religious afterlife beliefs. The patients see something new, unexpected, and contrary to their beliefs. Christian ideas of “judgement,” “salvation,” and “redemption” were not mirrored in the visions of our American patients. Furthermore, while we had many reports about visions of Heaven, visions of Hell and Devils were almost totally absent. . . . We reached the impression that cultural conditioning by Christian and Hindu teaching is, in part, contradicted in the visionary experiences of the dying. It seems to us that besides symbolizations based on inculcated beliefs, terminal patients do “see” something that is unexpected, untaught, and a complete surprise to them.²⁹

The core elements described above by Osiris and Haraldsson give only a general sense of the near-death experience. Here is a composite near-death experience

described by Kenneth Ring, another influential researcher, from his popular *Heading Toward Omega: In Search of the Meaning of the Near-Death Experience*:

The experience begins with a feeling of easeful peace and a sense of well being, which soon culminates in a sense of overwhelming joy and happiness. This ecstatic tone, although fluctuating in intensity from case to case, tends to persist as a constant emotional ground as other features of the experience begin to unfold. At this point, the person is aware that he feels no pain nor does he have any other bodily sensations. Everything is quiet. These cues may suggest to him that he is either in the process of dying or has already "died."

He may then be aware of a transitory buzzing or windlike sound, but, in any event, he finds himself looking down on his physical body. At this time, he finds that he can see and hear perfectly; indeed his vision and hearing tend to be more acute than usual. He is aware of the actions and conversations taking place in the physical environment, in relation to which he finds himself in the role of a passive, detached spectator. All this seems very real—even quite natural—to him; it does not seem at all like a dream or a hallucination. His mental state is one of clarity and alertness.

At some point, he may find himself in a state of *dual awareness*. While he continues to be able to perceive the physical scene around him, he may also become aware of "another reality" and feel himself being drawn into it. He drifts or is ushered into a dark void or tunnel and feels as though he is floating through it. Although he may feel lonely for a time, the experience here is predominantly peaceful and serene. All is extremely quiet and the individual is only aware of his mind and the feeling of floating.

All at once he becomes sensitive to, but does not see, a presence. The presence, who may be heard to speak or who may instead "merely" induce thoughts into the individual's mind, stimulates him to review his life and asks him to decide whether he wants to live or die. This stock-taking may be facilitated by a rapid and vivid visual playback of episodes from the person's life. At this stage, he has no awareness of time or space, and the concepts themselves are meaningless. Neither is he any longer identified with his body. Only the mind is present and it is weighing—logically and rationally—the alternatives that confront him at this threshold separating life from death: to go further into this experience or to return to earthly life. Usually the individual decides to return on the basis not of his own preference, but on the perceived needs of his loved ones, whom his death would necessarily leave behind. Once this decision is made, the experience tends to be abruptly terminated.

Sometimes, however, the decisional crisis occurs later or is altogether absent, and the individual undergoes further experiences. He may, for example, con-

10
tinue to float through the dark void toward a magnetic and brilliant golden light from which emanates feelings of love, warmth and total acceptance. Or he may enter into a "world of light" and preternatural beauty, to be (temporarily) reunited with deceased loved ones before being told, in effect, that it is not yet his time and that he has to return to life.

In any event, whether the individual chooses or is commanded to return to his earthly body and worldly commitments, he does return. Typically, however, he has no recollection of *how* he has effected his "reentry."³⁰

A crucial question is whether or not these near-death experiences are simply hallucinations of the dying brain. This suggested a fascinating line of research, part of which was initiated by the cardiologist Michael Sabom, who was initially a skeptic regarding near-death experiences, in his classic *Recollections of Death*. Sabom took special note of the fact that one aspect of the near-death experience is that it is simultaneously an out-of-body experience. Ring summarizes:

Sabom made a diligent search for detailed OBE (out-of-body experiences) accounts from NDErs [those who have had near-death experiences] on the grounds that such reports provide one of the few avenues through which to secure data about NDEs that can be independently corroborated. . . . If [for example] a patient whose eyes, let's say, are taped shut, suffers cardiac arrest and has an OBE during which he later claims to have seen two physicians, one of them black, whom he has never met before, hurriedly enter the operating room to assist in the defibrillation procedure whose details he then describes in correct sequence, this is obviously an account that does not depend for its veracity on the patient's say-so. . . . This is precisely what Sabom has done in a half dozen incidents where his respondents have given him highly specific and sequential accounts of their OBEs while near death. By interviewing members of the original medical team involved in these cases, talking to family members who had pertinent information, and checking the medical records directly, Sabom was able to produce impressive if not conclusive evidence of apparently accurate perceptions during OBEs. In short, according to Sabom, patients were describing events they could not have seen given the position of their body and could not have known given their physical condition.³¹

The work of Stanley Grof, a highly innovative psychiatrist who did careful research using LSD in psychotherapy with dying cancer patients, gives further interesting insight into the phenomenon of near-death experiences. In Grof's work, the patients he worked with, who were given LSD after very careful preparation and watched through the procedure, went through a set of phases

that began with the very difficult experience of physical death and ended in an ecstatic experience of rebirth. When these patients had completed the death-rebirth experience, they were characteristically convinced that at the time of actual death their souls would survive, and they had no further fear of death.

The Great Art of Making the Dying Physically Comfortable ✓

It is an expression of the malady of our time that while many people want to attend lectures on transcendent experiences in death and dying, far fewer people take the time to visit and sit with the dying, and fewer still are interested in the practical matters of making a dying person as comfortable physically as possible so that he and his family members have some chance to enjoy the last months, weeks, or days of life.

The reality is that practical knowledge is as important, and often more important, than an ungrounded spiritual impulse to assist the dying. As Sylvia Lack, M.D., told a training conference for physicians concerned with the care of the dying:

There is far too much talk in death and dying circles in this country about psychological and emotional problems, and far too little about making the patient comfortable. Any group concerned with service to the dying should be talking about smoothing sheets, rubbing bottoms, relieving constipation, and sitting up at night. Counselling a person who is lying in a wet bed is ineffective . . . If people are cared for with common sense and basic professional skills, with detailed attention to self-evident problems and physical needs, the patients and the families themselves cope with many of their emotional crises. Without pain, well nursed, with bowels controlled, mouth clean, and a caring friend available, the psychological problems fall into manageable perspective.³²

One of my favorite books on the practical aspects of dying is by Deborah Duda, *A Guide to Dying at Home*.³³ In the chapter called "Getting on with It: Preparations and Homecoming," Duda covers what you need to die at home. Here she lists everything from the doctor, medicines, and bed to such essential details as hot-water bottles, a dishpan for bathing, and drinking straws that bend.

Duda covers in detail how to choose a physician who will honor your wishes, how to work effectively with a physician, pain control, and giving shots or injections.³⁴ 11

One of the best health professional guides I have seen in this area is *The Physician's Handbook of Symptom Relief in Terminal Care*,³⁵ by Gary A. Johanson, M.D. of the Home Hospice of Sonoma County, California. The *Physician's Handbook* is a loose-leaf binder with color tab-coded sections that cover common problems the physician, patient, or family member may encounter. In offering this compendium, Johanson writes:

The degree of success achieved in skilled symptom control will greatly influence how effectively caregivers and families will be able to assist patients in realizing their emotional, spiritual and social comfort in the final days of their lives.

The greatest asset in terminal care is a listening/caring approach. The greatest skill is knowing when it is appropriate to apply which palliative measure.

No matter how much we deny it, the fact is that conventional treatment often becomes inappropriate, and therefore poor medicine in the terminal patient. We who care for these patients are not off the hook simply by plugging along on conventional treatment pathways when it is no longer appropriate. . . .

There is always something that can be done for terminal patients. None of us can expect to know all the techniques that have been developed in the area of terminal care. For our patients' benefit and our own education, we should not hesitate to consult a reference or a colleague for assistance.³⁶

This handbook is not only useful for physicians but also for patients and family members who want to be knowledgeable about the options that physicians and nurses are (or should be) considering. Many physicians have relatively little interest in or knowledge of how to provide the best possible support for a dying person. It is a very high and, in fact, noble skill of the healer. Having this information represents another area in which the patient or family member is able to work more effectively in partnership with physicians and nurses.

While Johanson's *Physician's Handbook* does an excellent job of covering the more technical aspects of symptom relief in dying, Duda provides a practical introduction to making the senses comfortable and to providing enjoyable experiences wherever possible.

Her discussion covers touch (massage, hair care, hugging, holding, and cuddling), moving the person, smells, cleanliness, creating beautiful environments, hearing (sound, music, reading), and taste and diet. The issues of intravenous (IV) feeding and dehydration represent an example of a critical area in which knowledge and forethought can make a vital difference in the dying experience. Says Duda:

IVs are used to nourish people who can't eat or drink enough to stay alive. The decision whether or not to use IVs in terminal care raises again the question of the quality of life versus the quantity. Feeding the body cells by means of IVs often prolongs the life of the body. The cost is discomfort, less ability to move and the need to have a nurse. Dad said, "When I have all those tubes in I feel like a patient. When I don't, I feel like me."

The result of not taking enough fluids into the body is dehydration. *The chemical imbalance created by a lack of fluids often causes a person to have a sense of well-being or euphoria* [emphasis added]. It's a relatively comfortable death. The main discomfort, dryness of the mouth and thirst, is helped by sucking on ice chips and clean moist washcloths. It generally takes only a few days for a debilitated person to die from lack of fluids.³⁷

Duda is supported by medical experts in this opinion on dehydration. Johanson suggests a policy for IV fluid therapy:

In the terminal patient, the benefits of dehydration can be many, including sedation, decreased vomiting, and decreased urine output and secretions. IV fluids should only be used if hydration seems like it will improve alertness, decrease nausea, prolong life in a positive way, or otherwise provide true comfort.

Conscious withholding of intravenous and other supportive measures is not a question of "non-treatment." Instead, it is a matter of what is appropriate treatment from a biologic, humane and spiritual point of view. Some patients suffer as much from inappropriate treatment as they do from the underlying illness itself.

In other words, IV infusion should be looked upon as primarily a supportive measure for use in acute or acute-superimposed-upon-chronic illnesses to assist a patient through a temporary period toward some recovery of health. To use such measures in the terminally ill, without such expectation of return to health, is generally inappropriate and therefore not good medicine. Such measures should ethically only be used if the treating physician is convinced they are clearly contributing to the comfort of the patient.³⁸

Dying and Grieving

Dying and grieving are deeply interconnected, so it makes sense to treat them together. The dying person must engage in *anticipatory grieving* for the loss of himself. The family and friends who will be left behind have what is often as sharp—and sometimes even sharper—a grief to deal with. They, too, may do anticipatory grieving, and they will also grieve later. (2)

Grieving is something that one can learn how to do. It is something that can cripple a life experience—or a dying experience—if it is drastically incomplete. Many cultures prescribe elaborate and effective systems of grieving. In the United States, we have lost most of these rituals—a very great loss, indeed. And so it has been the psychiatrists and other modern shamans who have taken on the job of helping us grieve our own deaths or the deaths of those we love.

One of the best known theories of the dying process has been presented by Elisabeth Kübler-Ross. In her famous book, *On Death and Dying*, she presents a theory of a series of stages in the human response to dying. The first stage of the dying process, according to Kübler-Ross, is *denial and isolation*:

Denial, at least partial denial, is used by almost all patients, not only during the first stages of illness or following confrontation, but also later on from time to time. . . . These patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life. . . . Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilize other, less radical defenses.³⁹

Actually, Kübler-Ross notes that the very first reaction may be a temporary state of shock, which is then followed by this initial response of denial.

The second stage for Kübler-Ross is *anger*.

The next logical question becomes: "Why me?" . . . In contrast to the stage of denial, this stage of anger is very difficult to cope with from the point of view of family and staff. The reason for this is the fact that this anger is displaced in all directions and projected onto the environment at times almost at random.⁴⁰

The third stage is *bargaining*:

The third stage, the stage of bargaining, is less well known but equally helpful to the patient, though only for brief periods of time. If we have been unable to face the sad facts in the first period and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening: "If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favorable if I ask nicely."⁴¹

The fourth stage is *depression*:

When the terminally ill patient can no longer deny his illness, when he is forced to undergo more surgery or hospitalization, when he begins to have more symptoms or becomes weaker and thinner, he cannot smile it off any more. His numbness or stoicism, his anger and rage will soon be replaced with a sense of loss. This loss may have many facets: a woman with a breast cancer may react to the loss of her figure; a woman with a cancer of the uterus may feel she is no longer a woman. . . . With the extensive treatment and hospitalization, financial burdens are added; little luxuries at first and necessities later may not be afforded any more. . . . All these reasons for depression are well known to everyone who deals with patients. What we often tend to forget, however, is the preparatory grief that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world. If I were to attempt to differentiate these two kinds of depressions, I would regard the first one as a reactive depression, the second one as a preparatory depression. The first one is different in nature and should be dealt with quite differently from the latter.⁴²

In Kübler-Ross's view, we can respond to the reactive depression with action—seeking to ameliorate the losses with word or deed. The preparatory depression, on the other hand, should not be met with any attempt to "fix it":

The patient should not be encouraged to look at the sunny side of things, as this would mean he should not contemplate his impending death. It would be contraindicated to tell him not to be sad, since all of us are tremendously sad when we lose one beloved person. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow he will find a final acceptance much easier, and he will be grateful to those who can sit with him during this state of depression without constantly telling him not to be sad.⁴³

The fifth and final stage is *acceptance*:

13

If a patient has enough time (i.e., not a sudden, unexpected death) and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate." . . . Acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for "the final rest before the long journey" as one patient phrased it. . . . While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of the outside world. Visitors are often not desired and if they come, the patient is no longer in a talkative mood. . . . He may hold our hand and ask us to sit in silence. Such moments of silence may be the most meaningful communications for people who are not uncomfortable in the presence of a dying person. We may together listen to the song of a bird from the outside. Our presence may just confirm that we are going to be around until the end. We may just let him know that it is all right to say nothing when the important things are taken care of and it is only a question of time until he can close his eyes forever.⁴⁴

While these are the five stages of dying for Kübler-Ross, it is often forgotten that she also accords a special place to *hope* throughout the five-stage process.

We have discussed so far the different stages that people go through when they are faced with tragic news. . . . These means will last for different periods of time and will replace each other or exist at times side by side. The one thing that usually persists through all these stages is hope. . . . In listening to our terminally ill patients we were always impressed that even the most accepting, the most realistic patients left the possibility open for some cure, for the discovery of a new drug or the "last minute success in a research project." . . . It is this glimpse of hope which maintains them through days, weeks or months of suffering.⁴⁵

Other Views of the Process of Dying

Kübler-Ross's vision of the stages of dying has many virtues, but it has been strongly criticized by many thoughtful professionals. Edwin S. Shneidman is one:

In the current thanatological scene there are those who write about fewer than a half-dozen stages lived through in a specific order—not to mention the even more obfuscating writing of a life after death. My own experiences have led me to rather different conclusions. In working with dying persons I see a wide

DEATH

1. Native Hawaiians. from Death and Dying in Five Asian and Pacific Islander Cultures: a preliminary study. Rhea Nichols, Kathryn Braun. 1996

GENERAL SUBJECTS ON DEATH/DYING

1. Society remains silent when confronting death and dying. Ellen Goodman.
2. The high cost of dying. Too much is spent delyaing the ienvitable.
Max Botticelli, M.D.
3. Going Gently ..into that..dark night. Adv. Feb 1, 981
4. Living in the Light of Death: Dying is what some patients did. Now, Dr. William Bartholome has his own terminal illness. by Larry Beresford.

Society remains silent when confronting death and dying

The newspaper comes to my doorstep this morning bearing its daily quota of obituaries. A teacher has died at 65. A costume designer at 81. A civic leader at 79. A company executive at 69.

The lives of these people are described as if the death notice were a resume. The causes of death — cancer, heart failure — are included as if disease itself were a flaw in the human system that science has yet to fix.

What is missing from these pages — what is always missing — are the descriptions of how they died. Was the teacher in pain or at peace? Did the executive have a living will and a doctor who listened? Did the civic leader linger attached to a machine? Was the designer's death one she designed?

I read these pages wondering what would it be like if we listed the way of death as well as the cause of death. Would that make a difference?

LAST WEEK, something remarkable happened. The newspapers in this country ran a story about a scientific un-breakthrough. A research project begun with high hopes to test ways of making death in the hospital more humane was pronounced a failure.

The flop was on page one, 20 years after Karen Ann Quinlan lapsed into a coma. It came after a whole generation of talk about high-tech dying and living wills and the right to die.

When the Robert Wood Johnson Foundation funded this eight-year study, there was a growing consensus among ethicists and doctors about how to change the way of dying. If doctors really were sure of the prognosis of a patient, if they knew what patients wanted and

**Ellen
Goodman**



didn't want, surely there would be less pain, fewer "heroic measures" and more care in the hospital care of the dying.

So, the study's project called **SUPPORT** — Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments — placed nurses in five teaching hospitals to facilitate these changes. But as Dr. Joanne Lynn, a co-director of the project says, "We did what everyone thought would work and it didn't work at all, not even a quiver."

Half of the patients still died in pain. Huge gaps remained between what patients said they wanted and what doctors did. Living wills didn't help. There was too little talk, too late. Too many people died alone, attached to machines.

The easy villains of the story would be the paternalistic doctors who remain convinced they know what's best for the patient even if the patient disagrees. There's enough truth in that image to make Boston University ethicist George Annas warn that "if dying patients want to retain some control over their dying process, they must get out of the hospital if they are in and stay out of the hospital if they are out."

A MORE benign interpretation is that the culture of medicine — from school to training to practice — teaches doctors to regard death only as defeat. Even when dealing with the terminally ill, they talk about life and death decisions when they

are really dealing with death and death decisions.

But Dr. Lynn believes that the problem runs deeper than doctors who don't listen. "This wasn't a group of doctors dedicated to finding the last possible date on the tombstone. What we learned was that the conspiracy of silence about death was stronger than we expected and the force of habit was also stronger than we expected."

On a day-to-day basis, neither doctors nor patients were talking about what the patients wanted. They were both following the cultural script, talking about the next chemotherapy, the next procedure. They were patching, fixing, going from crisis to crisis without ever asking. "How can I live well while dying?"

"WE ARE all involved in the dance of silence," believes Dr. Lynn. Even families go through this painful process wanting one thing: "to pass the mirror test. They want to be able to look at themselves when it's all over and say I was a decent person." Close up, that "decency" is still defined as fighting death. But when you stand back from the mirror, as this study does, it's a sorry reflection.

Hospitals are not the only places where we die. There are hospices and homes. There are as well the "tender mercies" of Dr. Kevorkian and the moral ambiguities of doctor-assisted suicide.

But the majority of Americans end their lives in hospitals. As long as hospitals reject a humane role in helping people die, we are failing dismally as doctors, as friends, as family and as fellow travelers through what the psalmist calls "the valley of the shadow of death."

□

Goodman is a Boston-based columnist on modern social issues.

EDITORIALS

The Honolulu Advertiser

Saturday, December 2, 1995

Too much
is spent
paying the
inevitable

By Max Botticelli, M.D.

The data are unequivocal and persistent. Since the 1960s about 30 percent of annual Medicare expenditures have been for care provided to patients who die in the same year; 12 percent are for care delivered in the last month of life. Thousands of Americans spend their final days in an acute care hospital receiving futile care.

Predicting the life expectancy of an individual is difficult, and physicians are admittedly not very good at it. But they are good at predicting the effect of a particular treatment on a patient's life expectancy, comparing the benefits of a given treatment with its potential for harm, and recommending a professional course of action.

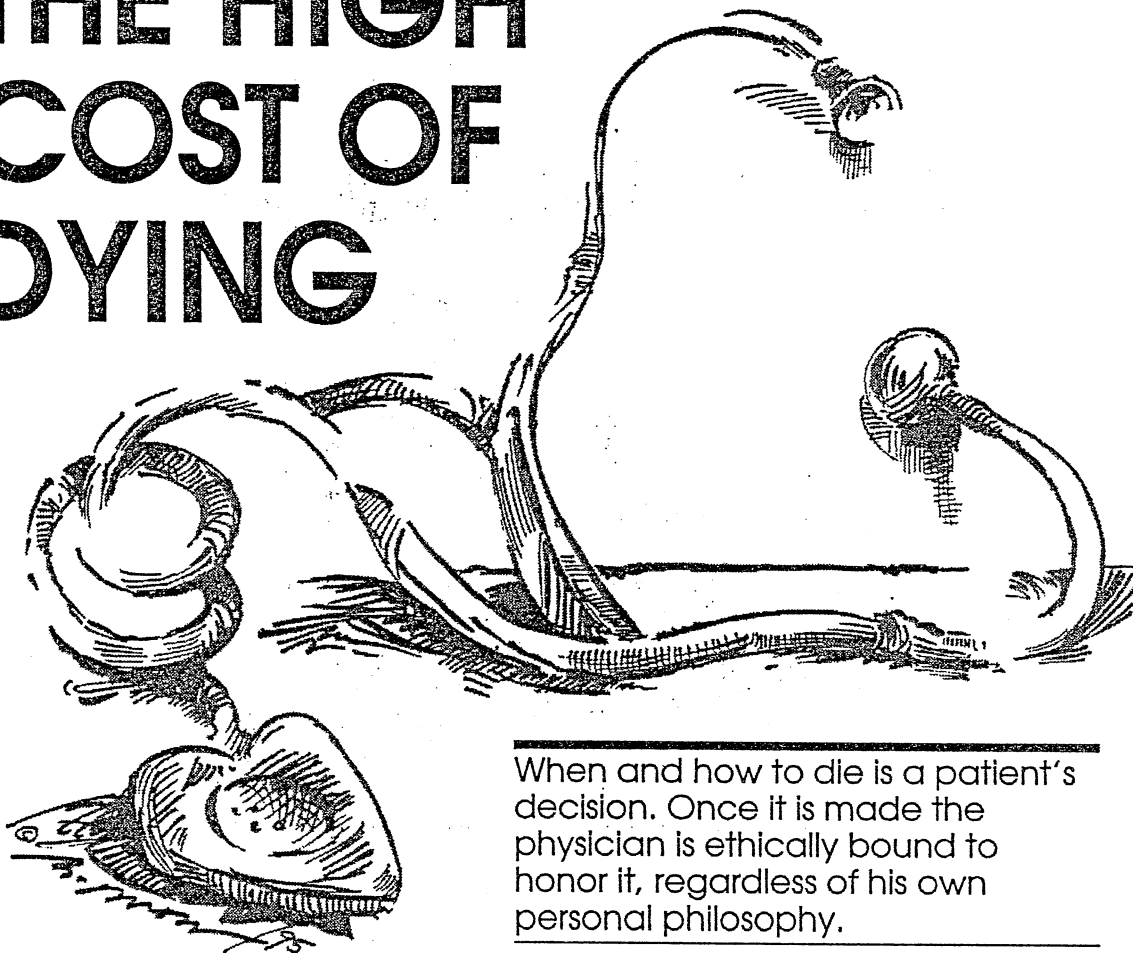
So for one reason or another a physician sometimes suggests a regimen that is unwarranted, and likely to be ineffective. The following examples of bad decisions illustrate why too much effort is expended trying to delay inevitable deaths.

■ A man in his 60s with terminal cancer received as much care as his physicians deemed appropriate and was referred to Hospice Hawai'i. Shortly after, he developed symptoms that a nurse felt might be relieved by medication. The dying man's physician was out of town and the call was referred to a colleague. He decided that the patient had developed a treatable complication and hospitalized him for treatment. The patient died ten days later. The cost of the futile care was \$40,000.

This example illustrates the power of a physician to change a patient's decision. The patient was very ill, near death, and unable to make any decisions concerning his care. His wife, a recent immigrant from an Asian country where the principle of patient autonomy is non-existent, had a language barrier that made discussion of complicated issues difficult.

It is easy for the physician to use his authority to override a previous decision, one that had been made carefully and thoughtfully by his colleagues

THE HIGH COST OF DYING



When and how to die is a patient's decision. Once it is made the physician is ethically bound to honor it, regardless of his own personal philosophy.

in concert with the patient and his family.

In addition, it exemplifies a commonly held belief within the medical profession that the responsibility of a physician to prolong life is paramount. This is the reason that the practitioner ignored the reality of the patient's impending death. As a result, his actions thwarted the sound judgment of his colleagues and the wishes of the dying man.

When and how to die is a patient's decision. Once it is made the physician is ethically bound to honor it, regardless of his own personal philosophy. A physician's role in the care of a dying patient may not include actively facilitating the patient's death, but most certainly does include discontinuing life-prolonging measures.

■ A man in his 30s was suffering from irreversible heart and lung disease, and acute leukemia. When his kidneys failed, his doctor offered him treatment of an artificial kidney. The dying man refused dialysis. A correct decision.

In this instance, the physician realized that the treatment was futile. But because she misunderstood the principles of patient autonomy, she offered the

patient treatment. While physicians must gain a patient's consent to perform procedures or institute treatments, they have no legal responsibility to provide treatment that by community standards is considered futile.

The threat of malpractice hangs heavily over many decisions made by physicians. Informed consent and patient autonomy are forces made potent by fear of litigation. Physicians can easily imagine being dragged into court by an unscrupulous lawyer, because they "failed to do everything possible." But it is fainthearted and unprofessional for a physician to use the threat of malpractice as an excuse to abrogate responsibility. Doing what is professionally correct often requires courage and conviction.

■ A patient with an inoperable cancer was treated with radiation and chemotherapy. The tumor responded and the patient was relieved of his distressing symptoms. When they recurred an operation was advised. At the time of surgery the tumor was confirmed to be too extensive to be treated with a curative operation. It was performed anyway. The patient died

from complications of the ill-advised operation.

This example is particularly distressing because it was probably financially motivated. In a fee-for service system, the more a physician does the more money he makes. This is a clear conflict of interest that most physicians are able to resist. Some, however, succumb to temptation and perform unnecessary procedures. Furthermore, those hospital

administrators who are aware that futile care is good for business do not discourage such unethical practices.

The soaring cost of health care cannot be laid solely at the feet of physicians who exercise poor judgment. The community at large is also at fault.

□

Dr. Botticelli has been a professor at the University of Hawaii's John A. Burns School of Medicine

STEPS TO A 'HAPPY DEATH'

Here's what can be done to improve the situation:

■ Stop striving to attain immortality on earth. The eventual death of our bodies makes good religious and biological sense.

■ Constitute a commission to set priorities for health-care services.

■ Make physicians aware of their responsibility to dying patients. The prescription of futile care is unethical and unprofessional.

■ Define standards for terminal care. Conformance

with these standards should be made a requirement for membership in professional medical societies.

■ Implement effective peer review by healthcare institutions.

Physicians have the professional responsibility for the care of dying patients. A happy death, not a miserable life, should be the goal of their care. The last year of a life can be a time of love and compassion.

Adv. Feb 1, 98

Going Gently .. into That... dark night

By Maria L. La Ganga

Los Angeles Times.

SAN FRANCISCO — This is Paul's dream of the perfect death: Retired math teacher, avid sailor, he circumnavigates the globe at age 99, is lost at sea and never seen again.

His hands shake a little with Parkinson's disease as he tells this story in his soft, wheezy voice. Dapper in plaid shirt and neat jeans, Paul sounds as if he is talking about someone else. Almost as if he will not be there when it happens. Lost at sea.

He repeats this story often in the neat apartment in San Francisco where we meet for 10 successive Monday nights, September to November.

Autumn deepens all around us. Leaves fall. Days shorten. We are here learning how to die.

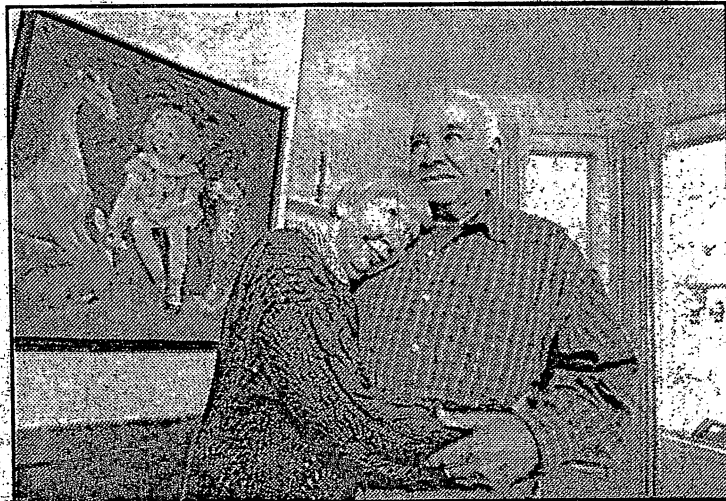
We are not boning up on how to kill ourselves, although the topic does arise on occasion. But it is somehow almost beside the point to the women and men who gather here hoping to craft a better death.

Pain is a far more important

topic when we peer closely at the end of life. God, too. Love, regrets, family, paperwork, morphine. We have much to discuss and not much time — 20 hours in Richard Wagner's living room.

We learn how to fill out documents that allow us to die without the aid of machines. We discover how our bodies will react, one week, one day, one hour before the end. We argue about the very best way to go: renal failure wins hands down, with its dreamy drift from unconsciousness to death.

A lot happens from September to November. Paul and Sophia, both 80, sell off some property, and celebrate 55 years of marriage. They give most of their belongings to their children, apply for rooms in a home for seniors, argue about whether or not to



go. Yet another friend of theirs dies. No. 6 in the last year or so.

'Active dying'

Adina travels further along in the process she refers to as "active dying." She is 43, has cystic fibrosis. Her oxygen tank soughs in the background. She coughs a lot. When we first meet, she is in danger of

As they prepare for their eventual deaths, Paul and Sophia, both 80, have given away many possessions but kept family portraits.

Inside:

Isle grief counselor helped wife "embrace death" / Page E10

See Death, Pa Listen and learn

breaking her First Commandment: I will die with the lungs God gave me. She is freshly back from a trip to Stanford University Medical Center, an exploratory jaunt in search of a transplant.

By November, she is cleared for surgery, on the list and debating what to do. She wears (and forgets) and wears (and forgets) the beeper that links her with the medical center and the organs that could come at any time — or not in time. She looks at her prescriptions and credit cards; she will likely expire before they do. She laughs. Sometimes.

By the end of our discussions, Sandy will make love for the first time in a very, very long time. Well-coiffed, perfectly made up, unable to stop smiling as she makes her announcement — yes, I did it — she has come a long way.

In September she was shy, maybe just a little dowdy, part way through radiation treatments, done with chemotherapy, at war with a body that betrayed her with breast cancer. A body that she was never all that comfortable in to begin with. And once they start cutting around in your parts, she says ... and her voice trails off.

I am here in part to listen, but also to learn. I am healthy but an actuarial nightmare: practically the only member of my family not to have had cancer. At 38 years old, I am without a female relative who made it to 50. My mother died fast in 1973, one quick yank of a ventilator plug after rapid brain cancer and ineffective surgery. My father died slowly two years ago, as his body parts fell to age, disease, a lifetime of smoking. They left the ventilator on. He dwindled.

This is a real conversation-stopper at most polite dinner parties, and that is precisely the point of this gathering. There are very few places to say things like: What happens to my body on my last day? How can I make sure it doesn't hurt at the end? I'm lonely. I'm dying. Maybe I'm not dying. But I'm afraid.

This is that place. It is not perfect. It is sometimes hard to bear. In most cities, finding something comparable is impossible. It is not for everyone. But it can be very helpful.

"What is magic about what happens here is that everyone is a self-identified mortal," Wagner says in October. A gay, defrocked Catholic priest who lost most of his friends to AIDS a decade ago, Wagner started this series of classes in 1995 for senior citizens and the terminally ill. At first, it was largely attended by gay men with the AIDS virus. Today, as AIDS treatment improves, it is largely women with cancer.

Working with the dying

Wagner earned a doctorate in clinical sexology while a practicing priest, but his doctoral research on the sexual attitudes and behavior of gay Catholic clergy knocked him out of favor with his church. While he has spent the last 14 years working with the dying, these days he is a sometime therapist who pays the bills

with a secretarial job.

He calls this group Paradigm: Enhancing Life Before Dying, a grand name for a worthwhile, but shoestring, operation. Lecturers donate their time. Wagner bakes the refreshments himself. Participants are asked to donate \$10 per session if they can.

There is no money to advertise. Sandy heard about Paradigm in chemotherapy. Wagner gave Sophia, white-haired and charming, a brochure on the group as she got off a bus. He does this sometimes with people who look old and open-minded.

In this article, some names have been changed to protect privacy. Wagner's is the only one unaltered. The stories are all true.

Different choices for the end

The first several Mondays are filled with revelation. Ellen, 71, says she wants to be immortal, plans on being cryogenically frozen in a tank filled with nitrogen for "reanimation" at some future

date, displays the Medic Alert necklace she is never without. Resuscitate-cool. No autopsy.

Sophia announces her plans for their future with a cheerful "Paul and I are considering going into a retirement community, and one of the things we have to do is plan what to do about our bodies." Later, she is thrilled to find a low-ball bidder—a full-service cremation for just \$395 per person.

We are given a list of 18 awful eventualities and pick our personal worst. We are confronting our fears. The top three: I'm afraid of being helpless and having to depend completely on others. I'm afraid of taking a long time to die. I'm afraid of losing control of my bodily functions.

Today is the first day . . .

We come bearing a homework assignment: What would you do in your last six weeks of life? The first five you would be ambulatory and relatively well. The last one you'd be in bed, but lucid. Ellen wants to rob a bank.

Sandy wants to travel—to Greece or Egypt, then New York, then Florida, then she'll rent a red car and drive to Missouri. Jennifer, infected with HIV and newly 30, wants to ride her motorcycle up the coastline.

When was the last time you did that, asks Wagner. And why don't you do it now? Here, it seems, is the crux of our 10 weeks together: Why don't you do it now?

We are all still around. Our final session has come and gone. We resume old lives equipped with new tools.

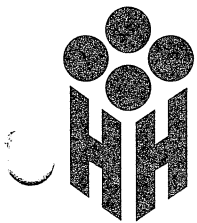
Jennifer has gone skydiving for the first time.

Adina's beeper has not gone off, forcing her to decide whether to risk a transplant that may—or may not—help her live longer.

Paul and Sophia remain—so far—in their home of 52 years. They've made another visit to Heritage House, admired the Christmas ornaments in the graceful lobby.

"We told them no," Paul says.

"No, we didn't," says Sophia with a smile.



Living in the Light of Death

Dying Is What Some Patients Did. Now, Dr. William Bartholome Has His Own Terminal Illness

by Larry Beresford

Stop me if you've heard this one before: professional over-achiever receives a terminal prognosis and is forced to really confront his mortality for the first time. The experience transforms him, teaches him what life had been about all along, and gives him an intensity, freedom, and lightness he's never known before. He claims his life is the best it ever was, and he wouldn't trade the experience for anything—not even a longer lifespan on the old pre-enlightened terms.

Hospice professionals know this story, having encountered it occasionally in their caseloads. What's unique about the case of Dr. William Bartholome, a 53-year-old medical ethicist, pediatrician and professor of medicine at the University of Kansas (KU) Medical School, is that he already was deeply involved in the end-of-life field before he received a cancer diagnosis in 1994. His extensive resume includes articles and lectures about ethics and decision-making at the end of life, as well as involvement in the medical care of hundreds of dying children (see HOSPICE Magazine, 1996 special pediatric issue).

Although his own life has been dramatically altered, many of Bartholome's views about the importance of patient autonomy and end-of-life care remain unchanged—only intensified from his first-hand experience. He shared them in a keynote address at the National Hospice Organization's 19th Annual Symposium and Exposition in Atlanta this October.

Dying is not primarily a medical condition, Bartholome believes, but a personally experienced,

lived condition. Too often, physicians fail to identify the terminally ill, and many die without ever having been cared for as dying patients—with grave consequences for the final chapter of their lives.

In recent presentations, Bartholome has outlined 12 arguments for "the value of wearing the label 'dying.'" including patients' need and right to know their condition and to be free from the burdens of futile, harmful medical interventions; and the opportunity to exercise their rights to refuse life-sustaining treatments and to address issues of life closure. In the absence of such identification, medical brinkmanship prevails, using medicine's full technical capacity to treat people right up to the brink of death, to the point where it becomes impossible to stop.

But above all these, he says, is the opportunity for living in the light of death. Bartholome has labeled his own diagnosis of metastatic esophageal cancer a precious gift. "I never understood the intensity of life before. Now I know a sunset can knock you down. I never had a sense that I could be or say whatever the hell I felt like being or saying, or that I had the ability to choose to invest my time on a minute-by-minute basis."

Another crucial advantage of wearing the dying label is becoming a hospice patient, with hospice's potential to restore control over one's life and the circumstances of dying, he says. "Most terminally ill patients in the United States are not receiving care as dying patients. Why not? Because no one has gone to them and said, 'This is your predicament, and we have a wonderful treatment for people in your predicament. It involves wearing the label dying. It's called hospice.'"

continued on next page

However, while Bartholome extols hospice for epitomizing what should be the essence of the health care, namely caring, he is disturbed at certain trends. He fears that the economic foundation of managed care is infecting hospice, the same as other health care providers. Hospice's evolution from a movement to an industry may have distracted it from the goal of transforming the way people die in America. He also fears that hospices might lose sight of the great insight that dying is not primarily a medical event.

Hospice has also failed in its responsibility to the five-sixths of Americans who die without ever reaching a hospice, in part because its insistence on being outside of the mainstream limited its influence. "As hospice providers, you have a special responsibility to the patients dying in the mainstream that you have not undertaken," he told the Ohio Hospice Organization's annual meeting last year. "Your concern ought to include how we do palliative care 'inside the belly of the beast,'" in the major medical institutions.

* * *

An ironic twist in Bartholome's dramatic tale is that ~~he's still alive and essentially symptom-free,~~ three years after extraordinary surgery to remove his esophagus, replace it with the upper half of his stomach, rolled into a tube, and excise any other obvious signs of the cancer, including a substantial chunk of his liver. Metastatic cancer of this nature "doesn't not come back," says the lanky, dryly witty Bartholome. As far as he's concerned, his ticket has been punched, but he's enjoying the unexpected gift of health that is "pretty disgustingly stable. . . In my doctors' view, as a result of my radical palliative surgery, I'm experiencing this wonderful last chapter. But I'm not thinking that I've dodged a bullet. I have never doubted the reality of my terminal diagnosis," not even while watching the video monitor of a diagnostic upper gastrointestinal scan.

"I was drinking the (radioactive) liquid, looking at the video and saying to myself, 'There's a fungating mass in this man's distal esophagus.' Then somebody inside me slapped somebody else inside me and said, 'That's your esophagus.'"

What's more, Bartholome has no interest in giving up his special status of being "marked" as terminally ill, or to stop living his life "in the light of death," because of the bounty it has brought to him. "It seems to me, once you've turned this corner, you

don't go back. You've established a relationship with life that's different." It's somehow deeper than the sages' commonplace teaching that any of us, at any time, could end up in the firing line of a runaway truck or falling masonry.

"I don't think people can get it that way as effectively as people who are marked (by a specific terminal diagnosis). Getting marked brings it home to you. You might be able to get it in other ways, like a near miss on the highway. Losing a child—that will mark you. You'll never be the same again after that. My favorite poet (Rainer Maria) Rilke said to see a rose and not see death inside of that rose is to miss what a rose is."

However, three years on, those who are close to Bartholome have grown tired of living their own lives always waiting for the other shoe to drop. "My wife Pam, says, 'I have no problem with your life being enriched by living in the light of death. I have even come to understand the extent to which living in the light of death could enrich my life. But don't ask me to live constantly in the light of your death. When I contemplate your death, I don't experience light, I experience dark. If you need people to talk to you and share the ennobling aspects of the experience, look to other people for that—don't look to me, or your daughters,'" he relates.

"In many ways, people who don't have a personal relationship with me are better able to connect with this aspect of my life. And those who are similarly marked (by a terminal diagnosis), they are my soul mates. They just seem to keep floating into my life."

~~After his surgery, Bartholome said no to chemotherapy,~~ and he will not consent to another CAT scan until his oncologist can assure him that "evidence produced by the scan would be meaningful to the point where I could 'close this damned cancer chapter,' as my family calls it." No doubt partly in recompense for inflicting his jaunty living-in-the-light-of-death routine on unwilling relatives, Bartholome early on made a pact to "do anything anybody who loved me asked me to do, as long as it didn't hurt me."

This has meant carrying a rosary and a frog talisman, taking the extract of echinacea root and drinking a daily glass of Native American medicine water. The latter is produced by holding a transparent vessel full of water up to the horizon in order to capture the rising sun. He also participated in a Native American medicine wheel ritual with a "dancing woman" or

traditional healer. "At the end of the ritual, I was just bawling like a baby. I said, 'I'm okay.' She said, 'You're telling me? I know you're okay.'"

Bartholome relates. "All these rituals are extremely satisfying, filling, moving, and provocative."

"My daughter Bridget also arranged for me to consult with a visiting Nicaraguan shaman who came through Kansas City. He had me strip down to nothing and he did this examination ritual all over my body. Then he went into this trance and he told me the story of my life. It was quite bizarre,"

Bartholome recalls. "Either he was really good—or he had some inside information. At the end of this whole thing I told him I was a doctor—which totally flustered him. Then I told him I had cancer. He said, 'I knew you had an operation, because I saw the scars. But there's no cancer. How did you take care of the cancer? You must have been carrying something with you every day.'" Bartholome gave the shaman his little jade frog, but immediately regretted it, and compensated "by buying frogs like crazy."

Today he discounts the question of whether or not these unconventional therapies "work," and says, "I've also allowed myself to let go of the cure paradigm. I see myself as having within me the force that will bring me to ground. I'm marked. As far as the calendar is concerned, I don't know. But I also think what you do with your illness makes a difference. I've had a hoot—I've gotten into anything and everything."

What do Bartholome's colleagues say about all this? "Well, sure, we could have predicted it." I was already seen by most doctors as a heretic. I've always been the outsider, the stranger. Aristotle said the philosopher should be like a scorpion," he insists. "The head of my department a year ago called me a gadfly. I like that, the traditional notion of what a gadfly is: a pest, an insect you cannot get rid of, constantly buzzing around."

Bartholome has also caused some institutional irritation as his attitude toward work has changed. Although he is still physically able to work full-time, he's less interested in his formerly packed schedule of institutional commitments and committee work. He is revisiting the question of what his career should be now, given the reprieve he has been granted, "which is linked to the question: why am I still here? Is there some purpose? If so, I haven't discovered it," he says, although he doubts the answer will be found in a committee room. He's more interested in bring-

ing palliative care to KU Medical Center in Kansas City, KS.

"I've developed the notion of a palliative care consulting service. We just cobbled together a business plan in the form that the system needs to see it. Supposedly they are committed to do at least that much." Because his medical center admitting privileges are limited to pediatrics, Bartholome can't be the adult palliative care program's medical director. However, he plans to use his expertise and moral authority as a cancer patient and future user to influence its development.

"Pediatrics I'm trying to do in a different way. I want to create an in-patient respite unit for children served by Kansas City-area hospices, so that parents could take some time off, and to transition hospitalized kids so they could be stabilized to go home." The model is the Butterfly Suite developed by Dr. Marcia Levetown at the University of Texas Medical Branch at Galveston, TX. Both of Bartholome's proposals are still in the formative stages, but they should be doable, he says.

Meanwhile, he has been working on his own "ritual of withdrawal from the world," drawing on Native American traditions, things he has read, rituals from other cultures and what he has observed over the years from families of dying children. He started collecting Mexican artwork from Los Dias de Los Muertos (Days of the Dead) and other talismans. "One issue is very, very clear. I want to be the recipient of the best that modern hospice care can provide," Bartholome wrote in the Spring 1997 Bioethics Forum newsletter.

With his family, Bartholome has already planned his memorial service and the disposition of his remains, as well as financial and estate planning issues. He intends to do a systematic life review by sorting through thousands of snapshots taken over the past 40 years. "Eventually I will withdraw into myself and my head will become my world," Bartholome has written. "During the final phases of this withdrawal process, I will be giving myself over to a process that remains a true mystery to me. . . Although I firmly believe that death entails the end of the self I have come to know over these years, I have no idea what comes next."

* * *

continued on next page

In a death-denying culture, Bartholome's quest must seem the very embodiment of morbidity. Yet that would fail to account for the lightness, humor and gentle self-mockery which he brings to all of his current interests, whether encounters with a Nicaraguan shaman or compiling arguments for the value of wearing the label dying.

Last December, this author spent four hours interviewing Bartholome in his vast, cluttered office in the Clendinning History of Medicine Library and Museum at KU. We finished up with his views on what comes after ("I mourn the passing of Bill. Bill was born to be worm food."). Then he showed me the convoluted route out the museum, walking with the slight forward stoop some tall men have, absentmindedly whistling *Some Enchanted Evening*. After pointing me down a long hallway, he gave a cracked smile and said, "Stay in touch. Who knows? I might be around for a while."

Reprinted from Hospice Magazine, November 1997 issue.

Larry Beresford is a San Francisco-based freelance journalist, a regular contributor to Hospice Magazine and the editor of Hospice Management Advisor Newsletter.

We wish to thank him again for generously allowing us to reprint this article for our readership.

Native Hawaiians

History

The Native Hawaiian people (or *kānaka maoli*) are indigenous to the islands of Hawai'i, establishing their arrival as early as 100 A.D. (Blaisdell & Mokuau, 1991). They are of Polynesian extraction, sharing a common ancestry with the indigenous people across the South Pacific, from New Zealand to Easter Island. The ancient Hawaiians lived in harmony with their environment and believed in the concept of sharing and caring for the group as a whole. Upon first contact with the West, in 1778, it is estimated that Native Hawaiians numbered a million (Stannard, 1989). The native population was reduced drastically as Native Hawaiians contracted and died from measles, tuberculosis, venereal diseases, leprosy, influenza, and other infectious diseases. The importation of labor to Hawai'i from China, Japan, the Philippines, and Korea was partly in response to the decimation of the Native Hawaiian population and, starting in the 19th Century, non-Hawaiians have outnumbered Native Hawaiians in Hawai'i (Blaisdell & Mokuau, 1991). Native Hawaiian traditions and customs slowly eroded as they were replaced with Christianity, written language, and education. However, a resurgence of pride in being of Hawaiian ancestry and a renewed study of hula, Hawaiian music, and Hawaiian language began in the early 1970's. In 1990, the number of Native Hawaiians in Hawai'i was estimated at about 201,000 (about 18% of the state's population), but only about 9,000 of these were full-Hawaiian (Hawai'i Department of Health, 1990).

Native Hawaiian Participants

The key informant for the Native Hawaiian group was a female social worker who is a project director with Kamehameha Schools Bishop Estates and also works in the emergency room on the Wai'anae Coast. Focus group participants included a male social worker employed at Queen Lili'uokalani Children's Center, a female social worker employed at that same agency who conducts a death and dying bereavement group, and a female health educator who works at the Wai'anae Coast Comprehensive Health Center.

Findings from the Interviews

Only the key informant was affiliated with an single organized religious group (Catholic), while the others described their religious beliefs as a combination of several different religions. The answers differed only when religion was involved. Otherwise, they were fairly consistent.

Philosophy, tenets, beliefs, and rituals regarding death and dying in Hawaiian culture. The key informant, who is Catholic, stated that Christianity plays a major role in Native Hawaiian views and beliefs. She said that all life is a gift from God

and that
hell is n
being n
Comma
feels th
commu
and bel
tradition

a part o
importa
family m
his pare
relations
that "de
she mo
complet
next rea
illustrate
had acc

particip
the beli
mana.
become
room.
songs t
a fan th
the she
you ha
this ho
had tol
days la

death c
for 4 da
to "talk
times a
days, fr
family c

and that when you die, "if you have led a good life, you will go to heaven, but getting to hell is not hard either. One can get to hell by committing mortal sins or by simply not being nice to people." She feels that although Catholicism teaches the Ten Commandments, the same concepts are important to her for cultural reasons. She feels that because of her Hawaiian culture, there is a greater commitment to the community and society and so she tries to be nice to neighbors and helpful to people and believes that her family always comes first. She added that Native Hawaiian traditions are incorporated into the beliefs of the church.

A focus group member explained that "death is a part of life" and is accepted as a part of life by most Native Hawaiians. Another participant felt that, for him, an important belief about death was that, in death, the deceased is reconnected with family members who have died before. He stated that when he dies, he "wants to see his parents and his family first, and then he'd see Jesus later" because he has had a relationship with his parents, but he has never met Jesus. The third participant agreed that "death is not something to mourn." She was taught that when a person dies, he or she moves on to another realm, another level. While on earth, people are here to complete a task, and when that task is completed, he/she dies and moves on to the next realm. A person's task can be completed in a day or a hundred years. She illustrated by telling about the recent death of her 19-year old daughter who, she felt, had accomplished more in her 19 years than had her 80-year old father.

The openness between this life and the next is illustrated in other examples. A participant said that her grandfather cautioned her not to touch a dead body because of the belief that the body is empty and can take the living person's personal energy or *mana*. If the dead removes the *mana* from the living person, the living person will become sick. Because of this belief, she will not touch a dead body in the emergency room. Another told that, after his father died, he and a cousin were arguing about what songs to play at the funeral and what day to have the service. In the middle of the fight, a fan that had belonged to his father flew off of the shelf. When he returned the fan to the shelf, he realized his father was sending him a message so he told his father, "if you have something to tell me, tell me in my dreams or I'm going to be scared to stay in this house!" A third told a story about her mother, who was gardening when the plants had told her something "devastating" was going to happen and to be prepared. A few days later, a cousin was killed.

Burial rituals. A participant shared her experience about the unexpected death of her 19-year old daughter. After the death, the family stayed inside the house for 4 days and had no contact with anyone outside the family. The purpose of this was to "talk story" about the daughter's death and her life. The family discussed the good times and bad times and helped each person in the family release her. During these 4 days, friends and people from the community brought in food for every meal so that the family did not have to cook and could focus on the daughter.

In preparing the body for burial, Hawaiian salt and ferns were put in the casket. The other participants noted that flowers are common at funerals and that the favorite food of the deceased is usually served after the service. Friends and neighbors help organize these events and support the family. After the service, many go to the beach to cleanse their spirits. In general, participants agreed that a Hawaiian funeral is a celebration of the deceased person's life, compared to mainland funerals which participants found "mournful and lacking in joy."

Beliefs regarding death and dying by age and/or gender. The participants did not see many differences in services by gender or age of the deceased. The exceptions were that there would be more grieving during the funeral for a younger person and, at a child's funeral, there would be toys and balloons, whereas at an adult's funeral, the awards, certificates, and other items of recognition the person had earned would be displayed.

Beliefs and rituals regarding death due to cancer, AIDS, etc. It was noted that the "c" (cancer) word is still whispered, not from shame, but because of the sorrow felt for the person, as cancer represents a "slow death from which there is no escape." With AIDS, open discussion of the disease depends on the openness of the family. If a person's sexual orientation has been a secret, shrouded in shame, the death becomes uncomfortable for the family. A participant noted that when his father was diagnosed with leukemia, he never told anyone and he had the disease for 5 years before the family ever knew. This was partly because the father refused to accept the diagnosis himself and continued to live as if he had never been diagnosed with leukemia. Funerals are similar, however, regardless of the cause of death.

Bereavement. Catholic Hawaiians would observe the 9-day Novena and then the 40-day service, which would help them work through their grief. Others observe the customs of their churches and/or the customs of the community. Either way, the informants agreed that, the whole community comes together around a death. A party is held after the burial that serves to celebrate the deceased's life and neighbors help organize and prepare food for this event. This way, the whole community participates in the bereavement and, by giving, the people in the community also feel better. Another participant talked about the support he received following the death of his mother. His boss allowed him to take off as much time as he needed. When he returned to work two weeks later, the workers and his clients brought him food and coffee and exhibited caring attitudes which he said helped with his healing. He doubted that this would have happened in a mainstream organization, where usually only a few days of funeral leave are allowed. In addition, many visit the graves of the deceased on special anniversaries such as the day the person died, the person's birthday, Christmas, etc.

Hawaiians feel that they can get signs and messages from the environment that are helpful in understanding death. When one participant's daughter died, the weather

was
dece
comf
an es
to ma
overh
gods)
the sp
memb
on the

which
grand
the gra
she wa
daught
deceas
was he
dream

cry" wh
the mei
sometir
more p
form of

accepta
because
conside
hand, a
giving de
decision
God." If
for the w
was not

B
mind wou
that man
hell. She
does with

was sunny and beautiful and it was Mahealani (a full moon), which is the time when deceased family members come back from "the other side." These signs were comforting, as they signified that the daughter was calm upon death and that she had an escort to the other side. When the mother went to the beach to gather ocean plants to make a lei for her daughter's funeral, it was a beautiful, sunny day with a rainbow overhead. A friend who had accompanied her saw many *aumakua* (family ancestral gods) while they were there and this helped her accept the death. It is believed that the spirit of the deceased returns on the third day after death at which time family members may have dreams about the deceased, or may get a feeling of being touched on the cheek or hugged by the spirit of the deceased.

Dreams are also important. All of the participants told stories about dreams in which the deceased appeared to convey a message to the living. One participant's grandmother came to her after her death. Since the granddaughter clearly missed her, the grandmother asked if she wanted to come along. She told her grandmother, no, she wasn't ready, and that helped her say goodbye. Another said that, after her daughter's death, she had a dream that she passed the dining room and saw many deceased family members sitting around the table eating a meal. Seated at the table was her daughter, who appeared happy to be reunited with her family members. This dream signified that her daughter was fine and had met up with the family.

Some Native Hawaiians have the ability to "wail," letting out a "weird, spooky cry" when grieving. As a person wails, they are also talking, describing (in Hawaiian) the memories of the deceased from beginning to end. Not everyone has this wail, sometimes just one or two people from a family, but the older a person becomes, the more powerful the cry. Although it can have a frightening sound, wailing is a traditional form of bereavement for Native Hawaiians.

Abortion and miscarriage. The Catholic participant felt that abortion was not acceptable. She explained that in Hawaiian culture abortions are unnecessary because a relative or friend will always *hanai* (adopt) the baby. Miscarriage is considered unfortunate and happens "because God needs a tiny angel." On the other hand, a focus group member stated that Native Hawaiians have practiced a ritual of giving deformed newborn babies to the ocean for many years. She said that the decision to abort is not between a woman and a man, but "between the woman and God." If a woman can't afford to take care of the baby, abortion is an acceptable option for the woman if it is her decision. She said that miscarriage is viewed as, "this child was not meant to be."

Beliefs about suicide. The Catholic informant said, "No one in his/her right mind would commit suicide and if so, it's usually because of someone else." She said that many Catholics believe that a person who commits suicide will be condemned to hell. She never heard people explain death by suicide as "God was calling" as she does with deaths from other causes.

Other participants thought that the stance of the Catholic Church on suicide was harsh and unfair. They do not believe a person who commits suicide automatically goes to hell. They also thought it was wrong that the Catholic Church would not allow the person who committed suicide to have a church funeral and burial. They talked about other approaches to suicide. For example, a participant noted that one of her daughters tried to commit suicide twice because of an unhappy relationship. As her mother, she went to a channeler who found from the spirit world that the daughter, in her past life, had committed suicide because of an unhappy relationship. She advised that the girl must change her "cycle" or she will come back after each death and relive the experience over and over. Once the daughter could see this, she worked to get out of the unhappy relationship and is feeling much better.

Euthanasia. All participants were in favor of passive euthanasia. One stated that, "for me personally, I tell my family to make sure they do all they can to save me, but then let me go and I won't come back and bother you guys." Another said that, in her family, they have all decided they will allow the person to "leave" and not keep them on artificial support. They felt that machines just extend death and, as a result, the spirit is stuck half-way in between this realm and the next. At this point, it was "better to allow them to go."

Beliefs regarding planning for death (e.g. living wills and funeral plans). The participants agreed that few Native Hawaiians talk about wills or living wills. A reason was that the property automatically goes to the spouse and then to the kids, so there was no need for a will. In addition, the older generation may believe that talking about death will bring on death. For example, when a participant tried to see if his parents had done any planning about their funerals, his mother became teary and his father was "pissed off" that the son had brought up this topic. On the other hand, participants noted that many Hawaiians made their wish known verbally. One participant has been very open with her family about the kind of funeral she wants when she dies. She also mentioned that other people had made their wishes known to her.

Beliefs regarding organ donation. The participants had varying feelings about organ donation. The Catholic was in favor of it and has designated that she is an organ donor on her driver's license. Another said she would not donate her organs, nor would any of her family, because she believed that God made her body and she should leave this world with her body as it is. The others said they were unsure about donating organs, although they recognized the merit in it.

How things are changing. Participants noted that grieving was more constrained and speeded up now. For example, a participant was appalled when she was handed a thank you card while signing the guest book at the last funeral she attended. Another said that he was stopped by an aunty when he tried to say goodbye



his mother one last time at the funeral. He said to his mother silently, "Sorry mom, I can't do my wailing here, I'll do it at home."

Advice for health care workers working with dying Native Hawaiian patients. The participants advised health care workers to "expect the unexpected" because there is a lot of diversity among Native Hawaiians. Ask the elder or the eldest child about the family's preferences and take cues from that person. When in doubt, tell an elder, "I don't know if I'm doing it right; can you help me?"

It is important in a hospital or emergency room setting to allow family and friends to gather around. Remember that the person who died is the main focus, not the medical staff. The staff should show respect by talking softly and not telling jokes to one another while the family is present. It was noted that families who come and view the body in the hospital tend to go through the grieving process better than those who don't come see the body. If a physician has worked with the person for a long time, he/she is considered part of the extended family and is expected to attend the funeral. If that is not possible, a phone call should be made to the family by the physician. A participant illustrated the importance of this by relating that, when her daughter died, she so appreciated the fact that the ambulance drivers hugged her and told her they did everything they could.

Table 6. A Summary of Responses from Native Hawaiians

Philosophy	<p>-Traditional Hawaiian beliefs are often mixed with Christian beliefs. Death is seen as a natural part of life. The deceased has finished his/her tasks on earth and moves to another realm to be reunited with ancestors.</p>
Burial rituals	<p>-Families may "talk story" about the life and death of the deceased to help release the deceased.</p> <p>-A Hawaiian funeral is a celebration of the deceased person's life, compared to mainland funerals which seem "mournful and lacking in joy."</p> <p>-At a child's funeral, there would be toys and balloons and more grief would be displayed.</p> <p>-Hawaiian salt and ferns may be put in the casket. Flowers are common and the favorite foods of the deceased are served after the service.</p> <p>-After the service, participants may go to the beach to cleanse their spirits.</p> <p>-Funeral rituals do not vary by cause of death.</p>
Bereave-ment	<p>-Catholic Hawaiians would observe the 9-day Novena and then the 40-day service. Others observe customs of their churches and/or community.</p> <p>-It is usual for the whole community to come together during a death. A party is held after the burial that serves to celebrate the deceased's life and neighbors help organize and prepare food for this event.</p> <p>-Hawaiians may find signs in the environment that help explain death. The deceased may appear in dreams to convey a message to the living.</p> <p>-Some Native Hawaiians "wail," letting out a "weird, spooky cry" when grieving.</p> <p>-Many visit the graves of the deceased on special anniversaries such as the day the person died, the person's birthday, Christmas, etc.</p>
Abortion and Miscarriage	<p>-Abortion: Beliefs vary. For Catholics, abortion is unacceptable and unwanted children can be adopted by other relatives. On the other hand, Native Hawaiians have given deformed newborns to the ocean for many years.</p> <p>-Miscarriage is considered unfortunate. For Catholics, "God needs a tiny angel." For others, "this child was not meant to be."</p>

<p>icide and hanasia</p> 	<p>-Suicide: For Catholics, suicide is unacceptable. Others don't agree that a person who commits suicide automatically goes to hell and should be denied a church burial.</p> <p>-Euthanasia: Passive euthanasia appears to be acceptable.</p>
<p>Planning for ath and gan nation</p>	<p>-Planning: Few Native Hawaiians talk about wills or living wills, as property automatically goes to the spouse and then to the kids and the older generation believes that talking about death will bring on death. Members of the younger generation are more open to this.</p> <p>-Organ Donation: Feelings were mixed, some in favor, some against, some undecided.</p>
<p>anges er Time</p>	<p>-Grieving is more constrained and speeded up now.</p>
<p>vice for alth Care orkers</p> 	<p>-Expect diversity among Native Hawaiians. Ask about the family's preferences. When in doubt, say "I don't know if I'm doing it right; can you help me?"</p> <p>-Allow family and friends to gather around. The staff should show respect by talking softly and not telling jokes to one another while the family is present.</p> <p>-Allow viewing of the body, as this facilitates the grieving process</p> <p>-A physician may be considered part of the extended family and is expected to attend the funeral or, at least, call to share in the loss.</p>

Choices in Healing

Michael Lerner

MIT Press

Cambridge, Massachusetts
1994

Part 6

Chapter 26

On Living and Dying

Even the wise fear death. Life clings to life.

Buddha

I write this chapter on death and dying with the greatest respect for the reader facing the possibility either of his own death or of the death of someone he cares about. I have had too many friends die of cancer to speak to you in any other way.

For those who may have difficulty beginning to read this chapter, I want to say right at the start that I believe there are 12 critical things to know about death and dying:

1. There is skill, choice, knowledge, and control in death and dying just as much as there is in the fight for life with cancer.
2. Some people believe that death is the end; others that life after death is a certainty. My own belief, as Rachel Naomi Remen puts it, is that *death is a mystery worth contemplating*. Death for me is a mystery in the deep sense of the term: a real possibility exists that life in some form continues after death, and intriguing scientific literature supports the spiritual writings and the experience of many

ing as well as good grieving support groups and therapists. I strongly recommend learning about these resources for survivors.

12. Our culture's attitude—in which death is a highly toxic subject and seen as a failure, either of the doctor or of the patient—is not only new historically but at odds with that of other cultures. In many cultures, dying is surrounded by rituals in which everyone participates. For many centuries in the West, this was also so. Death was often seen as the culmination of a life, and people gave great thought to how they might die well. It is possible in our culture to *detoxify death* by contemplating it, seeing what others have thought and said about it, and by giving ourselves time to be with it. In the face of sincere contemplation and prayer, the toxicity with which our culture has surrounded death often begins to dissolve.

All of this leads to exploration of what benefits we and those we love may receive from death and dying. We know all too well what the pain and losses will be. We know all too well that some people die with great difficulty and suffering, while others die peacefully. The question is whether or not we can find anything of value, in the midst of pain and loss, from death. The answer of some wise people over the centuries, and of many in our time, is that it is possible to find deeply meaningful and important experiences in the midst of facing death. In the rest of this chapter we explore some of these ideas in more detail.

The Literature on Death and Dying

One of the best ways to *detoxify* the subject of death and dying is to learn what wise people have had to say about their own experience with and meditations on death. In a sense, the classic and contemporary literature on death and dying provides a support group made up of some of the greatest saints, humorists, artists, cynics, and thinkers of all times. They speak across the ages to you—across time and space—with some very different ideas about how people have faced what William James called “the distinguished thing” I know they have helped me. Perhaps they may help you, too.

✓ One of the best places to start an inquiry into death and dying is *The Oxford Book of Death*, a great collection of poems, other writings, and sayings about

death. I have selected a number of quotations from *The Oxford Book of Death* ³ to give you a sense of *how* reading what wise people through the ages have said about death can transform our own attitudes.

The editor of the collection, J.D. Enright, is a well-known poet and critic. “Reading for this anthology,” he says, “I was moved to the thought that on no theme have writers shown themselves more lively.” A survivor of one of the Nazi prison camps, quoted in the anthology, echoed this view with his observation, “when in death we are in the midst of life.”³

“Death,” said Arnold Toynbee, “is the price paid by life for an enhancement of the complexity of a live organism’s structure.”⁴ There is a deep biological basis for this observation. As the Canadian naturalist David Suzuki explains, in primitive one-celled organisms, the original cell reproduced by dividing itself, so death was not inevitable. But complex organisms that could not simply divide developed sexual function as a means of reproduction. With the invention of reproduction, death appeared. Hence the very deep connections between birth, sexuality, and death.⁵ Montaigne put it simply: “Make room for others, as others have done for you.”⁶

Said Jung:

Life is an energy-process. Like every energy-process, it is in principle irreversible and is therefore directed toward a goal. That goal is a state of rest. In the long run everything that happens is, as it were, no more than the initial disturbance of a perpetual state of rest which forever attempts to re-establish itself. . . . Thoughts of death pile up to an astonishing degree as the years increase. Willy-nilly, the aging person prepares himself for death. . . . It is just as neurotic in old age not to focus upon the goal of death as it is in youth to repress fantasies which have to do with the future.⁷

Many writers agree that dying is more difficult than death itself:

PHAEDRUS: *But is death as horrible a thing as it's commonly asserted to be?*

MARCUS: *The road leading up to it is harder than death itself. If a man dismisses from his thoughts the horror and imagination of death, he will have rid himself of a great part of the evil. In brief, whatever the torment of sickness or death, it is rendered much more endurable if a*

people who have had remarkable near-death experiences. Forceful arguments exist on the other side.

3. Whatever our beliefs about death, it is a fact that *there is such a thing as dying well*, and that we can consciously work toward dying well the way pregnant mothers work toward birthing well—and with the same uncertainty and absence of judgment about how we will actually fare in the event.
4. There is no single way of dying well, but an infinite variety of ways. A good death might be described mentally and emotionally as one in which—in the face of whatever biological experience we shall have—as much movement toward wisdom and healing as possible takes place for the one who is dying and for those who love him. A good death might be described physically as one in which pain and discomfort do not exceed what can be decently endured.
5. It is very useful to recognize the distinction between our *fear of dying* and our *fear of death*. This distinction then helps us focus first on specific fears we have about the dying process.
6. Most people are more afraid of being caught in interminable suffering during the dying process than they are of death itself. The reality, as we have seen in the chapter on pain, is that, in most cases, severe pain can be controlled and made tolerable.
7. Another fear people have is that they will remain alive when life no longer feels worth living, when they have become a burden to people they love, or when their dignity has been taken from them. This is a more complex set of concerns to respond to, but one important fact, emphasized by the great physician Eric Cassell, is that *many people with cancer die within a relatively short time of having truly decided that they are ready to die*.¹
8. If death does not come to us at the point where we have truly decided that we no longer want to live, then we do have the option of taking our own life, if our religious beliefs allow it and if the suffering becomes intolerable. In the Netherlands, physician-assisted suicide for those facing a life no longer worth living is an acknowledged part of a public policy that requires the physician to follow a carefully prescribed protocol.² In the United States, a great debate is currently taking place over whether physician-assisted suicide should be legal. Many American physicians do assist patients in dying if all that remains is a painful existence

without dignity. Whether or not physicians are willing to assist us, ² many patients with life-threatening illnesses (AIDS patients have led the way in this) have simply learned what drug combinations are effective in suicide and have set those drugs aside for the day when life is no longer worth living.

9. *It is critically important to make sure that you have the best possible medical and nursing care while dying.* Those physicians who are wonderful when you are fighting for life may not be helpful when you are dying. The same is true of hospitals—a place that is superb for high-technology cancer therapies may not be the best place to die. One of the most difficult aspects of dying is the discomfort that may arise from many different sources. Helping a person relieve these symptoms and discomforts is a very high medical art that demands the interest, care, and attention of physicians, nurses, and caregivers. Finding the people in your community (they are often connected with a hospice) who are dedicated to this great human task can make a world of difference in the experience of dying. If you choose to die at home, the choice of home health care aides skilled in helping people die is at least as important as the physician and nurses you work with.
10. Some people are afraid that making practical estate arrangements or other arrangements for dying means that they have given up the fight for life. My general experience is that preparing for the possibility of death does not interfere with the fight for life at all—in fact it can enhance it, because you have taken away the worry of not having dealt with these very practical matters. Taking care of the things you want to take care of actually releases energy for the fight for life.
11. Part of preparing for death is giving some thought to helping loved ones with the grieving process. This can be tremendously important, because incomplete grieving often injures the rest of the life of a mate, a parent, or a child. In the process of a good death, a great deal of the mutual grieving of patient and loved ones takes place while the patient is still alive and participating. If this process takes place as consciously and fully as possible, the death can sometimes become, strangely, a great healing for all involved. While there is still grieving to do—a great deal of grieving, perhaps—it starts from a solid base. There are some excellent books on griev-

range of human emotions—few in some people, dozens in others—experienced in a variety of orderings, reorderings, and arrangements. The one psychological mechanism that seems ubiquitous is denial, which can appear or reappear at any time. Nor is there any natural law that an individual has to achieve closure before death sets its seal. In fact, most people die too soon or too late, with loose threads and fragments of agenda uncompleted.

My own notion is more general in scope; more specific in content. . . . My general hypothesis is that a *dying person's flow of behaviors will reflect or parallel that person's previous segments of behaviors, specifically those behaviors relating to threat, stress or failure*. There are certain *consistencies* in human beings. Individuals die more-or-less characteristically as they have lived, relative to those aspects of personality which relate to their conceptualization of their dying. To oversimplify: The psychological course of the cancer mirrors certain deep troughs in the course of the life—*oncology recapitulates ontogeny* [Shneidman's emphasis].⁴⁶

Another special observer of the dying process was Erich Lindemann, Professor of Psychiatry at Harvard, who studied loss and grieving for years before he developed cancer. Lindemann described his own process of *anticipatory grieving* in the face of his impending death from cancer.

First, he wanted *information* from his physicians, and he wrestled with all the complex questions about what a physician should and should not tell a patient and how the news should be transmitted. Second, he struggled with what to do with the feelings that his impending death brought up for him. Third, he found that the agreement with family and friends on *the ways in which he would be remembered* was of critical importance to him:

It can only be represented by symbols, such as a book, or—there is a building named for me in Boston, the Lindemann Mental Health Center, which means an awful lot. So you have something which continues your identity's existence by a global attribute, a book or a building which then allows the survivors to remember those things which are pertinent to *you*, the particular person, just as at various stages of your anticipatory grieving you think about various aspects of that life which you are now reconstructing.

Now [this] . . . was a revelation to me and led me to wonder, in looking at grief in patients, if they have similar tasks. They don't write books, but with members of their families, or the nurse, they have confidential exchanges about the sort of things they did with other people. They like to be visited by a lot of friends, so long as they don't feel too embarrassed about sharing their

emotions, and would like to pick up items of their lives which they shared with the future survivors. And they will rub in these experiences with the family and friends, so they will be sure to remember when they are gone. So this constructing of a collective survival image of oneself which will still be there when one happens not to be there any more in the flesh is the core of grieving, which, if it is done well, is apt to be an admirable process—a fascinating process if one is lucky enough to witness it. 14

Then Lindemann comes to a beautiful and rarely described issue:

Every once in a while one hears about some person who is confronted with a severe illness and is not going to live, who is an inspiration to somebody else. And from our observations, it is these people who do such a good job of recalling their own lives and their own shared experiences, constructing an image which is a tenable image of a human being. . . .

[Sometimes] there is not enough contact between the patient and his family. The family gets into a conflict over whether to stay or not, how much to share in the patient's illness; whether these sometimes trite things which the patient brings up are worth the time of the patient and everybody else. And for the family, a very important problem may come up . . . namely, that one does one's grieving so well that one emancipates oneself from the person who is going to die and then has no relationship anymore. The [family] don't know whether to visit or whether to stay away; if they try to pull themselves out of the bondage they will feel they are disloyal. This problem of a relationship which may be severed too successfully becomes a difficult one for the anticipatory griever. Sometimes patients who have a terminal illness come to terms with this illness, are all settled; and then when people still come, they don't want to see them anymore. One wonders what is the matter with them unless one is aware of the fact that a process has been going on, and one has to tap at what phase this process is now.⁴⁷

Lindemann describes how important to him it was to go and visit places that had had great meaning to him:

I really became hypermanic, in the sense that I raced around and wanted to do all the things that would be wonderful to do once more. In other words, see that people who are confronting death are not in an environment which is restrictive of *doing* possibilities; that they are still as mobile as is compatible with their ailments, and still as rich in possible experiences for a little while. I guess it isn't silly to make up for the things you won't have any more of later, and token fulfillment along that line can make an enormous difference.⁴⁸

Grieving for Survivors

"A person's death is not only an ending: it is also a beginning—for the survivors," writes Shneidman. Studies of widows who have recently lost a husband show a heightened likelihood of death from alcoholism, malnutrition, and other conditions. It seems "grief is itself a dire process, almost akin to a disease, and that there are subtle factors at work that can take a heavy toll unless they are treated and controlled."⁴⁹

The death of someone we love can induce a response very similar to that found in those who have experienced a disaster such as an earthquake or explosion:

Martha Wolfenstein has described a "disaster syndrome": a combination of emotional dullness, unresponsiveness to outer stimulation and inhibition of activity. The individual who has just undergone disaster is apt to suffer from at least a transitory sense of worthlessness; his usual capacity for self love becomes impaired."⁵⁰

Lily Pincus was a distinguished social worker who lived in England and wrote a book called *Death and the Family: The Importance of Mourning*.

All studies agree that *shock* is the first response to death. . . . It may find expression in physical collapse . . . , in violent outbursts . . . , or in dazed withdrawal, denial, and inability to take in the reality of death.

Mourners often complain that they were not prepared for what it would be like: "Why did nobody warn me that I would feel so sick . . . or tired . . . or exhausted?"; "Nobody ever told me that grief felt so like fear"; "I wish I had known about the turmoil of emotions . . ."⁵¹

The acute shock, says Pincus, usually lasts only a few days, followed by a *controlled phase* during which the mourner is supported by relatives and friends.

The real pain and misery makes itself felt when this controlled phase, and the privileges that went with it, is over, and the task of testing reality, coming to terms with the new situation, and the painful withdrawal of libido from the lost person begin. It is then that the mourner feels lost and abandoned and attempts to develop defenses against the agonies of pain. *Searching* for the lost person, an almost automatic universal defense against accepting the reality of loss, may go on for a long time. . . .

15 Most people are not aware of their need to search but express it in restless behavior tension, and loss of interest in all that does not concern the deceased. These symptoms lessen as bit by bit the reality of the loss can be accepted and the bereaved slowly, slowly rebuilds his inner world. . . .

As the bereaved becomes more relaxed, and tension, frustration, and pain decrease, *searching* may lead to *finding* a sense of the lost person's presence. . . .

There are no timetables for what have been called the phases of mourning, nor are there distinct lines of demarcation for the various symptoms of grief which find expression during these phases. For the bereaved, the most alarming and bewildering aspects of grief are those in which he can no longer recognize himself, for example, the often irrational anger and hostility, which may be quite alien to the mourner's usual behavior and may make him feel that he is going insane. . . . They express the ambivalence of the mourner toward all these people but most especially, and painfully, toward the lost person who is causing him so much distress by his abandonment.⁵²

For the shock that may immediately follow death, warmth and rest and a nourishing protective environment can be a real help. For the controlled period that Pincus mentions above, the support of friends and relatives can make a great difference.

The great challenge takes place as we begin to face life without the person we loved, and here the truth seems to be "the fundamental importance of being able to mourn and to 'complete the mourning process'." But, like the fight for life with cancer, there are no firm guidelines for how to complete the mourning process; each must be "allowed to mourn in his own way and his own time."⁵³

The mourning process, like the process of physical healing, involves the healing of a wound, a new formation of healthy tissue. In mourning, however, the cause of the injury, the loss of an important person, must not be forgotten. Only when the lost person has been internalized and becomes part of the bereaved, a part which can be integrated with his own personality and enriches it, is the mourning process complete. With this enriched personality the adjustment to a new life has to be made.⁵⁴

Conclusion

Of all the chapters in this book, this has been the most difficult to write. Writing this chapter immersed me in the awesome and varied literature on death, dying, and mourning. On the one hand I felt grateful for the experience because I learned in greater depth things that I can pass on to others in the Cancer Help Program and through this book.

But the simple fact is that as I write these words, death, in my eyes, has not lost its power. It may well be that the soul survives death. I was skeptical of this years ago, but now believe it to be as likely as not. It is certainly true that we can detoxify death—that we can remove the taboos of thinking and feeling about it, and that great comfort and understanding can come from this process.

But even if I knew for a fact that my soul and the souls of those I love will survive death, I am not sure the pain of death and loss would be gone. I remember the story of an enlightened Eastern teacher who lost his child to death. His students came to see him the next day and found him crying.

"Master," one said, "you teach us that all life is an illusion. How is it that you are crying because of the death of your child?"

"It is true that life is an illusion," the master responded. "But the death of a child is the greatest illusion of all."

I go back to the words I started the chapter with, the words of the Buddha: "Even the wise fear death. Life clings to life." We have read, and can read, of those who overcome this fear. But most of us fear death. There is no shame in this. Death remains a great mystery, the central problem with which religion and philosophy and science have wrestled with since the beginning of human history. Acknowledging this, we can, perhaps, come to face it with greater understanding, more preparation, and greater love.

References

- 1 Eric J. Cassell, *The Healer's Art* (Cambridge, Mass.: MIT Press, 1989), 210.
- 2 Peter A. Singer and Mark Siegler, "Euthanasia—A Critique," *New England Journal of Medicine* 322(26):1881 (1990).
- 3 D.J. Enright, "Introduction." In D.J. Enright, ed., *The Oxford Book of Death*, (Oxford: Oxford Press, 1987), xi.
- 4 Arnold Toynbee, "Life After Death." *Ibid.*, 3.
- 5 Maria Monroe, "Before There Was Death," letter to the editor, *Inquiring Mind* 6(2):2 (1990).
- 6 Montaigne. In Enright, ed., *The Oxford Book of Death*, 2.
- 7 C.G. Jung, "The Soul and Death." In Enright, ed., *The Oxford Book of Death*, 45.
- 8 Desiderius Erasmus, *Colloquies*, trans. Craig R. Thompson. In Enright, ed., *The Oxford Book of Death*, 46.
- 9 Arnold Toynbee, "The Relation Between Life and Death, Living and Dying." In Edwin S. Shneidman, ed., *Death: Current Perspectives* (Mountain View, Calif.: Mayfield Publishing Company, 1984), 10–4.
- 10 Ernest Becker, "The Terror of Death." In Shneidman, ed., *Death*, 15–6.
- 11 *Ibid.*, 18.
- 12 *Ibid.*, 19.
- 13 Geoffrey Gorer, "The Pornography of Death." In Shneidman, ed., *Death*, 26.
- 14 Philippe Aries, *The Hour of Our Death* (New York: Vintage Books, 1982), 589.
- 15 Steven Levine, *Healing into Life and Death* (Garden City, N.Y.: Anchor Press, Doubleday, 1987), 4–15.
- 16 Steven Levine, interview in *Inquiring Mind*, 6(2):1–6 (Spring 1990).
- 17 Dennis R. Leahy, "The People." In Eric Blau, *Common Heros: Facing a Life-Threatening Illness* (Pasadena, Calif.: New Sage Press, 1989).
- 18 Joan Borysenko, *Guilt Is the Teacher, Love Is the Lesson* (New York: Warner books, 1990), 15–7.
- 19 Sir James Jeans, *Physics and Philosophy*. In Larry Dossey, *Beyond Illness: Discovering the Experience of Health* (Boston: New Science Library, 1984), 139.
- 20 Gertrude R. Schmeidler, "Problems Raised by the Concept of the Survival of Personality After Death." In Arthur Berger et al., ed., *Perspectives on Death and Dying: Cross-Cultural and Multi-Disciplinary Views* (Philadelphia: Charles Press Publishers, 1989), 201–2.
- 21 *Ibid.*, 205–6.
- 22 *Ibid.*, 206.
- 23 *Ibid.*, 206–7.
- 24 *Ibid.*, 207.
- 25 Kenneth Ring, *Heading Toward Omega: In Search of the Meaning of the Near-Death Experience* (New York: Morrow, 1985), 35.
- 26 Karlis Osis and Erlendur Haraldsson, *At the Hour of Death* (New York: Hastings House, Publishers, 1986), 186. © 1977 by Karlis Osis and Erlender Haraldsson. Reprinted with permission of the publisher, Hastings House.
- 27 *Ibid.*, 188–9.
- 28 *Ibid.* 189–90

Making Your Choices

We come to the end of this book. This last chapter is an in- points we have discussed throughout the book organized ar of how you approach making your choices. Following th appendix, Choice in Resources, that discusses numerous sp both conventional and complementary therapies. You may w appendix after reading this chapter.

Remember, your choices do not have to be made all at once overwhelming as well as unwise. So do not think too far ah as you need to. Many months may pass before the next ch made.

Obviously I cannot describe all the permutations you may fac the way, but I would like to map out for you the critical mo in the chronological order in which most patients face them

At each point in facing cancer, you are given an opportunity knowledge, skills, and control. However, if you like, you ca choice not to learn too much. Some people feel they would li of the choices to their physicians.

- 29 Ibid., 191-3.
- 30 Ring, *Heading Toward Omega*, 36-7.
- 31 Ibid., 41-2.
- 32 Sylvia Lack, quoted in Deborah Duda, *A Guide to Dying at Home* (Santa Fe, N.M.: John Muir Publications, 1982), 150. Reprinted with permission from the publisher John Muir Publications. © Deborah Duda.
- 33 Deborah Duda, *A Guide to Dying at Home* (Santa Fe, N.M.: John Muir Publications, 1982).
- 34 Duda, *A Guide to Dying at Home*, 102-10.
- 35 Gary A. Johanson, M.D., *Physician's Handbook of Symptom Relief in Terminal Care* (Sonoma County, Calif.: Home Hospice of Sonoma County, 1988).
- 36 Ibid., iii-iv.
- 37 Duda, *A Guide to Dying at Home*, 128-9.
- 38 Johanson, *Physician's Handbook* appendix 1.
- 39 Elisabeth Kübler-Ross *On Death and Dying*, (New York: Collier, 1970), 38-9. Reprinted with permission of Macmillan Publishing Co. Copyright © 1969 by Elisabeth Kübler-Ross.
- 40 Ibid., 50-1.
- 41 Ibid., 2.
- 42 Ibid., 85-6.
- 43 Ibid., 87.
- 44 Ibid., 112-3.
- 45 Ibid., 13-39.
- 46 Edwin S. Shneidman, "Some Aspects of Therapy with Dying Persons." In Shneidman, ed., *Death: Current Perspectives*, 275-6.
- 47 Erich Lindemann, "Reactions to One's Own Fatal Illness." In *ibid.*, 262-3.
- 48 Ibid., 265.
- 49 Edwin S. Shneidman, "Postvention and the Survivor-Victim." Ibid., 412-3.
- 50 Ibid., 414.
- 51 Lily Pincus, "The Process of Mourning and Grief." In Shneidman, *Death: Current Perspectives*, 402-3. Copyright © 1974 by Lily Pincas. Reprinted by permission of Pantheon Books, a division of Random House, Inc.
- 52 Ibid., 405.
- 53 Ibid., 408.
- 54 Ibid., 409.

person surrenders himself to the divine will. For awareness of death, when the soul is already separated from the body, is, I think, either non-existent or else an extremely low-grade awareness, because before Nature reaches this point it dulls and stuns all areas of sensation.⁸

Contemporary Views of Death ✓

Some of the most interesting contemporary sociological views of death are collected in a book edited by Edwin S. Shneidman, *Death: Current Perspectives*. The first contribution is from Arnold Toynbee, who wrote a beautiful essay on death in which he emphasized that:

This two sidedness of death is a fundamental feature of death. . . . There are always two parties to a death; the person who dies and the survivors who are bereaved. . . . When, therefore, I ask myself whether I am reconciled to death, I have to distinguish, in each variant of the situation, between being reconciled to death on my own account and being reconciled to it on the account of the other party. . . . My answer to Saint Paul's question "O death, where is thy sting?" is Saint Paul's own answer: "The sting of death is sin." The sin that I mean is the sin of selfishly failing to wish to survive the death of someone with whose life my own life is bound up. This is selfish because the sting of death is less sharp for the person who dies than it is for the bereaved survivor.⁹

Ernest Becker won the Pulitzer Prize for *The Denial of Death*, which argued that our whole lives are organized around fear and denial of death. Heroism, Becker argued, is a "reflex of the terror of death":

We admire most the courage to face death. . . . The hero has been the center of human honor and acclaim since probably the beginning of specifically human evolution. . . . The hero was the man who could go into the spirit world, the land of the dead, and return alive. . . . When philosophy took over from religion it also took over religion's central problem, and death became the real "muse of philosophy" from its beginnings in Greece right through Heidegger and modern existentialism.¹⁰

Summarizing the work and thought on death from religion, philosophy, and science, Becker distinguishes between the "healthy-minded" argument that fear of death is not natural to man, and derives from repressed or unfulfilled living,

and the "morbidly minded" argument that the fear of death is natural, what William James called "the worm at the core" of man's pretension to happiness.⁴

Jacques Choron goes so far as to say that it is questionable whether it will ever be possible to decide whether the fear of death is or is not the basic anxiety. In matters like this, then, the most that one can do is to take sides, give an opinion based on the authorities that seem to him most compelling, and to present some of the compelling arguments. I frankly side with the second school—in fact, this whole book is a network of arguments based on the universality of the fear of death, or "terror" as I prefer to call it, in order to convey how all consuming it is when we look it full in the face.¹¹

Becker argues that the fear of death is biologically essential to the preservation of the species, and at the same time that continuous consciousness of this fear of death would be deeply counterproductive. He quotes the psychoanalyst Gregory Zilboorg: "If this fear were constantly conscious, we should be unable to function normally. It must be properly repressed to keep us living with any modicum of comfort."

And so, Becker says, "We can understand what seems like an impossible paradox: the ever-present fear of death in the normal biological functioning of our instinct for self-preservation, as well as our utter obliviousness to this fear in our conscious life."¹²

Another key point from this remarkable collection of contemporary views is Geoffrey Gorer's concept of *the pornography of death*. Gorer brilliantly argues that, while sex was pornographic to the Victorians, death has been the pornography of our time.¹³

Contemporary Psychospiritual Perspectives on Death and Dying

It is difficult in 1993 to realize what a transformation the last 30 years have brought in American attitudes toward death and dying. And indeed this transformation speaks volumes for the broader transformation of American consciousness over this period of time. As Phillipe Aries wrote in his classic book, *The Hour of Our Death*:

Before 1959 when Herman Feifel wanted to interview the dying about themselves, no doubt for the first time, hospital authorities were indignant. They

found the project "cruel, sadistic, traumatic." In 1965 when Elisabeth Kübler-Ross was looking for dying persons to interview, the heads of the hospitals and clinics to whom she addressed herself protested, "Dying? But there are no dying here!" There could be no dying in a well-organized and respectable institution. They were mortally offended.¹⁴

Part of the best evidence for the transformation of the American mind through the 1960s, 1970s, and 1980s has been the opening of a substantial part of the population to an intense interest in learning from and caring for the dying. One of the foremost exponents of this work is Stephen Levine, author of a number of fine books on dying. Here is an excerpt from *Healing into Life and Death*:

Our intention is not to keep people alive or to help them die either. Our work seems to be an encouragement to focus on the moment. To heal in the present and allow the future to arise naturally out of that opening. . . . We witnessed deep healings into the spirit of some who lived as well as miraculous healings in some who died . . . clearly healing was not limited to the body. The question "Where might we find our healing?" expanded. It was [about] the healing of a lifetime. The healing we took birth for . . . The deepest healing cannot be done solely in the separate. It needs to be for the whole, for the pain we all share. . . . Seeing it is not simply *my* pain, but *the* pain, the circle of healing expands to allow the universe to enter.¹⁵

Levine expanded on this theme in an interview in *Inquiring Mind*:

IM: What do you mean by surrender?

SL: What we [Levine and his wife Ondrea] mean by surrender is softening and letting go of resistance, trusting the process. Many people misunderstand surrender as defeat. Surrender is actually the optimum strategy for living, including dying . . . Surrender is really about letting go of the last moment and opening to the next. Of course everyone's process isn't the same. Some people work wonderfully with mindfulness mixed with loving kindness. Other people have so much regret about the way they've led their lives that we encourage them to work with forgiveness, forgiveness of themselves, forgiveness of those they reacted towards . . .

We have seen people in severe physical discomfort who when they started to surrender their resistance—to enter into contact with sense-

tion—experienced that multiple changing quality of the pain that they thought was so solid. Then they could begin to direct their analgesics into the areas where they were needed . . . 5

IM: How much difference does it make for someone who is dying to have done a lot of spiritual practice?

SL: When a person has a sense of something greater than themselves, whatever it might be, it is very helpful when they are dying. Also, someone who has done spiritual practice probably has a little more concentration to bring to the meditations for pain, for heavy states, or for forgiveness . . . People who have cultivated a willingness to go beyond safe territory—which means even beyond their practice—have an easier time with death.¹⁶

We can see in the work of the Levines the idea that the process of learning to live well is also the process of learning to die well and that cultivating a relationship with our innermost being serves us well at the time of death. Dennis Leahy, M.D. expands upon the idea of surrender as a way of healing into death: "[We have all] spent much of [our] lives in the conscious and unconscious cultivation of uniqueness. This process does not end as we begin to die. We see herein that in the process of letting go, our individualization may become more, rather than less complete. In this sense there is great hope."¹⁷

The Questions Raised By Near-Death Experiences and Reports of Communications with the Dead

Many people who come on the Cancer Help Program have had near-death experiences that have changed their lives—experiences in which they almost died, or did die medically, and were then revived. Others have had experiences in which people they loved who died returned, after death, with messages that were deeply reassuring.

One of the most moving of these experiences for me happened with Kim and Sarah, the couple whose fight for life I described in chapter 1. I visited Sarah in the hospital shortly before she died. At one point I said to her: "It is

absolutely not all right with me that this is happening to you, Sarah. But if you do die, I'd like to ask you a favor. It would make my life a lot easier if I heard from some friends who died that they were OK on the other side. So if you go, please try to come back and let me know you're OK." She promised she would.

Many months later I was getting a massage during a break in the late afternoon on the first day of a Cancer Help Program. I remarked to Jnani Chapman, the Cancer Help Program masseuse who was working on me, that I did not understand what was happening but that God seemed to be very present—that my body seemed to be filled with a strong charge of deep joyful and peaceful energy. It was a very unusual experience for me—I am not given to frequent experiences like this. Later that night, I got a message that Kim had called. I thought it might be to tell me of Sarah's death. It occurred to me immediately that if Sarah had died, perhaps that was connected to the extraordinary feeling I had had of the presence of God. Perhaps that was Sarah trying to keep her promise to me. I called Kim, reached him, and during the conversation I told him of my experience. He said Sarah had not yet been in touch with him, but that he very much hoped she would.

The next morning I received a faxed letter from Kim as follows:

Dear Michael:

Sarah died at 2:15 P.M. on February 19. The night after her death I had the most extraordinary and vivid dream. I was in a hospital being restrained by three doctors. They were pleading with me not to go into Sarah's room. They said her body had decomposed and that if I saw her in that condition it would leave me with a very unpleasant final vision. I became angry and pushed them aside and told them I had to see her. I ran to her room and opened the door. Sarah was reclining unclothed on her side, in the way of the odalisque in the painting by Ingres. Her body was radiant, full and perfect. Her hair shined like golden threads and her lips and cheeks were pink and glowing. I stared at her in amazement. The doctors were wrong: she had become perfect. I went to her bedside and sat down. Her eyes were closed and her limbs hung limp. I embraced her and as I did her chest heaved, her eyes and mouth opened, her lungs filled with air and she came alive. My heart soared and my eyes filled with tears of joy. Sarah looked up at me and said "Kim, I am not alive." I paused and then asked her, "Is it good or bad where you are?" She looked at me and rolled her eyes in the way she would when I said something really

6
dumb. She said, "Good and bad do not apply here." I said, "Well, is it OK? Are you OK?" Sarah's lips tightened and her eyes squinted as if to say, let me think about that one. Then slowly she nodded her head and said, "Yes, it's OK, but I need some time to get used to it." I held her shoulders and looked into her face and asked, "Sarah, when I die, will I be able to be with you?" She very simply said yes. Then her eyes closed and her body went limp again. I panicked and ran into the corridor and began a desperate search for the doctors. The halls were deserted. I decided to go back to Sarah's room, but could not find my way. I began opening the doors in the corridor, but all the rooms were empty. I then awoke sitting straight up in bed.

Waves of sorrow, sadness, incompleteness and emptiness flow over me on a regular basis. But when I think of this dream it gives me a deep sense of comfort.

I wanted to share it with you.

Peace and Love,

Kim

It could well be that Kim's dream was the vivid fulfillment of the wish of a grieving husband to know that his wife was well on the other side, particularly after I had suggested that perhaps my experience had been Sarah's attempt to keep her promise to communicate with me. But anyone with an open and inquiring mind who works for sustained periods of time around people facing death cannot help confronting the significance of near-death experiences, based on both reports from patients and on the clinical and empirical literature.

Joan Borysenko provides a beautiful personal experience in her book *Guilt Is the Teacher, Love Is the Lesson*:

Many years ago . . . I sat with a young woman who was dying. Her name was Sally, and she had been living with a rapidly growing and rare rectal cancer for the year or so that we knew each other. We worked on meditation and imagery techniques that helped relieve treatment side effects and brought Sally some peace. We talked of emotions, finishing old business, forgiveness, and grieving. We also talked of Sally's concept of death . . . that consciousness died with the brain rather than surviving in any way beyond the body.

When the day of Sally's death came, I was visiting her in the hospital. I was scared because I'd never been with a dying person before and didn't have any

notion what to expect. Her parents had gone off to have lunch when I came, so I had about 45 minutes to sit alone with Sally. To my great relief, she seemed comfortable as she drifted in and out of consciousness. We just sat together in the silence. Then after a while I screwed up my courage and asked "Where do you drift off to, Sally? Your face looks so peaceful." She opened her eyes and turned to look at me. Her eyes were full of love and wonder.

In a tiny, soft, and very amused voice, she said, "Well, you may have trouble believing this, but I've been floating around, touring the hospital. I've just been to the cafeteria, watching my parents eat lunch. Dad is having grilled cheese. Mom is eating tuna. They are so sad they can barely eat. I will have to tell them that my body may be dying but I'm certainly not. It's more like I'm being born—my consciousness is so free and peaceful." Sally faded out for a while and when she came back she told me: "It's so *beautiful*, Joan. I'm drifting up out of my body toward a kind of living light. It's very bright. So *warm*, so loving." She squeezed my hand a little, "Don't be afraid to die," she said looking at me with so much kindness. "Your soul doesn't die at all. You know? It just goes home. It just goes on from here" [emphasis added].¹⁸

I have wrestled for years with the question of whether I personally trust these beautiful accounts of the soul surviving death. For me the scientific literature on near-death experiences has deepened the question considerably, and tilted me toward a belief that there is a good chance that these accounts reflect a transcendental mystery.

The Scientific Literature on Near-Death Experiences

I find it intriguing that, at present, the scientific support for the survival-of-death hypothesis is much stronger than the scientific evidence supportive of any decisive "cure" for cancer among the unconventional cancer therapies. In other words, the evidence that we may survive death, while not conclusive, is certainly far better developed, and empirically more persuasive, than the evidence that any unconventional cancer therapy *reliably* leads most people to recover from cancer.

In addition, you cannot read the literature on near-death experiences and communications with the dead without slipping into realms of parapsychology that are difficult to evaluate and strain ordinary norms of credibility. That is, the *science* as reported is often reasonably good; but the *implications* of the

scientific reports, if we credit them, lead toward a whole transpersonal reality that many of us (myself included) are not sure whether we can actually credit. 7

For many, the question of the survival of the personality after death is a key question. One perspective, often voiced by writers in the physical sciences, and one which echos many of the great spiritual traditions, is elaborated by Sir James Jeans in *Physics and Philosophy*:

When we view ourselves in space and time, our consciousnesses are obviously the separate individuals of a particle-picture, but when we pass beyond space and time, they may perhaps form ingredients of a single continuous stream of life. As with light and electricity, so may it be with life; the phenomena may be individuals carrying on separate existences in space and time, while in the deeper reality beyond space and time we may all be members of one body.¹⁹

Gertrude Schmeidler, an emeritus professor of psychology at the City University of New York, has contributed a sober evaluation of "Problems Raised by the Concept of the Survival of Personality After Death" to a multidisciplinary discussion of the subject.

Historians and anthropologists, she points out, tell us that the majority opinion of mankind has overwhelmingly held that the personality survives death, but an important minority has thought otherwise. Yet there is great diversity of view cross-culturally regarding what form this future existence takes. Still, Schmeidler finds "one common thread running through all the discrepant ideas of future existence: the idea that the surviving spirit is recognizable."²⁰ Says Schmeidler:

The only self-consistent and complete set of answers, so far as I know, consists of attributing all that occurs to the will of God and then stating that the will of God is unknowable and out of reach of science. This means that from the scientific point of view, the commonly held belief that a recognizable personality survives death has no coherent theory to support it. But this does not necessarily mean that the belief is false.²¹

Schmeidler then turns to some of the types of data that address different specific questions regarding the personality surviving death:

One large set [of data] answers the question of whether the self can, without the intervention of its own body, interact directly with other bodies. This is a

PERSONAL HISTORY

DYING: AN UPDATE

The author's odyssey through a year of confronting AIDS.

BY HAROLD BRODKEY

THE ambulance people came, and I whispered to them that I could not walk or sit up. Or breathe. They went down for a gurney and for oxygen. Breathing through a tube in my nose and motionless and sheeted on a gurney, I was wheeled through our apartment and into the elevator and across the lobby, past the doorman, onto the sidewalk, into the air briefly, and then into the ambulance. This is how my life ended. And my dying began.

Ellen says I was heroic and completely in charge, and that I surprised her by agreeing *agreeably* to being treated for *Pneumocystis* rather than asking for sedation and being allowed to die. She says she thought then that we would die together, both of us—commit suicide simultaneously—in a few months, when everything was in order. But she didn't want me to leave her now, not this abruptly. Most of us who know Ellen know her as a fine-boned tyrant who looks a bit like a small Garbo. Her hair is gray, and she has never had a face-lift. She is of interest physically still—neatly formed and stylized, like the stopper of an expensive perfume bottle. She is incredibly willful, and she is my human credential. People think she is good-looking and trustworthy and sensible, whatever they think of me. It seems clear from how Barry—my doctor, Barry Hartman—and the harried nurses acted that they saw her that way. They all trusted her judgment and her will, not mine. I remember wanting not to be an exploitative fool in her eyes by asking her to nurse me through a terminal disease, and one with a sexual stigma. I wondered if she would despise me. I knew a woman once who'd had a good marriage, unmistakably so, within limits, and whose husband, a clever banker, fell ill and impressed everyone with how hard he fought to be himself

again, to get well again. That woman once said in my hearing, "I wish he would give up." His struggle went on so long, and so dominated everything, that it was killing her. And he was hardly alive except as a will to struggle.

At home, over the weekend, I had got so sick that I could not find a balance point in the gusts of horrendous sensation. It was strange how the sickness kept getting worse by the hour, with a kind of muffled rapidity. I'd never been ill that way. Again and again, it thudded to a level of horrendousness, consolidated that, and then thuddingly sank to a worse level still. Nothing was stopping the progress of strangulation. I had kept putting on a front for Ellen until, in a kind of extreme inward silence, nothing was working.

But when Barry said I had AIDS, I said I didn't believe him. He said, "Believe me." Then Ellen said something, asked him something about what was going to happen, and he said that after the *Pneumocystis* cleared up I had the possibility of a few years of life.

I said, "But it will be embarrassing." The stigma. Incontinence. (Would I have to wear a diaper?) Blindness. He said the good years were quite good, were livable.

I don't want to be defensively middle-class about this, but it was a middle-class decision I made, nothing glorious, to try to go ahead and have AIDS, live with AIDS for a while, and not die with the *Pneumocystis* then.

ELLEN says that when we were first told, on a Monday, she sat in the one chair in the hospital room. To prove that she is actually remembering in the Brodkey mode, according to Brodkey theories and method, she says that Barry leaned against the windowsill

with his arms folded while he told us I had AIDS. And that the weather was warm. And that I was strangely jovial and reasonable. I remember Barry propping himself with one arm on the sill and then refolding his arms and saying, "You *have* AIDS," and holding his pose and staring at me.

In the confused, muddled velocities of my mind was an editorial sense that this was wrong, that this was an ill-judged element in the story of my life. I felt too conceited to have this death. I was illogical, fevered, but my mind still moved as if it were a rational mind—the mind, everyone's mind, is forever unstill, is a continuous restlessness like light, even in sleep, when the light is inside and not outside the skull. I took inside me the first stirrings of acknowledgment of AIDS, not with the arching consciousness with which I try to write fiction—I didn't feel that isolation—but with a different sense of aloneness. And maybe I felt the wretchedness in Ellen. Maybe I was sensitive to what I had, so to speak, done to her now.

And then I saw it differently: after all, death—and AIDS—are a commonplace. "Big deal," I said. That didn't lighten anyone's face. "Jesus Christ," I said. "What a mess." Barry said something about tranquilizers and counseling to help with the shock and despair, the natural grief. "I'm O.K.," I said and went on grandly, "Look, it's only death. It's not like losing your hair or all your money. I don't have to live with this."

I wanted to make them laugh. I wanted them to admire me, it's true, but I also wanted Ellen to stop that inward shaking, and I was afraid to say "Christ, what have I done?" or "Look what's happened to me" or "It's all my fault." I have an odd cowardice toward grief. I would just as soon suffer without it. The two of them were watching me, ready to sympathize and comfort. Ellen

turned to Barry, who was disapproving. Or worried. "We can help when the despair hits; we have drugs," he told her.

But, you see, a traumatized child as I was once, long ago, and one who recovers, as I did, has a wall between him and pain and despair, between himself and grief, between himself and be-shitting himself. That's the measure for me—handling the whole weight of my life in relation to polite bowels. The rest is madness, rage, humiliation.

TO be honest, the effort of writing, and then my age, and the oppressive suffocation of the illness itself, and my sad conviction of the *important* validity of my ideas (of what my work presents), and my hapless defense of that work had so tired me that I was relieved by the thought of death. But I also wanted to make a defiant gesture at AIDS. So it became a matter of contrary style. The disease and its coercions (like all coercions) were contemptible. I figured that later on I would make meek friends with it while it killed me, but not just yet.

And I felt that if I had AIDS Ellen had the right, perhaps the duty, to leave me; my having that disease suspended all contracts and emotions—it was beyond sacrament and marriage. It represented a new state, in which, in a sense, we did not exist. What we were had been dissolved as if by radiation or the action of an acid. Perhaps the *sacrament* remained, but it was between her and her beliefs now: care wasn't, in my view, owed to me anymore. I wasn't me, for one thing. And she had suffered enough.

I am peculiarly suited to catastrophe, because of my notions and beliefs; I am accustomed to reconstituting myself in the middle of catastrophe. And my ideas, my language, support me in the face of disastrous horror over and over. I am like a cockroach, perhaps—with AIDS, with vanity, with a cowardice much greater than that of Kafka's Samisa. Ellen is not like that. She has an identity, of the real, familial sort. A good many people, including me, care about her. Her children are never alone in the world, and that sometimes irks them. She is gullible toward bad news in a rebelliously saintly way that tends to irritate me. Her rebelliousness extends

throughout her existence—it is toward God and death, toward society, toward men. How she reconciles that with the propriety she manifests day in and day out is beyond me. I tell her that we are cowards and artists and are in flight and are and have to be awful people to get our work done. She ignores me when I talk about art or life that way. She does and does not believe what I say or what I believe. "I cannot live like that" is what she says. I mean, I can see, often, the degree of *enlistment* in her being with me.

I have a number of kinds of humility, but I am arrogant. I am semi-famous, and I see what I see. I examine everything that is put in front of me—like a jeweller. I am a Jew from the Middle West, not at all like a New York Jew. I am so arrogant that I believe a formulation only if it has the smell or lift of inspiration. I have never, since childhood, really expected to be comforted.

IN the twentieth century, the arts have not pictured the reality of actual sex and actual love as they are in life, on actual days, over actual time—they are seen as, oh, socialist bliss, or as paradise before the nightmare strikes, or as non-existent (Joyce and Beckett, the sexual yet sexless Irishmen), or as obsession and victimization (Freud and Proust), or as some idyll of heat and whatnot. Hemingway was dominated by sexual terror, but how popular he was. For me, the greatest portrayer of high-art sexlessness was Balanchine, because he captured and beautified so physically the rage and longing and the attempts to escape loneliness. And then there is the sexlessness of Eliot—one should remember that Lawrence was driven out of England while dry Eliot came to be idolized. And perhaps rightly. Love and sex, after all, are unwise: Look at me. The foolish nature of sexual love is there in front of you, always. Civic duty, ambition, even personal freedom are opposed to it. We tend to think that popular art is sexual, and perhaps in a way it is—it does indicate that the act takes place, and you can see in it why the inclusion of sexuality and emotion in your life can lead to a horrific response. But it is not as sexual as Jon Vickers' singing, for instance. He

caused embarrassment in American audiences as Sinatra never did. He caused embarrassment in the way Billie Holiday did, in night clubs, from the sheer authenticity of the sexual-emotional event.

What happens in a competitive city, among people who are clever imitators, students, really (more or less sedulous apes), is that the paucity of such authenticity leads to the constant manufacture of what you might call a sore-nerved and sensitive counterfeit sex. Counterfeit sex is a large part of what New York is. People here rebel by means of a jealous promiscuity—a jealously restless sense of the happiness of others.

I WILL say peevishly that I was never accepted as gay by anyone, including someone who lived with me and claimed to be a lover. I did think that, for me, no decent relations were possible with women back then: the women were rotten with their self-expectation, their notions of femininity, their guilt. And I saw no male role I could play that was acceptable to me. Toward the end of my experience of homosexuality, before I met Ellen, I underwent the most outrageous banishment to a role of sheer, domineering, hated and worshipped masculinity. It was then that I was infected by one person I was interested in. He later left his lover and came to New York to die in my care and Ellen's.

AIDS had never been one of our fears; it was not one of my secret dreads. I am so shaken by what has occurred that I have lost much of the discipline about memory that I had before I was told I had AIDS. Ellen and I were in Berlin in November and December of 1992, and then we went on to Venice, and some people—everyone, really—said I was too thin. Neither Ellen nor I responded when a blackish spot appeared on my right cheek. We thought it was my macrobiotic diet or the effort of not being overcome by literary politics and leftover sexual jealousies, even while my sexual nature died away, a kind of public modesty. I had written a novel in one year, a novel I liked, that I was proud of, and I had expected such a labor to kill me. During that year, I was slow-moving, easily tired, and subject to small bouts of

giddiness. I was underexercised, too thin, and wobbly at times. And I was strained past my level of strength by the difference in reputation and treatment I received in various countries—great artist here, fool there, major writer, minor fake, villain, virtuoso, jerk, hero.

I THINK it was that the future had vanished for me, had become a soft, deadened wall. In the beginning, when Barry told me flat-out that I had AIDS, I didn't yet feel it, although I also saw that denial was futile. Barry was not even remotely real to me at that point. He was merely a conductor, a sort of lightning rod of medical error. I still didn't believe he was a good doctor—that came a short time later. The framework of the self wasn't changed by the words, the general feeling of its being my body and its having been my body all my life didn't dissolve, as it would in a few days. I had no sense of gestating my death.

Ellen says that she hung back and expected me to be violent, psychically, and to want death immediately once I accepted the diagnosis. Well, that was true. But I was also afraid of death, of my own final silence. And I was ashamed toward her, and angry at her. She does not steadily believe that I love her—it is one of her least endearing traits to expect proof at unreasonable intervals. And what is love? My measure of it is that I should have died to spare her. Her measure is for us to be together longer.

For the next two weeks, the world and all other issues were omitted. We were two people alone in a hospital room. We allowed no visitors, and the internes weren't interested in my case. (Barry explained that AIDS is medically boring now, and I did not have a recidive opportunistic infection, but the most common one.) Ellen and I had two weeks of near-silence with each other and my increasing helplessness. I tended to tangle the I.V. and misplace the oxygen tube.

As I started to say earlier, one of the first things that becomes distorted and then fades when you learn you're fatally ill is a sensible interest in the future. The moments become extraordinarily dimensionless—not without value but flat and a great deal emptier. Time be-

comes very confusing, perhaps uninteresting, pedestrian. But my not caring if I lived or died hurt Ellen. And I was grateful that I could indulge my cowardice toward death in terms of living for her.

She got back to the hospital after four horrible hours of night at home in

our apartment alone, racked by waking nightmare. She arrived soon after it got light and had a bed for herself moved into my hospital room.

She said, in an averted way, "I want more time with you."

And I said, from within my flattened world, "You're nuts. It isn't that much fun to live. Now. And you know it." I sighed. "But if that's what you want . . ."

"I do," she said.

OPTIMISM. Hopefulness. Our American fondness for advertising and our dependence on it culturally to represent not what works or is worth preserving but what is worth our working *for*—this, in lieu of tradition, is nervously life-giving, a form of freedom. It is also a madness of sorts, a dream-taunted avidity for the future to replace a sense of history.

But it is the basis of America—the forward-looking thing. We-will-create-a-nation, and we will have gardens and swimming pools and corrective surgery. Franklin Roosevelt's speeches—if you compare them with Churchill's, you can see what I'm talking about. You can see it in the rhythms and in the imagery and in the statements. Roosevelt proposed the four freedoms, and Churchill offered blood, toil, sweat, and tears. (Or compare Twain with Wodehouse. Or Groucho Marx with Waugh.) The American sense of tragedy is so diluted by daydream as to seem almost ridiculous. We Americans create symbols helter-skelter, as a form of advertising, an active unreality. Churchill had a quite distinct entity to govern, a well-defined nation to lead, one con-

stituted by its history. America is defined by what it does next: Roosevelt, like Lincoln and Kennedy and others, had to define the United States for us over and over; otherwise it would not have been clear what this nation was that we were actively supporting.

Compare Churchill's cigar with

Roosevelt's cigarette holder. Churchill's drinking was overt, but Roosevelt's wheelchair was almost never photographed. The Declaration of Independence and the Constitution and the Bill of Rights are strangely like ad texts, guarantees of the sort that you find in ads. And advertising is to nihilism and the threats of Heaven and Hell as mat-

ter is to antimatter. The foundations of middle-classness in America have nothing to do with social class in the European sense and everything to do with a Utopian attempt.

The American equivalent (which is hardly equivalent) of the landed gentry is a socially wobbly market of consumers who are rich and arrogant as all getout, easily intimidated yet not easily restrained. Here, because the culture is so unsteady (and so new), it is the how-to element that dominates—how to be *happy* or reasonably comfortable and in comfortable circumstances, how to deal with superior sorts of people who have status, who, say, enjoy opera. How to do this next, in the near, improved future. An American daydream, as in Twain (and Hemingway), is about rebuilding after the flood, about being better off than before, about outwitting this or that challenger, up to and including death.

Well, how do you manage to be optimistic *for the moment*? Without hope?

I INHERIT from my blood father and my blood mother and her father considerable physical strength. One time, when I was seven, I nearly died, because of an allergic reaction to an anesthetic, the ether derivatives then in use. (My mother, who died when I was two, returned in a hallucination, and I found it unbearable.) I went into convulsions and, according to the machines and measurements, I died: my heart stopped, my breathing stopped. Some young doctors and nurses and one old nurse saved me. I can remember their bustling labor, even the nervous smell coming off them. I had been more or less legitimately dead, but I managed to get up and walk partway across the hospital room that evening. My adoptive father called me Rasputin for a while: "Nothing can kill you."

-4-

Sick or well, all my life I've had enough strength for whatever I set out to do. But this time, no. That degree of strength was over. I knew how my parents had felt when their strength failed. It is extremely irritating. Certain melodramatic speeches do come to mind: "Kill me and get it over with." They both said that. I said it once or twice

myself but with more irony. I would save my strength and then leap—biliously, worm-in-the-muddishly—into speech: "This goddam hospital bed is so uncomfortable you might as well *kill me and get it over with.*"

I was aware mentally of the threat of death as a rather awful certainty of sensory fact, of physical fact, but only in words. I mean the mind looked on, weakly, and saw the state as a folksy joke, like a newspaper headline: "THREAT OF DEATH FOR HAROLD," or "HAROLD IS GOING TO GET IT THIS TIME," or "H. R. BRODKEY FINDS WHAT IT'S LIKE TO SUCK MUD." With a subheadline: "This Is Rotten, Says Ex-Amateur Athlete." Then the subheads: "The Statistics Look *Bad*," and "Killer-Diller Pneumonia Strikes 'New Yorker' Writer."

My parents were ill for most of my childhood, and I was aware of the implacable dissimilarity between people and events in the active world and people and events in the grip of medical reality, the medicines scouring and wrecking, or surgical intervention doing that, or radiation. I was prepared for the loneliness and irritability or even madness of being a patient. I had experienced it already in my life, that time when I was seven years old, and again when I was thirty-one and had hepatitis and felt terrible, and the hepatitis was wrongly diagnosed as advanced liver cancer, and I was told I had only a few months to live.

But I experienced no outburst of emotion, no rage or grief of the sort Joe Brodkey, my adoptive father, had. I realized that I was suffocating, as my blood father, Max Weintrib, had—he suffered from something that was described to me as senile asthma: the asthma starved his heart, and his heart gave out. But he raged and cursed, as did my adoptive mother, Doris, who had cancer and told all those around her that *they were getting on her nerves.*

But, except for the suffocation, none of those things was happening to me. I felt very little of anything, I mean as comment. It was a relief to have the illness unmasked, to have Death be openly present. It was a relief to get away from the tease and rank of imputed greatness and from the denial and attacks and from my own sense of

things, of worldly reality and of literary reality—all of it. In the last few years, mental and physical revulsion toward—oh, Lish, Mehta, and Lehmann-Haupt, Hilton Kramer, Barbara Epstein and Bob Silvers—had grown to the point where hiding and containing it had been a bit like having tumors that cleared up whenever I was upstate in the wilds or in Europe. The inadequacies of the work they did and in the awful work they fostered, the alternate revulsion and pity they aroused, I had had enough of. It was truly a perceptible relief to be out of their reach and into another sort of experience, even if it was terminal. It was a relief to have the future not be my speculative responsibility anymore and to escape from games of superiority and inferiority.

AN American idiom is "this fucking intimacy." And the phrase can imply a kind of impatience with it as well as the sexual nature of it: it depends on your voice and on whether you smile when you say it. In Ellen, who echoed with a kind of merciful tenderness my moods and so reconstituted me, the Jewish sense of ancestry and a rebel's sense of enlightenment and escape are both at play. She was hostess in the narrow hospital room to my mothers, my mothers' ghosts or spirits, and the line of fathers, the four millennia of unkillable Jewish males in their conceited stiff-neckedness, then all the dead and dying literary figures, then all the characters who die in the books I most admire—Prince Andrei and Hadji Murad and Proust's narrator's grandmother—and then all the widowed women back to Andromache or Hecuba. And she made room for the nurses and the nurse's aides, for the internes and the residents, and for Barry. I have never seen such intent or such subtle seduction: I cannot even begin to describe the silent promises, the hidden blessings she promised them, she promised them all, the ghosts, too. And the

death standing over me and stirring up the muck that refused to be the bottom in the onslaught of the revolting pneumonia.

I lived through her will from time to time during those days: I had her agility and subtlety vicariously. It was like that as long as she was awake, anyway, and as long as her strength held out. I felt a bit cheated, while she was awake, of the mortal solitude that comes at the end, but I had that merciful depth of her female self at my disposal.

Our regular lives, our usual life together, had been reproduced in a truncated form in a hospital room: flowers, fruit, a newspaper, quibbling with each other, a certain seclusion, a habit of judging—the usual

things, even at death's door, in death's presence.

But it was a hospital room, and I was dying, and I didn't have many private emotions. The husband in this marital scene was drugged to the teeth with prednisone, a steroid that walls off physical pain and depression by creating a strange pre-craziness of its own. I felt a rather awful clarity of humor, a nauseated comic sense; I was in an odd state. And the wife in the scene was overly gentle, sickroom gentle, terrified, and obstinately hopeful—not her usual self. She was afraid of gloom in this well-intentioned parody-caricature of our former life. The moments of grief I had were immediately contagious—well, the room was very small.

We would hold hands and I would say "Oh shit" or "This is shitty," and we would cry a bit. It seemed like a sufficient amount of poetry. I would say "Well, who cares?" or "I don't like this mushy stuff. Let's stop."

Equally invasive were the tender moments, Ellen bathing me and turning me, ninety-seven-pound Ellen, or changing the bed. Or her helping me into the bathroom. I had to be propped on her and on the wheeled pole of the I.V. I was determined to spare her my excrement. My head lolled. My legs gave way, but only once. I had no strength, but it is true that will power can do a great deal. It can't halt or cure AIDS, but it can take the place of physical strength and it can mock death and weakness: it can mock those things sometimes. Our bedtime talk or our toilet talk had to

avoid sentiment; I had no strength for sentiment. I showed off for Ellen. I talked about business and money, about the information I'd negotiated from the doctor.

But she was the one with hope. She was the one with the sense of drama. She was the one who, with some, ah, degree of untruth, exclaimed on being told that she was H.I.V.-negative, "Oh, I don't want to be clear. I want to have it, too."

An emotional remark. A bit of a marital lie, of marital manipulation. But true enough in that if I decided to kill myself she was still determined, so she said, to kill herself, too.

She wanted to die of what I was going to die of.

"That's bullshit, honey. It isn't what I want. Just can it, O.K.?"

HOSPITALS have become a mess; they've lost it. The breakdown of the middle-class conspiracy that was urban culture in the West shows in hospitals as a visible and basic and entire decay. Everything is improvisatory and shaky, even cleanliness and the administration of treatment. But perhaps because of obstinate kindness in some people, a determination to embody goodness, or some addiction to the priority of emergency, or because the meaning of rescuing someone from death appeals to the soul or to your sense of importance in the universe, the best nurses and nurse's aides appear and take care of you when you are dying.

Or, I should say, I got that kind of care. I got more of it if Ellen was there. The medicine came on time, the I.V. was properly adjusted—and the attention, in its smallest details, had in it an element of respectful shoving at the body and the spirit in its fall, a funny kind of summoning, an American summoning, not to glory but to make use of the technology and techniques of treatment, to profit from them. One is expected to make an effort to return to suburbia, to the tennis court, to make an obeisance to life.

I had already browbeaten Barry into saying that there are no miracles, no cures here. No one has been rescued from AIDS so far. The practical limit of survival varies, but one hears a lot about two to five years. Some of that time, you can, with luck and proper treatment, feel quite well. As a prize, as a goal, it is not very *American*. It is not Utopian, although Barry tried to make it that way with amazing generosity; he would raise his voice and smile, and his eyes would brighten; he would look like an inspired pitchman, and he would produce his pitch for *life*.

But it's not life. I rode for a while on my limited breath, on the cadence, the metre of it, in obedience to the muse of immediate survival. I was unable to breathe without oxygen and was racked by my reactions to the huge amounts of medication dripping or pumped into me, or swallowed—fifteen pills at bedtime. I thought I could feel myself being suffocated second by second. But the prednisone did in a way comfort me. What was strange was that all sense of presence, all sense of poetry and style, all sense of idea left me. It was gone, with not one trace, one flicker remaining. I had a pale sense of the lost strength it would take to think or feel a metaphor, and of how distant it was from me. Everything was suffocation and the sentence of death, the termitelike democracy and chemical gusts of malaise and heat, of twisting fever, and the lazy but busy simmering of the disease in me. Everything outside me was Ellen's breath and the color of the walls in the dim light and was the hospital noises and the television set on its wall mount and a ticking slide of the moments.

And nothing was a phrase or seed of speech, nothing carried illumination in it, nothing spoke of meaning, of anything beyond breath. Attentive to nothing but breath, perhaps in my dying I was alive in a real and complete way, a human way, for the first time after ten or fifteen years of hard work. I lay awake in an almost bright amusement.

Did you ever, as a child, play alone in a large cardboard box that a refrigerator came in? Or work alone in a large room? Or at night, when everyone else

was asleep? Whatever I say now applies to feelings inside such a box, the box I'm in. No one can possibly know the power of feeling I project inside my carton.

Medical attention, and the horrors of illness and death, great death, amused me in a quiet way. Amused? Well,

what do you feel when you're expected to fight against an often fatal pneumonia and you've been sentenced to death already? You are death meat. I don't see how you can cooperate in any ordinary way. You are a foot soldier, cannon fodder. Various functions of the body are endangered routinely. Tediously, you endure. You live in the tidal influx and efflux of medication. You make an attempt to go on as a person in the world. You smile at Barry. You smile at Ellen. You lie very still. But there is the grotesquerie of the patient, the mad person, the electrical flesh; the connection to the ordinary world is broken, yet not en-

tirely. And there is a cartoon aspect: the curses people hurled at you have come true. What do you suggest I do? Be unamused?

And Barry meant to amuse, in the sense that he meant to give me a jolt, a blast of energy and momentum. It was as if he caromed in and set us, like billiard balls, bounding about the narrow room mentally, with animation. At times, he was exhausted and maybe depressed, but he hid it almost rapturously, with medical-business-like adjustments, with watchfulness. He worked in relation to a not yet fully understood disease using clinical experience and analogy. Really, I was grateful that he bothered. His respect for my life verged on the idiotic. He could not win. Literally, he shone and prescribed and analyzed and stole for me a month here, perhaps two years there. He kept studying medications and my face and my eyes while he was handling other patients, studying other faces and other eyes. Barry was moving fast inside a straight line, a medical frame, without much respect for the inevitable medical defeat. He put on a show, put up a fight, and I applauded as best I could. The spirit was cracked in me, but I offered what version of spirit I could to him. I joined the coarseness of struggle: this was my loyalty to the regular world.



To skip ahead for a moment—for the sake of a moment outside the hospital—here is an entry in my journal from two months later:

Barry was so encouraging after my last visit that yesterday, when we arrived in the country, in the cooler air—with a fine wind and the stodgy trees attempting witty movements in the blowy air, and with the monkshood in bloom, very tall purple panicles next to our stone wall—I went entirely mad, carrying things, charging up and down stairs, and then collapsed, not seriously but totally, for eighteen hours. It was scary. But I went on feeling happy and released.

I COULDN'T really sleep. I was able on the prednisone only to doze in a kind of shallow unconsciousness. I believe in sleep. In the past, when I was

ill, or even just sad, I would sleep it off.

Now, when Ellen slept, I expected to meet, as it were, my own feelings. Toward morning I would doze. I woke each time precariously placed in horizontal stillness, protecting my lungs and heart as I had with my posture when I was awake. I woke aware that I'd dreamed, and there was a fraction's hesitation before it became obvious I would not remember my dreams, that they had been about death, and that my waking self would not reproduce any part of them for me.

IN life, I have struck people as being odd, demanding, and evasive. The New York *agreement* among people of my sort is that everything about each other's lives is knowable. You take a few clues, regard them with sophistication, and you know *everything*. In the end, this is a city that acknowledges no mysteries, one that is set on prying, or getting, or revealing. I find New York talk horrendous, the personal conclusions stupid, the idealization of others' experience and the demonization of others' experience hateful and contemptible. And the bottom-lining, the judgments made as if all were known, the lies, the fraud, the infinite oral thuggery here of Jews and Gentiles alike, the cold ambition, is, I repeat, unlivable.

What we really have in this city are able people, competent people, who as they rise in the world have more and more complicated professional lives. Quite logically, that eats them up, and the monstrous residue that is left is beyond emotion, but with an appetite for it, and a terrible and terrified longing and unsuitability for it. This monstrous

residue is beyond friendship, beyond anything. (It is capable of truly marvelous, if ogreish, companionship.)

I have been lectured on this subject, told I am wrong when I say what dregs they are, what dregs we are, what a creeping madness our adulthood becomes. The above has been denied to me by nearly everyone in New York. But surely they must know.

NO one can explain what it means to be marked out. The usual explanations, the traditional ones, have to do with sin—sins of the fathers and your own sins. But to be American is to be Nietzschean in half of yourself: You move beyond sin even if part of you still believes in it. You—or anyone—have to suffer your life or death under civil law, so to speak.

Part of the self is made of one's work: you get glimpses of meaning in that. A sense of your crimes can perhaps keep you alive. Or self-righteous indignation can save you. Doors fly open as in a farce, and something like Medusa's head swings into the corridors of illness like the end of a pendulum, turning you to stone. I kept wanting to cry out as Doris Brodkey had, or take refuge in rage as Joe Brodkey had. I wanted an inherited death. But I had, indeed, lost the past. This death seemed entirely mine, mine and Ellen's, alone.

Death is not soft-mouthed, vague-footed, nearby. It is in the hall. The weakness does not wash over me and disappear but stays. It has a stagnant air. It floods me, and the flood is soul-wide. The casing that my youth and strength and luck came in is empty and vibrates a bit. A fox cub, a small bird nervous in the shadow, a bag of tainted blood, a skeletal and stiff figure lying still is what my consciousness is. It is like a small bird's being fed to have one's whispered wishes taken seriously and to be spared predatory sympathy. Barry and Ellen are going to save me for a while.

DO you know the myth of my irresistibility? It isn't easy to talk about. The Fuck You Dreamed Of, Maybe. What a joke. It was a matter of rumor—of reputation, all part of the floating aura, the sharp aroma of New York gossip. I practiced amateurishly and assiduously, and with some enjoyment and curiosity, but I wasn't up to it. My sexual limits were physically very clear. I failed to be a hero of the nineteen-sixties. Or of the nineteen-seventies. I wasn't up to the role. I never approached stylishness and acts that Mapplethorpe pictured and made public. I was never in the Casanova range and league of Norman Mailer. What I did and whatever actual events fuelled the image—whatever humor or vanity I showed—it was clear that most of the myth was based on the claims and gossip of others. I had a life, but not that one.

Tennessee Williams, who went to my high school long before I got there, and who had some of the same teachers, touched on the subject of male irresistibility in terms of hustlers and handsome strangers passing through town, always in rags, and subject to humiliation. In imitation, a playwright, William Inge, dealt with it more directly, more reportorially, in the play (later a movie) "Picnic." And such actors as Paul Newman, Marlon Brando, and William Holden for a while embodied this notion in various roles in Hollywood, getting shot and falling into the swimming pool and so on.

The American representation of The Good Fuck (an experience you owe yourself) always dealt with the childishness of such figures and with their failure in the world—handsome orphans, beaten down, beaten back, dependent on aging movie stars or on Anna Magnani as a moneyed storekeeper in a small town or on Kim Novak's depth as a woman; these sexy, bankrupt, Christ-like orphans, these phallus bearers and suppliers were by definition without

power in the world. Brando had trouble playing Napoleon or Marc Antony or any other type but the phallic martyr. And the highly successful writers, the troubled Williams especially, and the successful and power-mad directors could never suppress their contempt for these men in their degrees of failure and lack of power. Billy Wilder's version in "Sunset Boulevard" is the most contemptuous.

I don't know of any British versions of such male irresistibility in the writing of the modern era except for Basil Seal in Waugh's books, and he is a killer at heart. Lermontov and Stendhal and Pushkin are kinder but still cruel. Some of the more ancient versions, such as Joseph or David in the Bible, are treated with less contempt, but then they are pictured in their worldly power, their success; they are said to be blessed.

The American version is always a fool. Well, why not? In my case, it was a stupid thing and a bit hard to believe except in terms of sentimental anecdote, as in tales about my adoption. It is fantastically embarrassing to say that I was adopted illegally and with great difficulty, and the difficulty was accepted

because of the infant's, the very young child's—the tales agree even if the photographs don't—extreme beauty.

The supposed beauty of a catatonic toddler as a small-town public "myth" among Jews is the substance of childhood drama—this irresistibility, these looks, these bones and features. From infancy, my life has been, always, always, on the verge of my being eaten alive: *I could just eat you up*.

It seems hardly earthshaking, this crap of *irresistibility*, but in life, in the literal reality this takes, it means gasps and anger at you and people crying because of you and a lot of gossip and various abduction attempts and threats of suicide because of you and your being followed on the street by people who are obsessed with you seriously, ludicrously. It means people hating you for a betrayal that never occurred, for what they feel is your luck, which they then want in their rage to undo. In my childhood, people talked a great deal about me and quarrelled over me—and threatened force. And there was violence, some of it directed at me.

I have seen, as an adult, children of such attention become quite violent

themselves, and hysterical, and strange. I think of childhood and adolescence as sexual, as filled with the sexual intrusions of others. I was told that Doris Brodkey first tried to buy me from my real mother when I was a year old. I would suspect that the fate of *irresistibility* in the ordinary world is established in infancy as a condition of existence for most of us. But that in my case it has also partly determined my death.

I remember people coming to the house to see me—I remember being brought out after being dressed and combed, and being passed from embrace to embrace. How I hated to be touched. Or even looked at. Sometimes I would kick and scream and not allow my nurse to dress me. I would even climb out the window of my second-floor room and hide on the roof rather than go downstairs. It was commonly said, "That child needs discipline." You'd be surprised how odd—and troubling—a child's "No" was back in the nineteen-thirties, and how temperamentally the grownups reacted. Decades later, in New York, in almost any field of endeavor, when a sexual proposition was made to you by anyone, for you to say "No" seemed to mark you as an amateur, as unprofessional, unserious, and to some extent as a fool.

Really, one sees people cursed with *irresistibility* as being finally interesting for how they fail. For how they can be hurt. For how they retreat, become scarred, or obese, or dead. When I am attacked, it reminds me of my childhood. Spite and the desire to humble you combine uncertainly in an angry way to make you laugh with shock and secret recognition. Sanity becomes very pronounced in you, as a defense. Every touch verges on abuse, on recruitment.

Few people will ever see you without an affronted sense of their own *irresistibility* and of themselves as objects of competing emotion. This trait makes others feel that you are taking something large and valuable away from them, and if you believe we know things by comparison or if you believe in democratic (competitive) exhibitionism, then you *are* taking something of value away from them: their projection of themselves as more worth loving than you are.

I was *in fashion* in New York in terms of this *irresistibility* off and on for

the last forty years. And it was an insiderish thing to be "in love" with me at those times. Other people won literary prizes or academic honors. I discriminated among emotions and suitors—and judged their quality as people, their odors, their intelligence, their powers of comedy and of being thrilling, their emotional intelligence. I had always, explosively, a kind of emotional citizenship, an undeserved welcome. I

felt this absurd *irresistibility* as a form of comedy, as a useless joke. I am trying to describe the nature of the temptation offered to the child and by the child, then the adolescent, then the young man in New York who is now the aging man with AIDS.

Another man might "love" me like someone cheating at croquet, but the croquet court had been laid out in *me*, a pleasure ground of a peculiar sort. You play dumb and pretend to be respectable, but you are an old, old hand, an aged whore at this stuff. Outwardly, you perhaps are more distinguished and puritan in your air than that. No one need admit that you are this sort of person. People who become obsessed with you like to tell you that you're nothing special, that you're ugly—a certain amount of high and low melodrama lies in wait for you every day. Ah, the bitter phone calls. I cannot find in memory a day in my life without some erotic drama or other. I probably have never gone a day without it. And the temper with which you bear your history—the erotic slyness or directness—may give you a quality very like beauty, whatever your history is, whatever you actually look like. Perhaps it is a real beauty, the courage to have had a life of some sort, in spite of the difficulty, I mean.

ANYWAY, the major drama of my adolescence was that my adoptive father, Joe Brodkey, who was ill with heart trouble (a handsome invalid, as one would write in pornography) assailed me every day for two years, sexually—twice a day, every morning and every evening, when I was twelve and thirteen. He had nothing else to do, really. He was ill. We were not the same blood. I am being very shy. He never succeeded in entering me, but it was somewhat scary and sweaty. Except that there was the pathos of his dying. And

there was my long history of boring *irresistibility*. And my mind, which was watching all of it. His blood pressure was fragilely high. I was too strong, too frozen, for very much to happen, for the drama to develop.

I am lying. I had to notice that he was heartsick—with feeling, clearly *in love*, in a way. And soon, somehow, when I didn't make a scene about the assaults, or whatever, a great many people

8-

car, but I fought and talked my way out of it. At school, my God, girls waited for me in the front hall, or in front in good weather. I was often surrounded by kids in the halls, and twice in one year, four times all in all, the mothers of girls whose approaches to me I had ignored complained to the school principal that I had hurt their daughters' feelings, and couldn't I be made to respond? My parents were telephoned, were talked to. Whatever I was, it was not taken to be a private property and mine. I understood my father's actions on this level, in this light.

One of the troubles with the reality of the passage of time is that the past can be lied about.

False precedent can be argued. Unexamined realities can be dropped from conscious equations. The thing itself, the sexualized courtship, arose from the boy's comforting and, on occasion, holding and rocking his forty-four-year-old father when his father was racked by death-fever or rage or panic. Life perhaps was defined by one's code of behavior. I would start to laugh and accept an embrace briefly, as in childhood—and then cut it short. It is your own moral judgment that arranges this refusal of your father even though he is dying. Such refusal is arrogant toward Daddy. Or at least it places a positive value on your own life. To ignore the feelings you arouse is indistinguishable from narcissism to someone who wants your attention. I am not complaining. I noticed that the denial of truth was what everyone called *tact*. He accursed me. Now I will die disfigured and in pain.

To tell a little of the story about me and my father less shyly, I would have to change the way I write. In real life, I experimented with homosexuality to break my pride, to open myself to the story.

MEDICINE and will and luck. Barry and Ellen. I didn't die. I didn't even have to be sent to intensive care. Then, outside the hospital, the light had a perceptible weight, and I blinked and flinched. The outdoor noises, city noises, flew and scratched. I struggled to control my breathing. And it was as Barry had said: I had not really known

knew about "the love story." I suppose my mother talked about it for reasons of her own. My mother said he-can't-live-without-you things and he's-hooked-you-have-him-where-you-want-him-you-talk-to-him-for-me things. Or Dad talked about it—he had rather nineteenth-century ideas of family and of male rights.

I confessed nothing. I complained to no one. My mother, herself ill with cancer and drugged, warned me oracularly, "If I were you, I'd learn to keep my mouth shut." I don't mean to be insulting to her memory, but she was excited, even inspired, by the situation, which—it took no great brains to see—helped keep both her and Dad alive: it interested them, this *love* thing.

Such assaults as Joe's have their aspect of wanting to lower you, but at moments everything was focussed, as if in the last line of a story, on a profound concern having to do with the creature in whom my identity was at the moment caught. Either of my parents would have killed the other for me. Sometimes they fought over me, and it seemed to be to the death—this is not uncommon, is it? My mother said advisingly, "You never seem nice if you have to say no." I was a "fine-looking young fella" (which I never actually quite was; I was weirder than that), "a young man with a good smile, if you want my opinion." She said, "You make do with what you're given." It was what she had to play with, to move on the suburban board, in the terminal boredom of her life.

Still, for me, there was the drama, the persecution. And such assaults, such oddities, comic and manic or melancholy or dangerous, occurred everywhere, as if by contagion—with the football guys, with old friends, with the mothers of friends, with strangers. I was even half abducted once, forced into a

how sick I was—dying, yes, but not how sick.

I felt myself dissolve into the space spreading around me. In the taxicab, in the streets, I was so crippled by filmy fluctuations of consciousness—on East Seventy-second, on Madison, on West Eighty-sixth, where the walls of brownstones seemed watery and then gauzy—that I was far more imprisoned by

weakness than I had been by the hospital and its routines. I was maddened by my silent passing out and coming to in the city stink as the taxi bounded and bounced. I stayed upright. Ellen was stiff-faced and brightly talkative beside me. "I can't respond," I whispered. She held my hand. Halfway home, I was so ill with exhaustion that tears of pain came to my eyes. I had no intention of admitting that I had made a mistake in forcing Barry to let me leave the hospital a few days early. I said, at least half a dozen times, "Boy, is it wonderful to be out of the hospital!" Then I gave that up and asked Ellen if she was managing, if this was too much for her. If she had said yes, I would have turned back. She said she was O.K.

We, I, made it to the apartment, and I climbed into my bed in my clothes. Ellen undressed me, set out the pills and the notebook in which she was going to log my symptoms and the hours at which I took the pills. I dozed and woke, but uncomfortably and without being refreshed by the sleep, which was as truly terrifying as falling off the edge of the world might be—to be so unrefreshed by sleep. I walked, crept, partly crawled to the stereo in my darkened bedroom and played one of Bach's partitas; it sounded harsh to me. I slept, always in an uncurative way, sometimes with music playing. Much of the time, I just listened to the distant sounds of street noises and of Ellen coming and going.

Sick and weak, each day, in the morning, for an hour or more, I stirred myself and worked on the last draft of a book I've written about Venice. Red and covered with spots (allergy to the drugs), I worked, and while I worked I felt nothing apart from a weakness of mind and some nausea. I mean, I had no reaction to the story or to the prose: I had to work with memories of response.

Sometimes I couldn't work at all,

couldn't focus, and I would cry, but only a bit, and crawl back to bed, or if I was working in bed I would cover my eyes with my hands and lie still and breathe and doze and then try again to work. I must admit I truly felt accursed. My mother, my real mother, died, according to family accounts, of a curse laid on her by her father, a wonder-working rabbi. When I was barely two, she died painfully, over a period of months, either of peritonitis from a bungled abortion or from cancer, depending on who related the story. Then Doris, my father's cousin, and Joe came for me and, later on, adopted me. I was told that Doris took me once to the hospital to see my mother and that I refused her embrace, clinging instead to the perfumed Doris; the rescued child was apparently without memory of the dying mother. (Perhaps that was the real crime, and not my obduracy with Joe.) So, in between working out when I could most probably have become infected with AIDS, I fell into a mood of being accursed, of being part of an endless family story of woe and horror.

I felt worse each day, almost as if as the emergency faded so did the mobilized strength. Endless sickness without death is more sickening than I would have imagined. I wanted to make, as a sort of joke, a version of the superhuman effort that Ellen wished for from me. But, you know, as you get older you get worn out in regard to superhuman efforts—you've made them for your child or in your work (superhuman for you) or in sport or love or for someone who is ill. And then the possibility is gone. Ellen was working at a superhuman rate, nursing me, helping me up and to the word processor and back to bed. She shopped, cooked, kept house, took care of pending business, dealt with whatever emergencies came up, answered the phone and lied to people about my illness, fed us and made conversation, and proofread the work I produced. She got us movies for the VCR and lay down with me and kept me company, and brought me ice bags when the fever rose and my head hurt, and kept the medication log and saw to it that I took the medications and my temperature when I was supposed to, and, when I asked her to, she sang to me.

She helped me dress and then un-

dress; she didn't approve of my staying in pajamas all day. Her omnipotence was at full stretch and had a softly shining and rather detached aura to it that enclosed my sense of being accursed and diluted. It was a cousin to that neurotic activity of will in able women which is so often written about with disapproval, and it was crazed, I suppose, that tirelessness, that as if inexhaustible tenderness. Clearly forced, or maybe not, it was far stronger and more unflagging in effect than any courtship intensity that had ever been directed at me.

We called no one. We were still telling the family and anyone else who telephoned that I had pneumonia, nothing more. In a rather transparent isolation, my arrogant deathliness and her burning gentleness were dancing together in a New York light in our apartment. It was like childhood, a form of playing house.

Then she said, "When are we going to tell the children?" She wasn't looking forward to it—it's not just embarrassment, you know: it's preliminary distress in case they're not very nice at first; and, on the other hand, as a parent you are ashamed to inflict this downer on them if they are warmhearted and do sympathize. The likeliest thing is that you'll have to console them.

"Later. In a few days, we'll start. I can't deal with it yet."

"That's all right."

She was careful, so that I would not blame myself. I felt myself to be thoroughly repellent. I had disowned my body now and was mostly pain and odors, halting speech and a sick man's glances. The truths in such domestic and emotional enclosures tend to go unrecorded. Things drift into the sanctuary from the outer world; the television is a window, and the telephone is a murmurous keyhole. Somewhere in this phantasmagoria, Ellen decided to wake me.

A kiss—how strange her lips felt, and the quality of life in them. Of course, I thought, of course. The sense

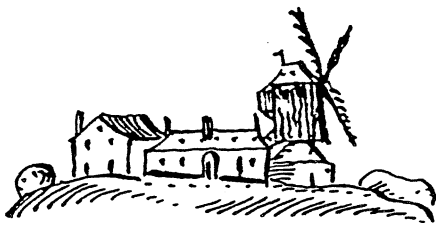
I had of her, the sensations: the heat of her skin, the heat of her eyes so close to me, everything in her was alive still and full of the silent speeches that life makes. She was warm and full of responsive motion. My lips and feelings had the deadness of a sullen child's.

I accepted her and her affection as truth, as being as much truth along those lines as I was likely to want. This meant that by the second week I was home we both realized that, in this limited world of mutual watchfulness and of unselfishness-for-a-while, this period was for us, in awful parody, honeymoonlike, and that this was acceptable to both of us, grief or death at the end or not.

Grief aside, nothing ugly happened at all. Since she didn't mind—or rather didn't show disgust at my ashenness—I grew more affectionate: the corpse put his arm around her. She noticed and commented on the strength of my heartbeat. "Yes, I've always been especially proud of my heartbeat." She kissed me on the lips with generous marks of interest and amusement. She said to me, "No one would believe that this was one of the happiest times of my life."

I roared with laughter, which hurt my stiff lung and made me choke. And I came alive again, for a little while. Well, why not? When the other things are over and done with, when savagery and silence are the impolite, real thing, you're not alone. You still pass as human among humans. There are things that have to be done, family things, literary stuff, things having to do with AIDS. I do them with her marks of interest and amusement on my face.

DYING, too, has a certain rhythm to it. It slows and quickens. Very little matters, but that little is of commanding importance to me. I feel the silence ahead of me as I have all my life felt the silence of God as a given and a source of reasonable terror. This is something one must bear, beyond the claims of religion, not the idea of one's dying but the reality of one's death. One schools oneself in an acceptance of the terror. It is the shape that life takes toward its end. It is a form of life. ♦



-10-



The author with his wife, Ellen Schwamm, at their home in New York City.

DEATH OF A SPOUSE OR PEER

Bereavement and grief in pair relationships

In spousal relationships, when one member of a relationship dies the other experiences the loss

- not only of another person
- but also of a portion of his or her own identity.

Furthermore, death of a spouse or peer changes the world, the other, and the self for a bereaved adult.

Bereavement and grief associated with HIV infection and AIDS in adults

What a person with HIV infection faces:

- a life-threatening illness as well as its immediate situational and developmental implications
- its acute and chronic challenges
- and the social stigma often attached to this diagnosis.

Others face grief and bereavement that is complicated by similar psychosocial factors:

- a) The disease may have led to disclosure of hitherto unknown lifestyle choices that are difficult for survivors to accept.
- b) A person who was emotionally and existentially tied to the deceased (the man's homosexual mate, e.g.) may be shunned by the family of origin and not permitted to take part in providing care or in funeral ritual.

All of this is a classic pattern of rejection, stigmatization, and isolation associated with disenfranchised relationships, losses and grievers.

DEATH OF A PARENT OR GRANDPARENT

Death is increasingly associated with the elderly—a group that experienced more than 1.5 million of the 2.1 million deaths in the U.S. in 1990.

This means that most adults expect their parents and grandparents to precede them in death.

Nevertheless, when such deaths occur, they often are difficult experiences for survivors.

END OF CHAPTER 13

Chapter 14 *The Elderly* 314

An Elderly Woman 316

The Elderly, Developmental Tasks, and Death 317

Encounters with Death 318

Attitudes Toward Death 319

Elders Coping with Life-Threatening Illness and Dying 320

Maintaining a Sense of Self 321

Participating in Decisions Regarding Their Lives 322

Being Reassured That Their Lives Still Have Value 322

Receiving Appropriate and Adequate Health Care Services 323

Elders Coping with Bereavement and Grief 323

Illness, Disability, and Loss 324

The Death of a Spouse or Other Significant Peer 325

The Death of an Adult Child 326

The Death of a Grandchild or Great-Grandchild 326

Loss of a Pet 327

Suicide Among the Elderly 328

Summary 329

QUESTIONS FOR REVIEW AND DISCUSSION 329

SUGGESTED READINGS 330





ngs

ngs

Please keep this report with your financial records.

FOX SEARCHLIGHT PICTURES

Pregnant teenager Juno (Ellen Page) takes her first ultrasound while her mother (Allison Janney) and best friend (Olivia Thirlby) stay with her for support.
included with this report.

Thank you for your continuing support of Church of the Crossroads, UCC.

'Juno' gives Page something to grow on

Review by Ty Burr
The Boston Globe

That smart, hip, human comedy you were waiting for all year? The one with dialogue like a sugar rush and performances like grace notes? It's called "Juno" and it just arrived in theaters. Go forth and multiplex.

The buzz is that the movie, about a remarkably assured pregnant teenager, was late 2007's darkish outsider farce along the lines of "Little Miss Sunshine." And in fact it's about as indie as that '06 hit, which is to say not very.

Director Jason Reitman is a scion of Hollywood (his dad is "Ghostbusters" director Ivan Reitman), and the cast includes such struggling unknowns as Jennifer Garner ("Alias"), Allison Janney ("The West Wing"), Michael Cera ("Superbad"), and Jason Bateman ("Arrested Development").

'JUNO'
Rated: R
Opens Friday
in theaters
★★★

Ah, but a first-timer named Diablo Cody wrote the pungent, deceptively sardonic script and the young actress Ellen Page arrives in this movie like a slacker Audrey Hepburn on the half-shell. The few of us who saw Page in 2005's suspense freakout "Hard Candy" knew she was capable of great things. "Juno" doesn't just confirm that promise, it's this close to a great thing itself.

IT'S ALSO THE latest example of the peculiar mini-genre, the coming-to-term pregnancy comedy. Like "Knocked Up" and "Waitress," "Juno" eschews the abortion center for the growth chart — the heroine's, not the baby's.

Juno MacGuff (Page), the suburban 16-year-old for whom the movie's named, is a concentrated movie version of a type that exists in life: The smart-mouthed, hyper-literate rockergirl who weaves ironic pop references into her daily speech. She seems fazed by nothing, yet Cody and Reitman know that as weirdly mature as the kid seems, she's still a kid, one who uses a bedroom hamburger phone to call the clinic. Page lets us see it, too, whenever Juno thinks no one's looking. The character's more active, sexually and intellectually, than the grown-ups give her credit for, but emotionally she's a work in progress. The movie's about how she comes to realize that and build on it.

First, though, it's about watching Juno cut a dry, perplexed swath through life. The baby's father is Paulie Bleeker (Cera), a geeky bandmate for whom she carries an inarticulate torch, and the movie shows enough of the fateful incident for us to understand it's the product of determined after-school curiosity rather than passion. (That's another thing the adults have conveniently forgotten.)

Juno decides to have the baby and give it to the nice childless couple whose advertisement she finds in the Pennysaver, next to the exotic bird ads. They are Mark and Vanessa Loring (Bateman and Garner), living in yuppie splendor in a nearby McMansion sub-development, and

just when both the girl and we have pegged the wife as an overwound power-tripper and the husband as a totally cool dude, the ground shifts. The film's also about how name-checking the right achingly hip rock bands is not in itself a qualification for parenthood, a point nicely undetermined by the film's own achingly hip soundtrack.

Cody's dialogue shoots from the hip with delightful invented IM-speak. "Honest to blog?" gasps Juno's best friend Leah (Olivia Thirlby) upon hearing the baby news, and that's when the movie had me, two minutes in. By the third trimester, Juno is acknowledging her iconic status in the school hallways: "They call me the Cautionary Whale."

THE PARENTS give as good as they get. Juno's father, an air-conditioning specialist played with droll warmth by J.K. Simmons (Jonah Jameson in the "Spider-Man" movies), and her stepmother, a nail technician given breadth, depth, and length by the marvelous Janney, take in the girl's situation with tight lips, then move forward. Because they love Juno and respect her intelligence, her stupidity in matters of contraception isn't a disaster but a disappointment, and that may be worse. "I thought you were the kind of girl who knew when to say when," her father says, to which Juno can only respond, "I don't know what kind of girl I am."

That's one of the few times the movie's arch

surface tension ripples with panic. If "Juno" has a fault, it's that the one-liners have so much top-spin that the cleverness can turn glib. Reitman proved in "Thank You for Smoking" that he could make intentionally overwritten dialogue fly, but he can't keep "Juno" from the shadow of its own preciousness.

Besides, the actual experience of being a pregnant teenage girl in America is — I'm just guessing here — probably not like this. Parents aren't this sanguine, physical discomfort isn't this minimal. Where's the fear, the doubt, the isolation? Juno is a great, empowering character because she takes everything in stride before being humbled (a little), but she also makes having a baby look easy, and that's the movie's charm and its dead end.

Ultimately, the birth that matters may be the lead actress' career. A pixie rather than a glamour puss, Page holds the screen with a natural quickness. The briefest hesitation, the slightest narrowing of the eye, and you know Juno has just stubbed her toe on a sadness she doesn't want to reckon with.

Page lets the character keep tripping until she has to look down, in a way it's as insightful a portrait of a kid stumbling toward adulthood as Dustin Hoffman's in "The Graduate." (It's also a good deal wiser than Cody's script.) The better part of "Juno" is watching its heroine grow up before our eyes. The best part is we'll now get to watch Ellen Page do the same.

the two sci-fi/horror film franchises return to wage a brutal battle in an unsuspecting Colorado town.

Atonement ★★★1/2

Adapted from Ian McEwan's book, a servant's son falls in love with a young, upper-class woman in 1935 Britain, just as her teenage sister falsely accuses him of sexually assaulting their cousin. It's a gripping film, with fine performances by Keira Knightley, James McAvoy and Saoirse Ronan, and even occasional artiness can't detract from the painful events at this story's heart-rending core.

Before the Devil Knows You're Dead ★★★1/2
Veteran director Sidney Lumet's latest digitally shot film is compact, nasty and altogether wonderful, a tale of brotherly greed and New York

comeuppance. Philip Seymour Hoffman and Ethan Hawke play siblings who hope a small robbery will take care of their financial problems. This film pares urban existence down to pure survival instincts, even as

#1 MOVIE IN AMERICA!

WALT DISNEY

NATIONAL TREASURE BOOK OF SECRETS

PG

NATIONALTREASURE.COM

©DISNEY ENTERPRISES, INC.

For Theatres and Showtimes: Check Local Listings or Text TREASURE
with your ZIP CODE to 43KIX (43549)
or Visit NationalTreasure.com

SORRY, NO PASSES

the late 1800s. She describes her life on the plantation as a free, safe, and a simple lifestyle. There were no restrictions and she and her siblings were free to do anything they wanted as long as it was after they had finished their chores. She and her playmates often spent the whole day outdoors always finding something adventurous to do. Only one fear was instilled in the children. They were told to stay clear of Filipino men, because they were dangerous.

Cathy explained:

Everybody used to be so afraid of the Filipinos, especially of the men, 'cause they used to kill. They would use cane knives to kill people. Our parents would make us so scared of Filipino people. They would say to us, "Don't talk to them. Don't go to their house." Their belief was when the Filipinos came (to Hawaii): they tried to get girls to fall in love with them and marry them. They tried to court the "locals," the different nationalities. So everybody was afraid of them. That's why when we went to school with Filipino children we sort of kept away, and yet they were good children.

Despite this prejudice against the Filipino men, for the most part people were respectful, accepting, and tolerant of other ethnic groups on the plantation. Cathy said that when she grew up ethnic groups were separated from each other by areas called camps. She lived in an area designated for those of Portuguese and Spanish ancestry. Her parents worked with other ethnic groups, but mingled socially only with other Portuguese and Spanish. In school Cathy interacted with children from other ethnic groups, but after school children generally played with children in their own camps. In 1938 the plantation changed the housing structure. Instead of separating the ethnic groups from each other they mixed the

53

HOSPICE OF THE MONTEREY PENINSULA

(non-profit corporation)

Tel. 625-0666

HOSPICE has served this community for the last four years.

HOSPICE emphasizes control of pain symptoms in patients facing a life-threatening illness
AND psychological support for them and their families.

HOSPICE PROGRAMS

1. CANCER SUPPORT GROUP

First started by group of cancer patients and their families.
Group meets on each Monday at 4 p.m. at Carmel Presbyterian Church.
Group under direction of a psychiatrist and nurse.
Group shares experiences about their illnesses and gives a feeling of mutual support to patients facing this difficult disease.

2. VOLUNTEER VISITOR IN-HOSPITAL PROGRAM

Program directed by a patient care volunteer coordinator.
Several hundred patients aided by program during last four years.
Patient's needs assessed by Coordinator by direction of a physician.
Needs are based on psycho-emotional and practical points of view.
Coordinator assigns a trained volunteer to each patient, and who maintains an ongoing contact with the patient during hospitalization, later at home, in Hospice or a convalescent facility.
Crisis coverage by program gives round-the-clock assistance from Volunteers to help patients in an acute situation.
Volunteers help Inpatients and families at Oncology (tumor) Unit at Community Hospital and other Units when requested.

3. HOSPICE HOMECARE PROGRAM

Program run by a public health nurse, supervising registered nurses and Home Health Aide.
Provides 24 hour, 7 days a week skilled nursing care for patients facing life-threatening illness.
Nurses and Aide get constant in-service training, confer with physicians on pain control, symptom control and medical expertise needed to best help the patient.
Counseling help for patients and their families.
If patient dies, the family is helped through this crisis and their period of grief.

4. HOSPICE INPATIENT FACILITY

First independent Hospice Facility providing Inpatient care in the country.
Hospice is a model for other communities interested in starting Inpatient care.
Initially financed by donations from the Public (YOU) and foundations.
Ideal level of nursing care provided in a psychologically beneficial environment.
Continued operation dependent on negotiations with Medicare, Blue Cross and Medical.

HOSPICE NEEDS

1. VOLUNTEERS FOR PATIENT CARE

Volunteers screened, trained to handle the specialized care needed by the patients at the Hospice and by their families.

2. VOLUNTEERS FOR FUND-RAISING, OFFICE WORK, TRANSPORTING PATIENTS

These volunteers need minimal training and small time commitments.
They are ESSENTIAL for Hospice to function.

3. COMMUNITY SUPPORT FOR MONEY TO OPERATE THE HOSPICE

Remember a significant part of Hospice budget and entire cost of Volunteer program comes from public donations (YOU) and grants from foundations.

PLEASE SUPPORT YOUR HOSPICE

THE HOSPICE GOES BACK TO TWO TRADITIONS -from Middle Ages

1. It was a place which welcomed the pilgrims who arrived hungry, tired, and sore as they crossed Europe on the way to the various sites of pilgrimage; it was a place of hospitality.
2. The other tradition is that of the mediaeval hospital.
There were other hospices "for the sick and poor" who were literally dying in the streets. It was when these began to be staffed by professional physicians and surgeons that they took the name "hospital".

ST. CHRISTOPHER'S HOSPICE

1. It is the work of Dr. Cicely Saunders, the dynamic 57 year old physican who started sewing the modern deathbed scene in 1967 when she opened London's St. Schristopher's Hospice.
2. It is a way station for the dying--a place where people in the final stages of degenerative disease can go when surgery, chemotherapy and radiation have failed to cure
 - a) purpose is to relieve pain and help patient die/to come to terms with it.
3. It is planned as a therapeutic environment designed from the patient's view point, with an at-home feeling.
 - a) "A kind of convalescent home--no, more like a family..." is the way one patient described it. Others say: "Not like a hospital--like a big parlour"; "A place where people know what they're doing"; "A kind of annex to a hospital--where you can get better slowly"; and where those who don't get better "have comfort to the end".
 - b) The Bulletin Board tells a lot: there's a notice about a party; a fashion show; the times of chapel services and the announcement of the births of a first baby to two different couples: "All six are doing well"
 - c) It's a place that's meticulous about little ~~thin~~ things:
 - such as matron or doctor getting into ambulance to welcome a new patient;
 - such as making it quite clear that dogs can come to visit ("actually we had a baby elephant inthe graden last week and it didn't go upstairs only because it was apparently too tired to get into the lift")
 - d) There's a clubroom for families of dying people; a day-care center for children of staff members.
 - e) In first full year of operation (1968), admitted 380 patients; in 1971 (489), in 1972 (519) and in 1973 (579)
4. Unit of care is not just patient, but also the family.
 - a) Patients often go back and forth between hospice and home
 - b) The health care is a team effort involving medical, nursing, and social workers, and family members.
 - c) when patient dies, social workers and volunteers follow the family to help them adjust to bereavement.
5. It'sa family community--a caring place.
 - a) Nurses are encouraged to sit on a patient's bed
 - b) where family members are encouragd to help in the care--giving a sponge bath, bring food from home.
 - c) Visiting hours are unlimited except for a day off on Monday--not for staff's convenience, but because Saunders believes that families need a day off to do the laundry and other personal chores without feeling guilty.

6. It is known for its expertise in controlling the symptoms of degenerative disease--the nausea, weakness, difficulty in breathing, etc, and most important the pain.
- a) Brompton's mixture--a centuries-old formula containing diamorphine (heroin) cocaine, alcohol, syrup, and chlorofomr water is used with excellent results, without psychological addiction and without sacrificing the patine'ts alertness.
 - b) Reason for its success in overcoming pain is that medication is given before it is needed, to prevent pain and fear of pain, as well as to prevent feelings of dependency in patients who have to ask for relief to get it.
7. Hospice has no sophisticated resusciatation equipment; no pathology lab, etc.

TRANSFER OF DEATH TO HOSPITAL HAS HAD PROFOUND CONSEQUENCES

One: hospital has local monopoly on death

- it has complex equipment
- competent personnel
- frequent interventions

Two: Death has been redefined

- does death occur when heart stops?
- when vital signs are gone?
- or when brain ceases to generate electrical energy?

"The brain is our master control; the heart is just a pump."

The old signs, such as cessation of heartbeat or respiration, are no longer sufficient.

They have been replaced by measurement of cerebral activity, the electroencephalogram.

Third: Death has ceased to be accepted as a natural phenomenon—death is now a failure.

This is the attitude of doctors who claim the control of death as their mission in medicine.

Fourth: "The acceptable style of facing death"

The hospital personnel have defined an "acceptable style of facing death"

-that is the death of the patient who pretends that he is not going to die.

-he will be better ⁱⁿ this deception if he does not know the truth himself.

-the patient's passivity is maintained by sedatives, especially at the end, when pain becomes unbearable.

-morphine controls the great crisis, but it also diminishes one's consciousness.

Fifth: Moral significance of death has been overlooked.

Death has been moved "as human experience from the moral to the technical order".

"Death is a technical matter, a failure of technology in rescuing the body from a threat to its functioning and integrity. For the moment it does not matter that death of a person cannot be removed from the moral order by the very nature of personhood, what matters is the mythology of the society. the wide-spread mythology that things essentially moral can be made technical is reinforced by the effect of technology in altering other events besides death."—Eric J. Cassell, "Dying in a Technological Society", Hastings Center Studies 2, no. 2 (May 1974) 31.

Cassell asks, "How can it be that questions of morality and human values (once) so basic to the care of the dying seem remote, 'strange', or tangential in the actual setting of care?"

"Being and Becoming Dead" in Death in American Experience, p. 163

The technological imperative:

the assumption that the medical technology that we invent must be used. If we can, we must.

"The tool, made as a means to an end, becomes an end in itself. e.g. the cardiovascular machinery, invented to support traditional indicators of life, has become the locus of life

coming a dominant concern for the hospice programs.

Oliver Bohner

III

The dictionary defines hospice as a house of rest for weary pilgrims, travelers and strangers. During medieval times in Europe, religious orders established way-stations to accomodate weary travelers to refresh themselves, be fed and to rest.

Later, early medical institutions incorporated the hospice concept of providing personal attention and care for the sick and dying poor.

A group of Catholic widows established a hospice for poor women who had incurable cancer in 1842 at Lyon, France.

The hospice programs in the United States are modeled after the St. Christopher's Hospice in London, founded by Dr. Cecily Saunders.

Today, there are more than eighteen hundred hospices throughout the United States.

IV

In 1974, St. Francis Medical Center, because of its interest in death and dying and the care of the terminally ill, applied and received a federal grant to begin an integrated rehabilitation program for cancer patients, the first of its kind in Hawaii.

The cancer rehabilitation services program (CARES), became so successful that in 1976, St. Francis expanded its program into the homes of the cancer patients with the concept that the familiar surroundings and family support, enhanced the care of the patients.

The St. Francis Hospice Program is based on the philosophy of the St. Francis Medical Center and their concern for the quality of life of dying patients regardless of race, religion, sex or age. The program provides a specialized health care plan for the dying so that they may spend their final days pain free, preferably at home, and if this isn't possible, in a home like setting.

The hospice teams' aim is to control physical, emotional,

spiritual and social pain which affords the patient the opportunity for reconciliation and life fulfillment. After the patients' death, this approach continues through the availability of bereavement support services for the survivors.

The objectives of the St. Francis Hospice Program are:

1. To always consider the patient and his/her family as the unit of care, rather than just the patient.
2. To focus on the quality of survival through a caring and supportive process rather than on the disease and its treatment.
3. To provide patients the opportunity to remain in their home setting, as long as this is feasible, with the support and availability and expertise of the interdisciplinary team.
4. To provide a home-like inpatient facility for respite or crisis situations.
5. To provide palliative care for the hospice patient by implementation of appropriate medical and nursing skills as well as other techniques related to pain symptom control.
6. To provide an interdisciplinary team approach in order to better assess and meet the physical, psychological, social and spiritual needs of the hospice patient.
7. To carefully screen, select, train and utilize hospice volunteers as an integral part of the interdisciplinary team.
8. To provide a well-developed communication support system for staff and volunteer.
9. To provide a support system to the patient/family and/or significant others during the terminal illness as well as following the loss of a loved one.
10. To provide twenty-four hour, seven-day-a-week availability for hospice patients/families relative to medical and nursing needs as well as drugs and biologicals.

V

All volunteers are required to go through a six week training which consists of two and a half hour sessions on tuesdays and thursdays for a total of twelve sessions.

A brief description of each session follows.

Session one was an indoctrination session and provided the student an overview of the hospice program. It included the history of hospice and the history of the St. Francis program. It spelled out the philosophy goals and objectives of the program and what the volunteer program is all about. It described the volunteer programs' goals and objectives, basic requirements for hospice volunteers, skills to be attained, desirable qualities of a volunteer as well as undesirable qualities and the need for on-going training programs. We also discussed the various tasks that we may be asked to do in relation to the patient as well as the family and the hospice staff. We were given hints on how to become an effective volunteer.

In exchange for the training, we were asked to commit ourselves for at least two years, visiting assigned patients from four to six hours a week.

The bottom line for the volunteer is to provide presence to the patient and family as well as emotional support through active listening and caring.

Session two was designed to reach each volunteer through sharing a little about ourselves and present our personal experiences with death and to reflect back on that experience.

Session three was a class on communication skills and techniques. We looked at the various factors that influence communication such as culture, sex, social position, anxiety, fear and so forth. We discussed communication with a dying patient, verbal as well as non-verbal. And all important, how to become a good listener.

In this session, we looked at Kubler-Ross' stages of dying.

Session four was a continuation on basic communication skills. We covered empathic listening, putting your house in order, (will, power of attorney, etc..) and heard volunteers present

actual cases and how they handled them.

Session five's objective was to experience active communication skills through role playing exercises. We divided the class into four groups and acted the scenario presented and later critiqued our actions.

Session six involved the various documentation requirements of each volunteer such as volunteer in-patient notes, activity log, contact log, volunteer's journal etc..

We also learned about federal funding, hospice benefits, and medicare benefits.

The emphasis was on what to and how to document hospice activity skillfully.

Session seven dealt with pain and symptom control. The objective was to identify the various types of pain and how it relates to the overall management of the terminally ill patient.

A broad definition of pain was presented by three panelists. They talked about physical pain, psycho-social pain and spiritual pain. They talked about pain control which included the use of relaxation and imagery techniques as well as a broad spectrum of medication available in pain control.

The team explained the role of the volunteer in management of patients in pain.

Session eight identified the volunteer's role as a member of the team focusing on what is expected of the staff and volunteer in the support of patients and families that they are assigned to. In addition, the gift of self and caring, interpretation of caring and compassion and death were other topics discussed.

The role of the volunteer in in-patient services, out-patient services and home services was also presented with emphasis on evaluating the patient's condition, physical signs of dying, medical emergencies and or death in the home and finally procedures to follow when death occurs.

Session nine was the basic precaution in caring for the terminally ill patient with infections. Much discussion about the care of patients with Aids.

The hospice programs through out the country are seeing an increase in the number of Aids patients entering the program.

I have selected not to work with the Aids patients because of my fear of the disease and in part ignorance about the disease. Until I feel comfortable with it I will continue to ask not to be placed with an Aids victim.

The bottom line in this session was cleanliness and precautions.

Session ten was an interesting session dealing with the various cultural views in relation to death, grief and bereavement among the major ethnic groups in Hawaii. A panel with representation from the Hawaiian, Filipino, Chinese and Japanese communities presented the material. They presented not only the modern view of each culture but also those brought over from the mother country and in the case of the Hawaiians, the ancient views as well.

Session eleven made us understand the dynamics of the grieving process as it relates to the patient, family, staff and in the case of Aids patients their lovers. The session taught us what to expect from the patient, family and ourselves.

We were presented an over view of St. Francis Bereavement Program, bereavement support services after death occurred, (in the case of Aids, suicide protocol relative to a surviving partner).

The final session dealt with stress and burnout of the worker. It included causes of stress, symptoms of stress and intervention techniques to help the stress victims.

A summary of the volunteer training program was the final phase of the training.

In the tenth session and on my request, I was assigned to a man whose wife is suffering with breast cancer. My role is as a support for the cancer patient's spouse. Although Mr. M. insists that he doesn't require any help at this time, I still contact him on a bi-weekly basis. I feel that although I am not in direct contact with the dying person, I am making an initial start in that direction.

I'm not sure how well I'll do in working with the dying. I know that it won't always be as easy at the first case. However, I'm willing to give a hundred percent to the program and maybe learn about dying and accepting death as part of living.

for MITS only

37.

NATIONAL HOSPICE ORGANIZATION

HOSPICE PRINCIPLES AND STANDARDS (6TH REVISION)*

HOSPICE PHILOSOPHY

Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

DEFINITION OF A HOSPICE PROGRAM OF CARE

A Hospice is a centrally administered program of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families. Services are provided by a medically supervised interdisciplinary team of professionals and volunteers. Hospice services are available in both the home and an inpatient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and around-the-clock on-call basis. Bereavement services are available to the family. Admission to a Hospice program of care is on the basis of patient and family need.

* (Accepted by NHO Board of Directors February 23, 1979)

STANDARD

PRINCIPLE

- | | |
|---|--|
| 1. Appropriate therapy is the goal of Hospice Care. | 1. Dying is a normal process. |
| 2. Palliative care is the most appropriate form of care when cure is no longer possible. | 2. When cure is not possible, care is still needed. |
| 3. The goal of palliative care is the prevention of distress from chronic signs and symptoms. | 3. Pain and other symptoms of incurable disease can be controlled. |
| 4. Admission to a Hospice Program of care is dependent on patient and family needs and their expressed request for care. | 4. Not all persons need or desire palliative care. |
| 5. Hospice care consists of a blending of professional and nonprofessional services. | 5. The amount and type of care provided should be related to patient and family needs. |
| 6. Hospice care considers all aspects of the lives of patients and their families as valid areas of therapeutic concern. | 6. When a patient and family are faced with terminal disease, stress and concerns may arise in many aspects of their lives. |
| 7. Hospice care is respectful of all patient and family belief systems, and will employ resources to meet the personal philosophic, moral and religious needs of patients and their families. | 7. Personal philosophic, moral, or religious belief systems are important to patients and families who are facing death. |
| 8. Hospice care provides continuity of care. | 8. Continuity of care (services and personnel) reduces the patient's and the family's sense of alienation and fragmentation. |
| 9. A Hospice care program considers the patient and the family together as the unit of care. | 9. Families experience significant stress during the terminal illness of one of their members. |
| 10. The patient's family is considered to be a central part of the Hospice care team. | 10. Family participation in care giving is an important part of palliative care. |
| 11. Hospice care programs seek to identify, coordinate, and supervise persons who can give care to patients who do not have a family member available to take on the responsibility of giving care. | 11. Not all patients have a family member available to take on the responsibility of giving care. |

12. Hospice care for the family continues into the bereavement period.
13. Hospice care is available 24 hours a day, 7 days a week.
14. Hospice care is provided by an interdisciplinary team.
15. Hospice programs will have structured and informal means of providing support to staff.
16. Hospice programs will be in compliance with the Standards of the National Hospice Organization and the applicable laws and regulations governing the organization and delivery of care to patients and families.
17. The services of the Hospice program are coordinated under a central administration.
18. The optimal control of distressful symptoms is an essential part of a Hospice care program requiring medical, nursing, and other services of the interdisciplinary team.
19. The Hospice care team will have:
 - a. a medical director on staff
 - b. physicians on staff
 - c. a working relationship with the patient's physician.
20. Based on patient's needs and preferences as determining factors in the setting and location for care, a Hospice Program provides in-patient care and care in the home setting.
21. Education, training and evaluation of Hospice services is an ongoing activity of a Hospice care program.
22. Accurate and current records are kept on all patients.
12. Family needs continue after the death of one of their members.
13. Patient and family needs may arise at any time.
14. No one individual or profession can meet all the needs of terminally ill patients and families all the time.
15. Persons giving care to others need to be supported and replenished in order to continue to give care.
16. The need for quality assurance in health care requires the establishment of standards for practice and program operation.
17. Optimal utilization of services and resources is an important goal in the administration and coordination of patient care.
18. Attention to physical comfort is central to palliative care.
19. Medical care is a necessary element of palliative care.
20. The physical environment and setting can influence a patient's response to care.
21. There is a continual need to improve the techniques of palliative care and to disseminate such information.
22. Documentation of services is necessary and desirable in the delivery of quality care.

PHILOSOPHY OF HOSPICE NURSING

While death is a natural occurrence, dying itself can be a major life crisis. The hospice nurse believes in the innate value of human life, in the potential for self-growth during and after times of crisis, and in the right of each human being to freedom of choice.

Styles of coping with crisis and stress vary widely among individuals. Hospice nursing management is based on a holistic view of each patient, with attention to the physical, psychological, and interpersonal needs as defined by the patient and family.

The primary goal is comfort care and quality of life after reasonable measures for cure have failed. Specifically this means keeping patients alert, comfortable, and pain free in the place of their choice, in the manner they wish, and to give them the support needed to live and die in their own way, with dignity maintained.

Another goal is to identify patient/family needs and then design interventions that will fulfill those needs. The hospice nurse supports existing coping methods or provides guidance in the development of alternatives.

The hospice nurse assumes primary responsibility for care yet functions as an interdisciplinary team member. Hospice nursing can be practiced in any setting (home, hospital, extended care facility), given acknowledgment of the importance of the underlying philosophy. At Hospice of Marin, that philosophy is the guiding focus of care.

THE ROLE OF THE HOSPICE NURSE

ASSESSMENT

Initial Assessment

Orientation to HOM services

Obtain baseline information

- Vital statistics
- Medical history
- Current treatment
- Response to treatment and disease process
- Patient/family understanding of disease
- Presenting problems
- Current medications
- Physical assessment
 - Body system function
 - Functional abilities/ADL's
 - Pain assessment
 - Relief measures
- Psychosocial
 - Support systems
 - Coping mechanisms, behavior
- Patient/family goals and needs, expectations from HOM

Identify problem areas

On-going Assessment

NURSING DIAGNOSIS

Establish Plan for Intervention in Problem Areas

Monitor for Potential Problems

INTERVENTION

Symptom Control (eg, pain, nausea, vomiting, problems with elimination, SOB, dysphagia, anorexia)

Assess for cause/contributing factors and institute appropriate relief measures with MD approval

Direct Patient Care (eg, monitor vital signs, provide bowel care, decubitus care, dressing changes)

Home health aide for personal care

Teaching (patient/family, caregiver)

- By repetition, role modeling, reinforcement
- Provide on-going supervision with assessment of continuing learning needs
- Provide information necessary for follow-up with medical/treatment regimen (eg, mouth and skin care, use of equipment, transfer techniques, safety, nutritional requirements, wound/catheter/colostomy care, anticipated course of disease, decline, death)

Attendance at Time of Death

- Assist with calling MD for pronouncement of death
- Offer assistance with spiritual needs
- Notify mortuary
- Assure dignified care, preparation, and removal of body
- Support family members by confirming their role in the patient's living/dying process

Bereavement Follow-Up (as indicated)

- Attend funeral
- Family follow-up (individual or group)

Emotional Support

- Accept/affirm patient/family's life style
 - Reassure re normalcy of feelings
 - Develop trust through sensitive approach
 - Support individual coping mechanisms
 - Promote independence/responsibility throughout course of disease
- Assist patient/family to set priorities
 - Adjust to changes in status throughout course of disease
 - Solve daily living problems
 - Set short term realistic goals, reorder time
- Provide continued availability (prevents fears of isolation and abandonment)
 - Visit regularly
 - Maintain 24-hour call seven days a week
 - Listen actively (be sensitive, flexible, accessible, non-judgmental)
 - Encourage environment for open expression of feelings
 - Provide information re disease, Tx regimen, alternatives
 - Respond to questions and concerns honestly and realistically
 - Assist patient to make informed choices
- Be a patient advocate
 - Facilitate open communication within family
 - Communicate with physician, hospital staff
 - Coordinate care and services

EVALUATION

- Judge Effectiveness of Intervention
- Monitor On-Going Care Planning

INTERACTION AS MEMBER OF INTERDISCIPLINARY TEAM

- Consult with Team Members
- Refer to Other Disciplines on Team

THE ROLE OF THE HOSPICE COUNSELOR

Families facing terminal illness of one of their members often experience a profound crisis. The hospice counselor's goals are to help the family minimize stresses and problems arising from the situation and to maximize the positive aspects and opportunities for growth.

At Hospice of Marin, counseling and psychological support are provided by a family counselor (MFCC) and an art therapist.

Counseling/psychological support consists of listening, of giving permission and encouragement to family members to express their thoughts and feelings, and of helping them understand and accept the wide range of normal emotional responses to grief.

In individual sessions or family conferences, the family counselor helps people to express feelings of anger, resentment, powerlessness, guilt, and sadness, and to discuss their fears and concerns about the dying process, the various treatments proposed, the actual death, or funeral plans. The counselor can also help the family to clarify the options open to them and make the decisions that are right for them.

Some people respond more readily to nonverbal methods. HOM has found art therapy to be an effective tool to express feelings that are difficult to verbalize. The art therapist uses drawing, painting, clay, collage and other media to synthesize psychotherapeutic techniques with the creative process.

Art therapy is an effective vehicle with young children affected by illness in the family since their verbal skills often are inadequate to express their emotional awareness.

With patients, art therapy can provide respite from the constant focus on physical needs and allow expression of feelings beyond conscious awareness. Some patients prefer to keep a journal or to write poetry. Any of these creative expressions can enhance the person's self-esteem and open up new opportunities for growth.

Whatever form it takes, whether provided in the home, hospital, or office, support from the hospice counselor can help family members understand what they are experiencing and adjust to the impending separation and loss. After the death, it can help them work through their grief, integrate the loss into their lives, and move beyond bereavement to new experiences and new relationships.

In selecting staff for this vital component of hospice care, HOM looks for experienced counselors who are sensitive, who understand family dynamics and human responses to loss and grief, who have excellent communication skills, and who are comfortable with illness, dying and death.

HOSPICE CHAPLAINCY

Chaplaincy is a specialized interfaith institutional ministry to persons confronted by clearly defined physical, emotional, and spiritual needs. Hospice chaplaincy is ministry to those who are dying and to those who are experiencing the loss of a loved one.

As used here, hospice chaplaincy is a collective term denoting a variety of resources and persons engaged in meeting the spiritual/religious needs of families facing terminal illness. While it includes the traditional prophetic, pastoral, and priestly dimensions of ministry, it is not restricted to the hospice chaplain but brings in all who share in providing spiritual support--other members of the interdisciplinary hospice care team and the religious leadership and resources of the community.

It is a role that must be negotiated with each patient/family to take into account their history, belief system, any differences in beliefs within the family, affiliation with a particular faith/church, and available resources when referral is appropriate. Hospice chaplaincy is limited by time, by the information available about the family, and by little prospect of extended follow-up. It is a specific service provided within a particular framework.

Chaplaincy is a listening role. It can help the patient to recollect what is past, to deal with regrets and unfinished business which may be causing pain, and to rejoice and give thanks for what has brought love and meaning to life. It can help the patient to see her/his life in a new perspective and increase awareness and readiness for what lies ahead.

In a hospice program it is the responsibility of the chaplain to make sure that patient/families are offered spiritual support in keeping with their belief systems. Specifically, the chaplain will ascertain whether a family is affiliated with a particular faith or church. If so, the chaplain will offer to contact clergy of that faith on the family's behalf, to serve as liaison for that support, and to support the family's pastor in his ministry.

If the family has no affiliation but desires religious/spiritual support, the chaplain during the illness will provide direct spiritual support or delegate care to one of a resource group of clergy of various faiths in the community. Such support can help the patient to recognize God's presence and love in the midst of uncertainty, suffering, and death and can encourage the patient or family members to "let go" by offering appropriate prayer, scripture, sacraments, or rites during the patient's decline.

At the time of death the chaplain will prepare and conduct a funeral service for non-affiliated families who desire a religious service. Such a service can provide continuity of care to surviving family members and can help, along with the work of other hospice team members, to initiate a wholesome grieving process.

HOSPICE OF MARIN, 77 MARK DRIVE #17, SAN RAFAEL, CA 94903

MANAGING A HOSPICE VOLUNTEER PROGRAM

1. Principle: Know what you want volunteers to do.
Methods: Consult with staff regarding needs.
Job descriptions: time commitment, duties, qualifications
2. Principle: Recruit from appropriate sources.
Methods: Articles in newspapers, bulletins
Posted notices
Speaking engagements
Word of mouth
3. Principle: Let inappropriate volunteers screen themselves out.
Methods: Orientation meeting
Statement of expectations
Written job description
4. Principle: Interview in depth.
Methods: Open questions
Explore reasons for wanting to volunteer
Explore experiences relevant to hospice work
Second interview by appropriate staff
5. Principle: Provide training for the specific job: policies and procedures, how job fits into the whole, expectations of staff.
Methods: Lectures
Experiential
Interaction with other volunteers and staff
6. Principle: Provide supervision.
Methods: Regular reports
Periodic formal evaluation
Feedback from staff and patient/families
Follow up on anything you hear
7. Principle: Provide on-going training.
Methods: Attendance at patient care conference
Monthly meetings
Inclusion in staff inservice

LAY PATIENT CARE VOLUNTEERS IN A HOSPICE PROGRAM

Lay volunteers are carefully selected and trained to be part of the patient care team. Their specific function is to provide patients and families with practical support services such as shopping, transportation, errand running, visiting, child care, and light housekeeping or gardening. Volunteers are assigned to these jobs at the request of the patient/family.

Volunteers work under the Volunteer Coordinator whose duties include:

1. Recruiting and interviewing prospective volunteers, screening out inappropriate volunteers, and referring them to other volunteer opportunities if appropriate.
2. Setting up procedures for initial training of volunteers and for on-going training.
3. Setting up evaluation procedures and record keeping systems for volunteer activity.
4. Assigning volunteers to specific jobs, monitoring their performance, and facilitating solutions to any problems that develop.

Volunteers are expected to adhere to the same rules of confidentiality and respect for patient/family belief systems as are professional staff. Volunteers are inappropriate for hospice programs if they have not resolved personal losses in their own lives or if they wish to impose their own beliefs about death and dying on others.

Volunteers receive on-going support and training through conferences with the Volunteer Coordinator, through monthly group meetings which address their current concerns, and through attendance at the weekly patient care conference when families with whom they are working are scheduled for discussion.

HOSPICE OF MARIN, 77 MARK DRIVE #17, SAN RAFAEL, CA 94903

MANAGING CHRONIC PAIN

CHRONIC PAIN: GENERAL

Pain is either acute or chronic. Acute pain usually has teaching value and informs us of a new injury or illness. The chronic pain that may accompany degenerative diseases is of little value once the diagnosis has been made and appropriate treatment begun. Pain that recurs or persists can in itself be debilitating and should receive careful medical and nursing attention. Chronic pain can be relieved through a variety of approaches with readily available medications. Non-chemical approaches to pain are also invaluable and must be studied and applied as indicated.

Chronic pain never occurs alone. It is always accompanied by:

- memories of past pain
- anticipation of pain yet to come
- anxiety
- depression
- anorexia, weakness, and weight loss
- insomnia and frustration
- isolation, withdrawal and hostility
- disturbed communication with caregivers and family
- thoughts about suicide

The pain threshold may be lowered in chronic pain conditions so that even minor disturbances take on immense proportions. Chronic pain affects the totality of existence with impact on other physical conditions, on the emotions, on social matters and on one's theological beliefs.

In working with patients with chronic pain it is necessary to look at the total patient/family/caregiver situation:

- What is the environment like? Who is there?
- What family dynamics are operative?
- What strengths, weaknesses and resources are present? Available?
- What is the patient/family's understanding of this illness?
- What fears, fantasies and misunderstandings are present?
- What is the physician's attitude toward the total situation?

CHRONIC PAIN: MANAGEMENT

Successful management of chronic pain includes:

- initial evaluation of the patient/family
- physical examination and diagnosis
- review of prior approaches to pain control
- evaluation of patient/family dynamics

HOSPICE OF MARIN, 77 MARK DRIVE #17, SAN RAFAEL, CA 94903

- consultation with attending physician and other personnel
- introduction of non-invasive methods to relieve pain
- development of common vocabulary to describe relief of pain
- development of system of recording medications, relief and changes
- discussion of pharmacological approach to pain relief; instruction
- repeated evaluations and examinations with re-adjustment of dosages
- coordination of interdisciplinary team
- 24-hour availability of medical/nursing support

PAIN CONTROL VOCABULARY

It is helpful to have patients learn to quantify their degree of pain or discomfort so that they can make a note of any changes in intensity or duration. This has the added benefit of moving the patient from a totally passive state in the face of pain to one of active involvement in bringing pain under control.

To begin developing communication about pain levels one should ask: "If ten signifies the most intense pain you can experience and zero is total freedom from pain, what is your level right now?" Most patients with severe pain will respond with a number in the seven-ten range; those with milder pain with a lower number. One should also ask them to describe the pain and to identify the area(s) of origin. Show them a blank chart, a "Comfort Control Chart," and ask them to record their degree of comfort/discomfort on this chart every four hours around the clock. Also ask them to add any comments about the nature or site of the pain and any other significant changes or symptoms - and to make these notes directly on the chart. This provides a graphic representation of progress (or lack of it) in the joint patient/caregiver attempt to relieve chronic pain.

The goal of such an effort is the development of "Pain-Free Intervals" of increasing duration. It is not sufficient to have a two or three hour pain-free interval between four-hourly doses of analgesic medication. That merely indicates that not enough of the proper analgesic is being administered - or that the optimum dose of an inadequate analgesic has been provided. The attainment of prolonged periods of time without recurrent pain is possible in almost all instances. There will be certain patients who experience significant relief of chronic pain except during physical motion. These patients are spoken of as having "residual movement pain" (RMP).

To achieve pain-free intervals in patients with chronic pain it is necessary to abandon the "PRN" approach to analgesic medication. It is also necessary to switch from "incomplete" analgesics like meperidine and use medications with a more potent analgesic effect, eg. morphine, dilaudid or methadone.

The difficult transition for most physicians and nurses is to prescribe and administer medication for relief of pain even though the

patient may not be experiencing recurrence of pain. Yet regularly recurrent pain under the old "PRN" method of analgesia contributed to a lower pain threshold and the need for increasing doses of medication to relieve pain. With the regular administration of adequate doses of analgesic medication, it may be possible to lower the dose of drug without witnessing recurrence or "break-through" of chronic pain.

APPROACHES TO ANALGESIA

All approaches to analgesia can be grouped into two major divisions: those that provide relief of pain without the internal use of chemicals or the introduction of any substance into the body (non-invasive), and those that call for the introduction of a substance or electrode into the body to produce a change in the way in which pain is perceived or transmitted (invasive). Many successful approaches include a combination of both non-invasive and invasive techniques.

Some non-invasive approaches and techniques are:

- positive attitude
- suggestion
- relaxation techniques
- focused attention
- hypnosis
- massage
- acupressure
- transcutaneous nerve stimulation (TNS)
- meditation
- biofeedback
- music, lighting, stimulus reduction
- counseling techniques aimed at reduction of anxieties about pain, other symptoms and the disease process. This might include exploration of spiritual concerns and the development of supportive work in this area.

Some invasive approaches and techniques are:

Chemical

- | | |
|-------------------|---|
| A. Analgesics: | (morphine,
dilaudid,
methadone,
codeine,
aspirin,
acetaminophen) |
| B. Co-analgesics: | (aspirin,
non-steroidal
anti-inflammatory drugs,
B-complex,
l-tryptophan, etc.) |

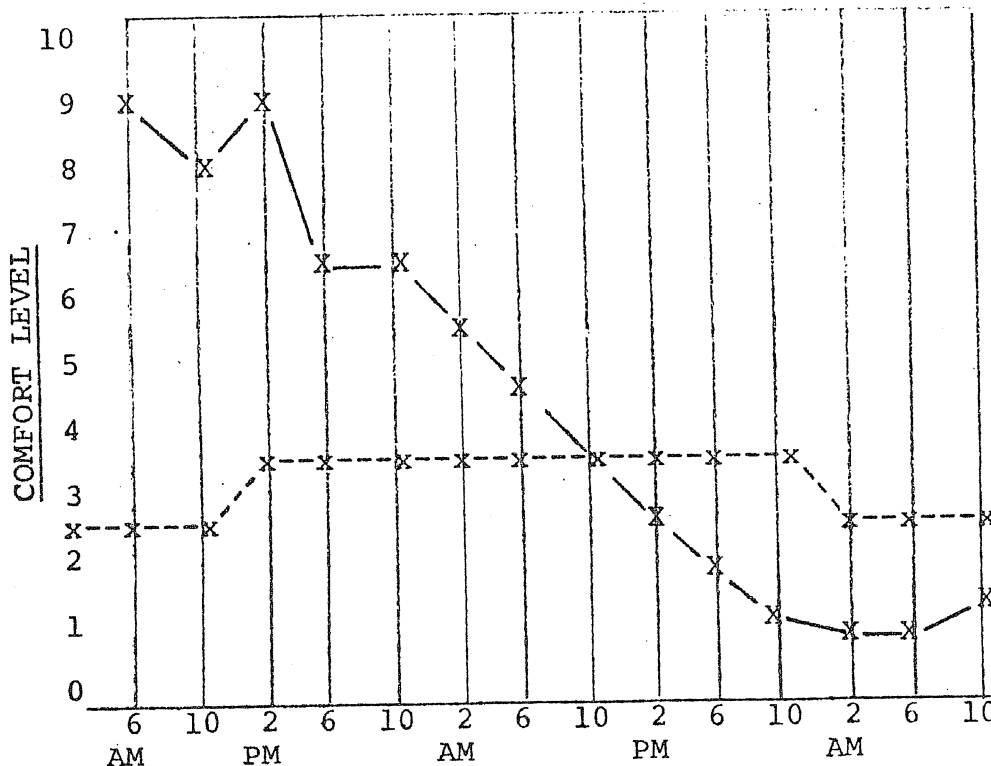
Surgical

- A. Interruption: (nerve blocks - temporary/permanent)
- B. Augmentation: (spinal cord electro-stimulation, peri-aqueductal gray matter electrode implantation)

AcupunctureCOMFORT CONTROL CHART

It is important to keep a graphic record of the approach to relief of pain so that there can be a central site for recording changes in symptoms and to show the interrelationships between taking the right amount of medication at the right time and the ultimate control of chronic pain. A record of this sort is also of great assistance in determining inadequate approaches to analgesia and in determining the degree of patient/family compliance with the prescribed approach.

Here is a typical Comfort Control Chart for the first phase of treatment:



The medication level was initially set at 25 mgm q four hours around the clock, based upon a conversion from a previously

administered dose of IM narcotic. This level proved to be inadequate, and so the dose was elevated to 35 mgm q four hours. After pain relief had been obtained the dose could be reduced to a level that initially was ineffective. Relief of chronic pain (Pain-Free Interval) can result in an apparent elevation of the pain threshold.

ANALGESIC MIXTURES

There are a number of commonly used preparations for the oral administration of narcotics for pain relief. They have come into use because of the longer life expectancy of certain diseases secondary to new methods of control. They have also been developed to offset the necessity for repeated injections, both in hospital settings and in home care. Some mixtures have therapeutic efficiency because of only one of their many ingredients. All have side effects. Some of the side effects are so discomforting to some patients that they opt for the pain rather than endure the side effects. Physicians and nurses should become familiar with the direct and side effects of the analgesic medications for it is of no value to use the right medication in the right patient for the right reason only to have the patient not use the drug properly because the physician and nursing team have not given sufficient or proper instruction regarding the possible side effects of the medication.

Schlesinger's Solution - was developed at Johns Hopkins Medical Center at the turn of the century. It contains:

morphine
ethylmorphine
scopolamine

It is a concentrated solution with the ethylmorphine added to increase the solubility of the morphine in water. The scopolamine is added to produce a dissociative reaction, a loss of memory of the pain. Scopolamine produces hallucinations, delusions and illusions together with amnesia and is therefore not readily accepted by a significant proportion of patients. It can be prepared without the scopolamine. It then becomes an oral morphine solution in water.

Valstek's Solution - contains both methadone (dolophine) and dextroamphetamine. Methadone is a long-acting opiate that is transported primarily in the lipid fraction of the serum (morphine is transported primarily in the aqueous portion of the serum). Dextroamphetamine is added for two reasons: to counteract the drowsiness that results from initiation of methadone therapy and also in the belief that amphetamines (and cocaine) potentiate the analgesic effect of the opiates. The advantage of this type of solution is that methadone can be prescribed on a q 8 hour or q 12 hour dosage schedule. However, patients who are anorexic and debilitated do not metabolize or transport methadone as well as others and may exhibit undue sedation necessitating transfer to an aqueous transported opiate like morphine.

Brompton Mixture - was developed at the Brompton Chest Hospital near London. There are several formulations of Brompton Mix. The

most commonly used formulation in England in the early days of hospice work included:

- heroin
- cocaine
- alcohol
- chloroform water
- simple syrup
- flavoring agent
- water

A phenothiazine syrup was frequently administered at the time of dosage to counteract the emetic nature of this mix. (Most of the opiate drugs stimulate the chemoreceptor trigger zone of the medulla and induce nausea and vomiting; this is a natural reaction, not an allergy, and must be explained as such to patients and families.) Low-level phenothiazines will counteract the emetic effect. Some phenothiazines, in addition, have a direct analgesic effect.

Heroin is diacetyl morphine. Controlled double-blind studies have shown it to be no more effective than morphine as an analgesic. Heroin has the advantage of greater solubility and thus takes less volume when used for IM or subcutaneous injection. But heroin is difficult to obtain through conventional medical channels in this country; therefore, morphine has come to be substituted for the heroin in Brompton Mix.

Cocaine is not an essential ingredient of the mix although some individuals express a greater feeling of well-being while on an opiate mixture containing cocaine. A number of centers have reported problems because of confusion resulting from the presence of cocaine in an opiate mixture. There has been insufficient double-blind controlled study of this to adequately evaluate the objective and subjective influence of cocaine on the efficacy of opiate analgesic mixtures.

Chloroform water has been deleted from the formulation because of the warning of the Food and Drug Administration that chloroform contributes to cancer of the liver. Chloroform water was added in the English formulation simply to provide an aromatic vehicle.

Simple syrup and flavoring agent can be added or eliminated on an individual basis according to the desire of the patient. Water is used as a solvent. Alcohol is not necessary as a solvent. Since some persons with liver disease or impaired enzyme function have difficulty handling the alcohol in opiate mixtures, alcohol should be considered optional.

self-mourning, "mourning for oneself as one is dying".
bemoaning their pending nonexistence, bemoaning the partial losses
experienced in present illness and decline that render them less than
they used to be, grieving over the pending loss to the world of
memory and wisdom, accumulated using lifetimes now about to end, and
mourning for what might have been had there been more time.

This self-mourning is an important aspect of the 'death work' of the
last days of dying: a healthy sign of proper self-respect, and
especially poignant since the dying know their talents and secret
aspirations best of all.

*self-mourning is centrally a process of finding meaning
for one's own finite & fragile existence.*

For now, there is no good way to die

By Art Caplan

There is no more dangerous place to die than an American hospital. We have made a complete hash of dying, turning it into a lonely, isolated, painful and expensive process.

Short of legalizing euthanasia, no one has a clue about a solution.

If you doubt that the picture is so bleak, take a look at the findings of what is known as the Support study, published in the Nov. 29 issue of the Journal of the American Medical Association. 1995

The study, which focused on five well-known hospitals, looked at the treatment of 4,301 adult patients who were not likely to live more than six months.

The researchers found that fewer than half the physicians knew when their patients wanted no effort made at resuscitation.

The average number of days spent in intensive care on a mechanical respirator or completely comatose before someone died was eight.

After the death, half the family members interviewed said their loved one had experienced moderate or severe pain some time during their last three days of life.

Having discovered that too many terminally ill people are being too aggressively treated — with the inexcusable exception of pain control — for too long, the Support investigators came up with an educational program to alleviate all the misery.

Highly trained nurses were assigned to 2,652 patients who were just as sick as the group previously studied. The nurses talked directly with the patients and their families about pain control, preferences about resuscitation, advance directives, living wills and their dire prognoses. On average, they met with patients, fam-

ilies and their physicians four times during the roughly six months before each patient died.

The result of the intensive educational and communication efforts? Nothing.

There was no difference whatsoever in the group of patients where nurse advocates diligently tried to inform patients and doctors about their options and solicit their views about dying, as compared with a similar group of dying patients who were not assigned a special facilitator. There were just as many days spent in pain, in a coma, hitched to a respirator and just as many unwanted attempts at cardiopulmonary resuscitation.

The researchers conclude their ghastly report with the gingerly statement that "the study certainly casts a pall over any claim that if the health-care system is given additional resources for collaborative decision making... improvements will occur." Well, not just a pall, but a 500-ton dead weight.

We Americans die miserably and the Support study makes it clear we

have not a clue what to do about fixing the problem.

A start would be to acknowledge that death is taking place in the wrong settings.

Death is not simply a biological event to be managed by technology. It is an emotional event that affects both patient and family. It has as much to do with guilt, sin, regret and redemption as it does CPR and respirators.

In today's intensive-care units there are far too many people who are handy with a respirator but not much good at conversation, spiritual support or the administration of pain killers. Until the terminally ill can die in settings where people have the time and the skills to permit a peaceful and humane death, too many of us will continue to spend huge sums of money to die in ways we do not want in places we would never wish to be.

□

Caplan is director, Center for Bioethics, University of Pennsylvania.

DEATH - 10b

1. The end of life. Hassaun Jones-Bey. Stanford Medicine, Spring 1997 4 pages
While in many ways enriching our lives, technology has also obscure
our perception of the end of life.

WHILE
IN MANY
WAYS
ENRICHING
OUR
LIVES
TECHNOLOGY
HAS
ALSO
OBSCURED
OUR
PERCEPTION
OF THE
END
OF LIFE

the end of life

BY HASSAUN JONES-BEY

photograph by keith carter

American society is re-evaluating what to do about death and dying — an examination pushed by the needs and desires of an increasingly aged population, by debates over physician-assisted suicide and by a public reform movement to cut the cost of health care.

Correcting widely held misperceptions about death and dying is an important first step in that re-evaluation, say some members of the Stanford University Medical Center community. Along with promoting a better understanding of what takes place at the inevitable end of life, health care institutions, including Stanford Health Services (SHS), are starting programs to help their patients through the final transition.

Misperceptions about death come from many sources, Stanford clinicians and medical ethicists say. One such source is television.

"In modern life, most people have experienced death only by watching TV," says James Hallenbeck, MD, medical director of the Veterans Affairs hospice facility in Menlo Park. "So for them, as a general rule, death is a violent act. They've never seen people die peacefully. So they have horrible fantasies that maybe the body is going to explode [or] maybe they are going to scream in horrible pain. I explain that for most people death is just like going to sleep."

Misperceptions also result from the fact that death is no longer a common part of the average American family experience. While television gives us a misleading image of death, modern medicine institutionalizes it, says Barbara Koenig, PhD, executive director and senior research scholar at Stanford's Center for Biomedical Ethics. Fifty years ago most people died at home; now more than 60 percent of deaths occur in hospitals and another 20 percent occur in nursing homes.

Another reason for Americans' unrealistic impressions is that the American experience of death has changed since the turn of the century, Koenig adds. At that time people more often died in their 40s — of a number of infectious illnesses and injuries that are seldom fatal today.

Today, most people die of chronic problems such as congestive heart failure. They tend to be in their 70s and 80s, and while they cannot be cured, they need a lot of care, both in and out of the hospital, to make what remains of their lives as comfortable and peaceful as possible.

Misperceptions are able to persist because doctors often have no training or experience in dealing with death and with dying patients and their families, says Trisha Jenkins, an SHS assistant nurse manager. A 20-year veteran of one of Stanford's intensive-care units, Jenkins has worked with the hospital ethics committee for the last seven years to try to sort out tough issues related to death and dying.

Since dealing with death is rarely discussed in medical school, it should be no surprise that many doctors lack these skills. For example, "[T]he *Cecil Textbook of Medicine*, a widely used classic, devotes only three pages to treatment of patients in the terminal phase of illness and separates that discussion from the 2,300 pages devoted to discussion of specific illnesses, as if death were generic and as if each individual disease, if treated correctly, would not lead to death," writes Christine K. Casse, MD, chair of the American Board of Internal Medicine End-of-Life Patient Care Project (see sidebar).

Another source of modern American misperceptions about the end of life is our society's love affair with technology. "Technophilia," as SHS chaplain Christina Miller calls it, has for many people obscured or replaced the traditional cultural and religious affiliations that helped them to understand and accept their mortality.

This technophilia manifests itself in generally accepted standards of medical care that often commit health care workers to continue trying to cure a patient, even when everyone involved feels they should not.

GRAVE WORDS

Stanford alumna Maren Monsen, MD, observed this during her residency in emergency medicine at Stanford. A terminally ill person who might slip into the final stage of death at home, due to cardiac arrest for instance, would be dragged through a bizarre yet uninterrupted sequence of events if the family happened to call 911, says Monsen, now an emergency room physician at San Francisco General Hospital.

She saw that paramedics, required to resuscitate the patient on the way to the hospital, and emergency room staff, obligated to continue working on the patient, may not discontinue efforts, no matter how useless, until the family agrees or until complete do-not-resuscitate documentation arrives.

Experiences like these led Monsen, who has also studied film at New York University and the London International Film School, to produce *Grave Words*, an award-winning educational video aimed at helping physicians communicate with dying patients.

But the problem is more complicated than just providing physician education, says Koenig, because medical technology has evolved to such a point, particularly since the 1970s, that knowing when someone is dying is no longer a simple matter.

In *Alpha & Omega: Ethics at the Frontier of Life and Death* (Addison-Wesley, 1989), Emlé Young, PhD, clinical professor of medicine (ethics) and co-director of the Center for Biomedical Ethics, describes scenarios that can occur at the intersection of biotechnology and death, while offering a framework for making difficult decisions ethically.

"Up until the '70s, we didn't think about it very much," Koenig says. "We just treated everyone until we literally could no longer physically sustain their biological existence."

The first major technological step in indefinite life support took place when the ventilator was moved out of its original surgical support role and into the ICU, she says. Then other technologies, such as kidney dialysis, followed and still more, such as artificial liver devices, are being developed.

"So now we don't die naturally, we die culturally," she says. "We die now by choice. It's when we decide that we're ready or someone else decides that we're ready, or when we decide to commit suicide."

A CLOSER LOOK

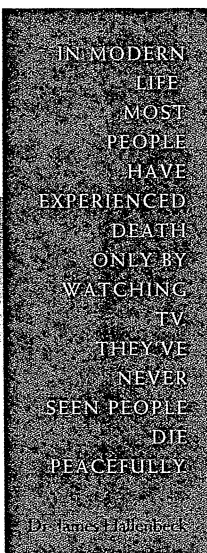
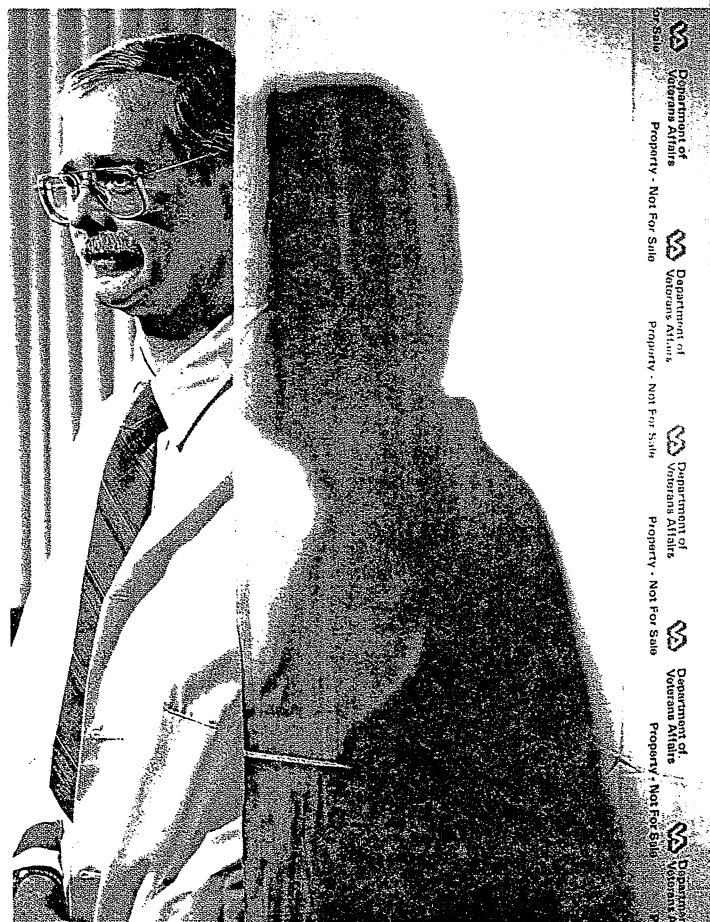
In some respects, the debate over physician-assisted suicide has caused people to take a much closer look at death. Yet, clinical observations

often provide perspectives that do not surface in the public debate.

William C. Fowkes, MD, professor of medicine and co-chief of the division of family and community medicine at Stanford, says that many of his terminally ill patients know that they could easily commit suicide by simply drinking the entire bottle of morphine that they have at their bedside to relieve their pain. Fowkes, who is also medical director of the Columbia-Good Samaritan Hospice Program in San Jose, adds that he has never known one of his patients to take that option.

Fowkes also makes a striking observation of ethnic differences in end-of-life decisions, based largely on his work with the Outreach Medical Group, a part of the San Jose-based residency for family physicians working with terminally ill patients.

He reviewed more than 500 cases over a five-year period in which terminally ill patients or their families had to decide whether to prolong life by continuing intravenous feeding or to terminate life by removing the nasogastric feeding tube. Fowkes found the percentage



seizing the moment

ORGANIZATIONS EMBARK ON
CREATIVE EFFORTS
TO SPARK
SOCIETAL CHANGE

By Hassaun Jones-Bey

A burgeoning public and professional education movement seeks to update the image of death and dying in America. Barbara Koenig, PhD, executive director and senior research scholar at Stanford's Center for Biomedical Ethics, points to the Robert Wood Johnson Foundation as one of the most influential participants, partially because it funded a pivotal four-year study documenting not only how uncomfortable dying can be in American hospitals, but also how the problem persisted even after physicians were made aware of patients' discomfort. The report was published in the Nov. 22, 1995, issue of the *Journal of the American Medical Association*.

In addition, the foundation has also invested \$1.7 million in an educational campaign called Last Acts. In February, the campaign sprouted into a 72-organization coalition, chaired by former first lady Rosalynn Carter, with the aim of updating America's perspective on death.

"With all that is going on in this area [of death and dying], we are seizing the moment," announced the foundation's president, Stanford alumnus Steven A. Schroeder, MD. "Last Acts will be much more than platitudes about a good death. It will challenge patients, families, health care professionals, medical educators, the clergy and other stakeholders to undertake new and creative efforts to improve care at a critical time in people's lives. It will push for specific reforms across the board — reforms that, if successful, will involve millions of Americans."

The Project on Death in America, funded by the Open Society Institute, is the other major participant in this national education movement, says Koenig, who chairs a Last Acts committee on diversity issues at the end of life. Information on the Project on Death in America, and on many key players in the death and dying movement, can be accessed through the Last Acts resource directory. It lists more than 300 resources related to end-of-life planning and care submitted by national organizations, educational and research institutions and government agencies.

An online directory is accessible on the World Wide Web (<http://www.rwjf.org>). A printed directory can be obtained by contacting the Robert Wood Johnson Foundation, Princeton, N.J., (Telephone: (609) 243-5776; Fax: (609) 452-1865).

PROFESSIONAL EDUCATION RESOURCES FOR PHYSICIANS AND HEALTH CARE WORKERS INCLUDE:

- *Grave Words*, an educational video for physicians, produced and directed by Maren Monsen, MD, and sponsored by Kaiser Permanente. *Grave Words* won first place in the communications category in the American Medical Association's international health and medical film festival in December 1996. The video is available through Fanlight Productions, Boston, Mass. Telephone: (800) 937-4113.
- Educational materials from the American Board of Internal Medicine's End-of-Life Patient Care Project. Telephone: (800) 441-ABIM; Fax: (215) 382-4701.
- The American Academy of Hospice and Palliative Medicine, Gainesville, Fla. Telephone: (352) 377-8900; Fax: (352) 371-2349; URL: <http://www.aahpm.org>.
- The National Hospice Organization in Arlington, Va. Telephone: (703) 243-5900; Fax: 703-525-5762; URL: <http://www.nho.org>.
- Care Beyond Cure program of the Annenberg Center for Health Sciences at Eisenhower Medical Center, Rancho Mirage, Calif. Telephone: (800) 321-3690; Fax: (619) 773-4513.
- Stanford Geriatric Education Center, Palo Alto, Calif. Telephone: (415) 723-7063; Fax: (415) 723-9692; URL: <http://www.leland.stanford.edu/dept/medfm/gec/page1.html>.
- Stanford University Center for Biomedical Ethics, Palo Alto, Calif. Telephone: (415) 723-5760.



ing quality of life against preservation of life.

Fowkes says that from his perspective, even cardiopulmonary resuscitation as a life-extending procedure has been oversold. "My colleagues know that if I drop dead in the parking lot, they are to step over me and look the other way," he jokes.

The issue of cardiopulmonary resuscitation provides a perfect example of the need for both professional and public education to help people make informed choices. In *Grave Words*, Monsen emphasizes the need for physicians to accurately describe this often painful and ineffective procedure to their patients.

In researching the literature as background for her film, Monsen found that the public's beliefs about resuscitation are at odds with reality.

In one study (reported in the June 13, 1996, *New England Journal of Medicine*) she found that television programs such as *ER*, *Chicago Hope* and *911* gave the impression that two-thirds of resuscitated patients survived to discharge. In another study, physicians predicted a survival-to-discharge rate of 26.5 percent, when the actual rate was only 3.8 percent (*Journal of General Internal Medicine*, January 1996).

Other studies have shown a 7 to 15 percent survival-to-discharge rate after resuscitation for inpatients on medical and surgical wards, and a less than 1 percent survival-to-discharge rate for patients who arrive in the emergency department without a pulse.

CONTINUUM OF CARE

To provide an alternative to the uneven odds of cardiopulmonary resuscitation (CPR), SHS is starting a new home hospice program this

C O N T I N U E D O N P A G E 3 0

who died with a nasogastric feeding tube in place was about five times higher among Asian and Hispanic patients than among non-Hispanic whites.

While no particular cultural perspective on how to deal with dying is necessarily more correct than another, Fowkes says, different perspectives about death can lead to very different attitudes when balanc-

tients spend years being misdiagnosed. "Some of my female patients were told that they had asthma, or that they were just anxious or depressed. One was told she was just fatigued because she had recently had a baby," Doyle says.

The disease starts when the tiny blood vessels in the lungs constrict or get blocked or destroyed, making it more difficult for blood to flow. That puts high pressure on the right side of the heart, which pumps blood to the lungs to be replenished with oxygen. The elevated pressure strains and enlarges the heart, eventually leading to heart failure.

Flolan works by dilating the constricted

pressant drugs like Phen-Fen and the recently approved dexfenfluramine (Redux) for more than three months have a 23-times higher risk of developing PPH, says a report in the *New England Journal of Medicine* last August (see sidebar).

The report also confirmed associations between PPH and other risk factors: cirrhosis, HIV infection, family history of pulmonary hypertension, and the use of cocaine or intravenous drugs.

Doyle says several Stanford patients had used diet drugs, a few had used methamphetamine (an illegal drug in the same class as many diet drugs) but most patients have no history of using either.

"If you take a diet drug, the chance of developing PPH is extremely small. Maybe you're willing to take the risk. The problem

"We can't discharge patients until they and their support persons are proficient at mixing the drug, hooking up to the catheter and operating the infusion pump," she says.

Every day, patients have to change the cassette that holds the medication; and it must be done quickly or symptoms return within minutes.

"This is where patient education is really important," Doyle says.

Flolan and the delivery system cost \$7,000 to \$10,000 a month. Insurance companies pay for it, but the paperwork hospital staff must complete to obtain it is staggering, Doyle says. She and Griffin hope to get more administrative support, as the program grows.

The new program has treated about 15

IF YOU TAKE A DIET DRUG, THE CHANCE OF DEVELOPING
PPH IS EXTREMELY SMALL. MAYBE YOU'RE WILLING TO TAKE THE RISK.

THE PROBLEM IS, IF YOU GET PPH, IT CAN BE FATAL.

blood vessels, which takes the pressure off the right side of the heart. As a result, breathing gets easier and the heart returns to normal size. The drug can be dangerous in high doses because it could drop blood pressure drastically and cause death.

In secondary pulmonary hypertension, various diseases like pulmonary fibrosis or emphysema destroy the pulmonary vessels, so physicians treat the cause. But in primary pulmonary hypertension, researchers don't know what causes the blood vessels in the lungs to constrict.

People who take popular appetite-sup-

is, if you get PPH, it can be fatal," she says.

Regardless of PPH's cause, the disease subsides for many people on Flolan. Some Stanford patients who started taking the medication several years ago during a clinical trial at the University of California, Los Angeles, continue to be stable.

Taking the drug requires an intense commitment because it must be carefully regulated and administered. "It's very complicated," says Paulette Egging, home pharmacy program manager. Egging and her team teach each Flolan patient, before and during the patient's hospital stay.

people with Flolan since August and has fielded another half-dozen referrals since then, says Griffin, who has received a number of inquiries recently, partly because of a deluge of media coverage about the side effects of diet drugs. Word about the program is spreading through a PPH support group in San Jose, one of 10 support groups in the country sponsored by the United Patients Association for Pulmonary Hypertension Inc.

"From the general practitioner's point of view, PPH is rare," Doyle says. "From where I sit, I feel like it's an epidemic." SM

THE END OF LIFE

CONTINUED FROM PAGE 29

spring for terminally ill people who would prefer to spend their final moments peacefully. The program has currently enrolled seven test patients and has applied for a certifying survey from Medicare, says Hallenbeck, who in addition to directing the VA hospice in Menlo Park, also directs Stanford's new hospice.

Operated through Stanford's existing home care program, the entire program is called Stanford Hospice and Homecare. But while the home care service has always provided palliative-care services, the hospice group has instituted a multi-disciplinary team approach to terminal-patient care that includes everyone from physicians and nurses to social workers, spiritual counselors and community volunteers, says Pam McFarlin, the hospice and home care coordinator.

For instance, even after the patient dies, hospice care offers bereavement services to

the family for up to a year.

There are other excellent hospices in the area, McFarlin says, but Stanford's hospice will help avoid the need to transfer terminally ill patients to a different facility and a different health care team in the last few weeks, or even days, of life.

"At that time it is extremely stressful for families and patients to have to get to know a whole new group of people and a whole new system," she says.

Both McFarlin and Hallenbeck see the new hospice as a way to extend Stanford's reputation for the highest quality curative medicine to include the highest-quality palliative medicine also.

"I would like to see the day when people come to Stanford not just for the miracle cures or for the most high-tech medicine but because it's the best medicine across the entire spectrum," Hallenbeck says, "from very aggressive care, when that's appropriate, to care at the end of life, emphasizing quality of life, when that's appropriate." SM

OUNCE OF PREVENTION

CONTINUED FROM PAGE 17

or to stop computer game play may mask a more serious psychological disturbance.

Not all risks of computers and the Internet arise from psychological disturbances. The greatest risks include eye-strain, wrist strain, back pain.

And then there is also the risk of learning something worthwhile, because a lot more than just sex and cults can be found on the Net, including Shakespeare, the National Cancer Institute and the San Francisco 49ers, as well as connections to almost everything you've wondered about. So, go surfing — in good mental health.

DR. STEIN, a clinical research fellow in psychiatry and behavioral sciences, is a computer addiction specialist and was a member of the U.S. Food and Drug Administration's 1996 panel on FDA-Regulated Medical Products on the Internet. She can be reached by e-mail at ssteinmd@leland.stanford.edu.

Chapter 7	<i>Hospice Principles and Caring for the Dying</i>	144
	<i>Glenda Williams: Illness, Dying, and Death in Institutions</i>	145
	<i>Recognizing and Responding to the Needs of the Dying</i>	147
	<i>Hospice Philosophy and Principles</i>	148
	<i>Programs That Care for the Dying</i>	150
	<i>Hospitals</i>	151
	<i>Long-Term Care Facilities</i>	153
	<i>Hospice Programs</i>	157
	<i>Summary</i>	160
	<i>QUESTIONS FOR REVIEW AND DISCUSSION</i>	161
	<i>SUGGESTED READINGS</i>	162

Chapter 7 *Hospice Principles and Caring for the Dying* 144

*Glenda Williams: Illness, Dying, and Death in
Institutions* 145

Recognizing and Responding to the Needs of the Dying 147

Hospice Philosophy and Principles 148

Programs That Care for the Dying 150

Hospitals 151

Long-Term Care Facilities 153

Hospice Programs 157

Summary 160

QUESTIONS FOR REVIEW AND DISCUSSION 161

SUGGESTED READINGS 162

CHAPTER 7. HOSPICE PRINCIPLES AND CARING FOR THE DYING

HOSPICE IS A FORM OF PALLIATIVE CARE FOR THOSE WHO ARE COPING WITH DYING

What is Palliative Care?

Palliative care means addressing symptoms rather than their underlying causes.

In other words, palliative care is essentially an affirmation of life and a rejection of the statement that "there is nothing more that we can do."

Palliative care is especially significant for those who are dying. For them, it makes the difference between another good day of living and another terrible day of dying.

Saunders observed that palliative care represents "the unique period in the patient's illness when the long defeat of living can be gradually converted into a positive achievement in dying."

GLENDA WILLIAMS: ILLNESS, DYING AND DEATH IN INSTITUTIONS

It is the story of Glenda Williams with two healthy children, who discovers that she has cancer of the breast. She undergoes treatment and goes through treatment provided by hospital, outpatient clinics and community home care program. Finally, when her pain became less manageable, she is transferred to the hospice inpatient unit, where she died.

But before her death Glenda continued to marvel that people associated with the hospice program had time to just sit and be with her; this form of care seemed different because people did not spend all of their time talking about disease, treatments, and death.

RECOGNIZING AND RESPONDING TO THE NEEDS OF THE DYING

What people need most when they are dying is:

- relief from distressing symptoms of disease
- the security of a caring environment
- sustained expert care
- and assurance that they and their families will not be abandoned.

These needs require of us, a new understanding on several key points:

1. a new understanding of the situation of those who are coping with dying.
2. nature of pain in terminal illness
3. appropriate therapeutic regimes for terminally ill
4. value of holistic, person-centered care and interdisciplinary teamwork
5. creation of social organization of programs serving those coping with dying.

HOSPICE PHILOSOPHY AND PRINCIPLES

1. Hospice is a philosophy, not a facility
2. The hospice philosophy affirms life, not death.
3. The affirmation of life that is central to the hospice philosophy is expressed in an effort to maximize present quality in living.
4. The hospice approach offers care to the patient and family unit.
5. Hospice is holistic care.

6. Hospice offers continuing care and ongoing support to bereaved survivors after the death of someone they love.
7. The hospice approach seeks relevant ways to combine professional skills and human presence through interdisciplinary teamwork.
8. Hospice programs make services available on a 24-hour-a-day, 7 day-a-week basis.
9. Hospice programs support their own staff and volunteers.
10. The hospice philosophy can be applied to a variety of individuals and their family members who are coping with a life-threatening illness, dying, death, and/or bereavement.

PROGRAMS THAT CARE FOR THE DYING

1. Hospitals
2. Long Term Care Facilities
3. Hospice Programs

HOSPITALS

1. The word hospital is derived from medieval Latin hospitale, meaning a place of "reception and entertainment of pilgrims, travellers, and strangers".

Hospitale is the basic root of several English terms, including hostel, hotel, hospital, hospitality and hospice.

2. In the ancient world, the original places of reception took in pilgrims, travelers, the needy, the destitute, the infirm, the aged and the sick. Thus, a broad range of people were served by the ancient hospitale.
3. Then our textbook covers the changes that occurred in the emergence of the modern hospital.
 - from the new understanding of disease and the human body
 - from educational function to the curing of the disease
 - and the emergence of technology/science into medicine.

The following notes are not from the textbook

THE HOSPITALS

1. Today, few people die at home—they die in hospitals.
As soon as an illness seems serious, the doctor usually sends his patients to the hospital.
2. The hospital is the scene of the normal death, expected and accepted by medical personnel and others.
3. Note the progression:
 - the dying man abandoned to his family the control of the end of his life, and of his death.
 - the family, in turn, passed this responsibility on to the scientific miracle worker—the doctor/hospital.
4. Now, the doctor deals with questions:
 - what is death
 - who is dead
 - when is one dead
 - how long to keep the patient alive.

TRANSFER OF DEATH TO HOSPITAL HAS HAD PROFOUND CONSEQUENCES

One: hospital has local monopoly on death

- it has complex equipment
- competent personnel
- frequent interventions

Two: Death has been redefined

- does death occur when heart stops?
- when vital signs are gone?
- or when brain ceases to generate electrical energy?

"The brain is our master control; the heart is just a pump."

The old signs, such as cessation of heartbeat or respiration, are no longer sufficient.

They have been replaced by measurement of cerebral activity, the electroencephalogram.

Third: Death has ceased to be accepted as a natural phenomenon—death is now a failure.

This is the attitude of doctors who claim the control of death as their mission in medicine.

Fourth: "The acceptable style of facing death"

The hospital personnel have defined an "acceptable style of facing death"

-that is the death of the patient who pretends that he is not going to die.

-he will be better ⁱⁿ this deception if he does not know the truth himself.

-the patient's passivity is maintained by sedatives, especially at the end, when pain becomes unbearable.

-morphine controls the great crisis, but it also diminishes one's consciousness.

Fifth: Moral significance of death has been overlooked.

Death has been moved "as human experience from the moral to the technical order".

"Death is a technical matter, a failure of technology in rescuing the body from a threat to its functioning and integrity. For the moment it does not matter that death of a person cannot be removed from the moral order by the very nature of personhood, what matters is the mythology of the society. the wide-spread mythology that things essentially moral can be made technical is reinforced by the effect of technology in altering other events besides death."—Eric J. Cassell, "Dying in a Technological Society", Hastings Center Studies 2, no. 2 (May 1974) 31.

Cassell asks, "How can it be that questions of morality and human values (once) so basic to the care of the dying seem remote, 'strange', or tangential in the actual setting of care?"
"Being and Becoming Dead" in Death in American Experience, p. 163

The technological imperative:

the assumption that the medical technology that we invent must be used. If we can, we must.

"The tool, made as a means to an end, becomes an end in itself. e.g. the cardiovascular machinery, invented to support traditional indicators of life, has become the locus of life

itself until life's only purpose seems to be, ironically enough, the further support of medical devices." Hans Joans, "The Philosophy of Technology", Hastings Center Studies 9 (February 1979).

LONG-TERM CARE FACILITIES

Long-termcare facilities can be divided into several types:

First: there are board and care homes or shelter care facilities these are essentially residential facilities offering:

- a place to live
- obtain one's basic meals
- companionship

Second: is the intermediate care facility.

Care in such a facility is typically provided by nursing assistants or aides.

Third: there are skilled nursing care facilities in which care is provided by professional nurses.

HOSPICE PROGRAMS

Hospice programs are the newest social structure in our death system, one that has already become a major way of caring for those who are coping with dying.

Hospice programs engage professional persons, volunteers, and the public in complex interactions.

Today, hospice programs emphasize care for those who are in the final stages of the journey of life.

Services are designed primarily to provide care for those who are terminally ill.

The work of Dr. (and now also Dame) Cicely Saunders

She founded the St. Christopher's Hospice in southeast London in 1967.

She developed medications for the management of chronic pain in terminal illness.

The program came to Canada in 1975; in U.S. in 1974.

In 1982, a hospice benefit was approved as an aspect of Medicare reimbursement for health care.

Admission criteria required:

- a diagnosis of terminal illness
- prognosis of less than six months to live
- and the presence of a key caregiver in the home.

In 1990, more than 200,000 patients were served by the Medicare hospice benefit.

Spirituality

First: it enters other dimensions of human person:
body, feelings, mind.

1. Spirit engages in a struggle to liberate each of these dimensions toward unity and wholeness.
2. Spirit enters these dimensions without destroying their integrity. Rather, it includes them and coordinates their movements into a wider unity and wholeness.
3. What this means: spirit is constantly recreating person. It is the process whereby a person becomes a whole person, fully alive.

Examples of what happens when Spirit enters Body (sexuality)

Allows sexuality to transcend itself to become love:

- now, one can be oneself
- accepts others as person
- willingness to be transformed for sake of other

Example of what happens when Spirit enters feelings:

It allows us to affirm our feelings (guilt, depression, etc)

Why we lose touch with our spiritual depth and fall into confusion?

- Our human nature is open and fluid, not fixed
being so open, we are subject to both uncertainty/pain
being so open, we get easily hurt, anxious

- Our uncertainty about our identity makes us anxious, so
we pretend we can attain certainty, toughness

What is way back to wholeness?

lies in direction of learning to remain open/vulnerable

Example of what happens to Mind when Spirit enters it:

1. Mind raises questions, analyzes, creates meaning.
2. When Spirit enters mind, it pushes mind to sense of mystery

And to that mystery, spirit makes a response.

For example, mind raises questions about basic human concerns-
like loneliness, suffering.

And toward such concerns, Spirit makes response (not answers).

3. With Mind we look at things; in Spirit, we behold.

Second: Spirit works by seeking the other

1. Not to change people, but seeks to be Presence; presence of someone who cares.
2. When you become a presence, then, you realize that:
 - Spirituality does not solve problems
 - offers no answers for our many questions
 - it does not work for result.
3. Simply being with someone is difficult:
 - because it asks of us that we share in other's vulnerability
 - enter into experience of weakness/powerlessness
 - become part of uncertainty
 - give up control
4. What presence does: it creates Aloha Space
A friendly space where others can enter and discover themselves
as created free.

Creating space for others is far from an easy task:

it requires hard concentration and articulate work

WHAT BLOCKS SPIRITUALITY

1. Control. Gotta be my way; within my control.

Irony of control: when you're in control, you win from world, others
only its superficial secrets; little of its inner meaning is disclosed.

-6-

*"We are haunted by the image of
exterminating ourselves as a species
by means of our own technology."*

Life After Death

In the face of death, there is a compelling and universal need for a sense of connection and immortality. Life requires a perception of connection that extends beyond death. This sense of immortality is not just our denial of death. More importantly, it is our effort to find our connection with all of human history, with the continuity of life. It is a need that is part of humankind's quest for mastery, continuity, and meaning.

This sense of continuity of life is profoundly threatened today. We have a new relationship with death. We are haunted by the image of exterminating ourselves as a species by means of our own technology. As a consequence, the traditional expressions of immortality (bio-social, ancestors; theological, the need for transcendence; creative, immortality via creative works; being one with nature) by which man has maintained his sense of continuity with life have been threatened.

And yet, from near-death experiences we continue to have some sense of "something beyond." Raymond Moody in his *Life After Life* summarizes the common elements of the near-death experience:

A man is dying and, as he reaches the point of greatest physical distress, he hears himself pronounced dead by his doctor. He begins to hear an uncomfortable noise, a loud ringing or buzzing, and at the same time feels himself moving very rapidly through a long dark tunnel. After this, he suddenly finds himself outside of his own physical body, but still in the immediate physical environment, and he sees his own body from a distance, as though he is a spectator. He watches the resuscitation attempts from this unusual vantage point and is in a state of emotional upheaval.

After a while, he collects himself and becomes more accustomed to his odd condition. He notices that he still has

a "body," but one of a very different nature and with very different powers from the physical body he has left behind. Soon other things begin to happen. Others come to meet and to help him. He glimpses the spirits of relatives and friends who have already died, and a loving, warm spirit of a kind he has never encountered before—a being of light—appears before him. This being asks him a question, nonverbally, to make him evaluate his life and helps him along by showing him a panoramic, instantaneous playback of the major events of his life. At some point he finds himself approaching some sort of barrier or border, apparently representing the limit between earthly life and the next life. Yet, he finds that he must go back to the earth, that the time for his death has not yet come. At this point he resists, for by now he is taken up with his experience in the afterlife and does not want to return. He is overwhelmed by intense feelings of joy, love, and peace. Despite his attitude, though, he somehow reunites with his physical body and lives. Later, he tries to tell others, but he has trouble doing so. In the first place, he can find no human words adequate to describe these unearthly episodes. He also finds that others scoff, so he stops telling other people. Still, the experience affects his life profoundly, especially his views about death and its relationship to life.

A word of caution. Knowing and giving too many details and precise answers to what happens after death can easily become self-deception. Beware!



Dr. Mitsuo Aoki, professor emeritus of religion at the University of Hawaii, has done extensive work in the area of death and dying—a field he pioneered in Hawaii. He was instrumental in promoting and later establishing the work of Hospice and Make Today Count (for terminally ill

persons) in the islands and he has trained hundreds of persons—both professional and lay—in working with the terminally ill and investigating the process of grieving and healing. In 1982, he was selected as one of 12 finalists in the U.S. for the Thomas Jefferson Award for volunteer service. In 1983, the University honored him with the Regents Medal for Excellence in Teaching. His students affectionately call him their favorite "cosmic dancer."

*"An awesome change takes place, a
'knowing,' oftentimes a few hours
or a few days before death."*

-5-



the ground—leaves, branches, trunk. But the tree is not a tree without its roots. Grief can take us to the roots of life itself. There is no hiding place; you see the depth of your desires and judgments. You also see the depth of freedom and love.

The first response in the process of grieving is that of shock, numbness, disbelief, and denial. We are overcome by the feeling of unreality; it is as though it were happening to someone else. These are other responses, too: guilt, resentment, anger, remorse, emptiness, loneliness. These are strong feelings, powerful and frightening to the bereaved. Anger and aggression are common. We feel deserted by the deceased, whose absence causes pain and hence anger. Guilt takes on many forms. It may be acted out in unreasonable accusations; it may show up as anger against others, a substitute for anger at oneself; it may show up in depression when anger is directed inward. The closer the relationship, the deeper the guilt may be.

We may also keep on searching for the dead—in

everything, in dreams. We see the dead person's face in familiar places; we seek clues for his or her presence. Because of this longing, we seek comfort and consolation from others. Yet there is no real consolation, for we want the return of the dead person. And because there is no consolation, we may feel cut off or rejected.

Grief peaks about four to six weeks after the loss of a loved one and usually lasts about three months but can linger for as long as a year. When the loss is accepted, the work of mourning begins. We begin undoing the various processes that went into building relationships. All bits of interaction are reviewed, and we re-experience past relationships and memories. There is a lot of ambivalence, acceptance and negation, and a predominating sadness.

In the early part of the process, the whole external world of the bereaved seems disorganized. Everything seems pointless, and the world we thought was organized seems to collapse. Gradually, this world reintegrates. We move on to resolution and learning to begin to live

Burial practices

1. Burial practices are a particularly good indicator of death-related attitudes among the New England Puritans.
 - a) At first, absence of ceremony and restraint of emotion reflected the Puritan reaction to the excesses of "papist" practices.
 - b) The corpse was regarded as a meaningless husk, burial was swift and simple, and excessive displays of sadness or grief were discouraged.
 - c) Funeral sermons were not delivered at the time of burial.
2. In latter half of 17th century, Puritan society in New England experienced many changes that threatened prospects for its holy mission.

Hence, developed more and more elaborate funeral practices:

- gloves were sent to friends as a form of invitation to funeral
- church bells were rung on day of funeral
- funeral procession conducted coffin to burial ground
- after burial, friends were given food and costly funeral rings as tokens of attendance.

Prayers was conducted at the funeral and funeral sermons took on the form of eulogies.

Gravestones carved with elaborate verses praising the moral and religious character of deceased began to mark the sites of burial.

WESTERN ATTITUDES TOWARD DEATH

Focus on the work of French cultural historian, Philippe Aries.

Views of Philippe Aries are set forth in three books:

1. Western Attitudes Toward Death: From the Middle Ages to the Present
2. The Hour of Our Death. 1981
3. Images of Man and Death. 1985

From these three books, we pull out two basic ideas on the theme of death:

One basic idea: there are four themes always connected to the idea/experience of death:

- Awareness of the individual
- Defense of Society against Untamed Nature
- Belief in an Afterlife
- Belief in Existence of Evil

Second basic idea: how attitudes toward death have changed in Western society from the early Middle Ages to the present.

Divided into five basic patterns:

- Tame Death
- Death of the Self
- Remote and Imminent Death
- Death of the Other
- Death Denied: Forbidden Death

Each basic pattern is divided into two primary components:

- attitudes toward death itself
- attitudes toward the dead

**TABLE 2.1 Death-Related Attitudes in Western Thought:
Five Patterns and Two Themes According to Philippe Ariès**

<i>Same Death</i>	<i>Death of the Self</i>	<i>Remote and Imminent Death</i>	<i>Death of the Other</i>	<i>Death Denied: Forbidden Death</i>
THEME 1: ATTITUDES TOWARD DEATH				
The moment of death is familiar, simple, and public	The moment of death is a final ordeal; it affects the Last Judgment by God of the person			The moment of death is banished from view
Focus is on the community	Focus is on the dying person		Focus is on survivors	Focus is on survivors (or bureaucrats?)
Death is a sleep, until the Second Coming of Christ	Death leads to heaven or hell	Death is a natural event but is also frightening; ambivalence is the main feature	Death is an intolerable separation from the beloved; it is a sleep awaiting a reunion. Death is also a release into nature; there is little mention of God or hell.	Death is dirty and indecent
Afterlife is nonthreatening	Afterlife may involve suffering			
THEME 2: ATTITUDES TOWARD THE DEAD				
Bodies are buried in common graves in cemeteries near churches; the powerful are buried in the churches themselves	For upper classes, coffins are used and the grave site is marked; others still buried in common graves	Cemeteries move away from churches; serve <i>only</i> as burial grounds	Private graves are common; cult of the dead (visiting graves, etc.)	Coffins are "caskets"
Cemeteries are public squares		Fascination with cadaver; dissection becomes a "fashionable art"	The dead are disembodied spirits that may continue to be in this world; rise of "spiritualism"	Emphasis is on visitation, attempt to make dead appear to be "alive" ("sleeping")
		Survivors keep some part of the dead loved one (heart or hair); the "eroticization" of death		

SOURCE: Ariès, (1981).

DEATH AND THE FOUR THEMES

Philippe Aries, The Hour of our Death, 1981.

In this book, Aries claims there is a relationship between man's attitude toward death and the four themes:

- Awareness of the Individual
- Defense of Society against Untamed Nature
- Belief in an Afterlife
- Belief in Existence of Evil

I. AWARENESS OF THE INDIVIDUAL

1. Death is the key to self-understanding. Anticipation of death reveals to us who we are.

- a) It is an intellectual revolution
 - in that death helps us define human nature
- b) It is also an experiential understanding
 - in that death puts us in touch with our deepest feelings, both anxiety and hope.

"The more absolute death seems, the more authentic life becomes."
John Fowles

Poem by Nikolai Berdyaev, "If there were no Death in our World"

Death is the most profound and significant fact of life:

It lifts the very ^glast of mortals above the greyness and banality of life. (last)

And only the fact of death puts the question of life's meaning in all its depth.

Life in this world has meaning only because there is death.

If there were no death in our world, life would be deprived of meaning. Meaning is linked with ending.

And if there were no end, if in our world there was evil and endlessness of life, there would be no meaning to life whatever.

The meaning of man's moral experience throughout his whole life lies in putting him into a position to comprehend death.

2. Death reveals man as individual. Death puts us in touch with sense of a real, individual existence

- the individual is on the way to becoming decisive
- man concentrates on essentials
- an individual achieves integrity
- finds meaning in life
- take charge of one's life
- assumes a total plan for life

3. Death reveals us as persons in community

- a) We are more than just individuals; we are an integral part of community.

John Donne, "No man is an Island, entire of itself; every man is a piece of the Continent, a part of the main; if a clod be washed away by the sea, Europe is the less. Any man's death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bell tolls, it tolls for thee."

II. DEFENSE OF SOCIETY AGAINST UNTAMED NATURE

1. Nature is both order and disorder (chaos)
 - a) Man tries to control the disorder of Nature. He does it by creating defense system, namely, creation of culture/society.
 - b) This defense system achieved and maintained by:
 - creation of morality/religion
 - establishment of government/law
 - founding of economy, etc. etc.
2. Two weak spots in Nature: Sex and Death
 - a) This bulwark erected ^{against} ~~against~~ Nature had two weak spots: sex and death. Through these two spots, a little of savage violence always leaked.
 - b) Human society took great pains to reinforce these weak spots:
 - it did everything it could to tone down the violence of sex and the aggressiveness of death.
 - c) It confined sexuality by means of taboo:
 - tried to curb its expression; reduced its power; and prevent deviation
 - d) It divested death of its brutality, incongruity and its tragic dimensions
3. How? By ritualizing it; creating ceremonies
 - a) Rituals are the search for the full life, the good life.
 - It is first and foremost a technique. First for promoting the good life
 - Second: for averting evil.
 - b) By means of techniques of ritual, men imagined they can do two things:
 - first: they took firm control of material world
 - second: at ~~the~~ ^{same} time transcended the world by fashioning their own invisible projects; raised them over and above material decay and death.
 - c) There is a dark side to rituals.
 - We have used rituals against one another—so that some people become victims.

III. BELIEF IN AN AFTERLIFE

1. Man's universal urge—sense of connection.
 - a) In face of death, there is in man, a compelling and universal need:
 - a sense of connection an immortality in face of death.
 - b) This need is ~~part~~ ^{part} of organism's quest for mastery, for continuity, for meaning.
 - c) This sense of immortality is not just our denial of death.
 - But more importantly, it is the search for a way of experiencing our connection with all of human history, with continuity of life.

IV: BELIEF IN EXISTENCE OF EVIL

1. Death is never experienced as a neutral, natural phenomenon only.
 - a) Death reveals the "dark underside" of human nature and behavior.
 - There is in each of us: dark fears, inner contradictions; capacities for unspeakable cruelties, etc, etc.
 - b) Death is the "shadow" which has absorbed all the substance of life:
 - it is heavy with meaning and nonetheless elusive ^
 - it is tragic. "Time, like an ever rolling stream
Bears all its sons away."

One interpretation: Story of Adam and Eve

1. Death is natural, but at the same time, it becomes unnatural.
 - If death is natural, why do we rebel against death wherever it appears?
2. The source of this idea is found in story of Adam and Eve.
 - a) Note what happens after the plucking and eating of the forbidden fruit. They hid from God. Adam admits that fear had driven

him into flight from God.

b) Then begins the intellectual wrestle with guilt occasioned by God's question.

-Adam tries to clear himself of guilt: "the woman whom thou gavest to be with me"

-Eve was unable to bear responsibility before God: the serpent was the tempter.

c) Adam and Eve are not cursed. Severe afflictions and terrible contradictions now break upon both of their lives.

-For the woman: hardships of pregnancy, pains at birth; profound desire for the man; and humiliating domination.

-For the man: hardship and skimpiness of his livelihood which he now must seek for himself

-Then follows the prospect of death as man's return to the earth. "You are dust, and to dust you shall return."

How the Adam and Eve story provided the theological interpretation of Death as Unnatural.

1. It was God's intention that man as man should enjoy life forever.

For God made man in His image. Death does not belong to the will of God for man.

2. But in the story, man disobeyed. Because of man's disobedience, God drives them both from the Garden of Eden "lest he put forth his hand and take also of the tree of life and eat, and live forever." Genesis 3:22-23.

3. Death is now considered, not as natural, but as unnatural.

"We do not fear death because we have to die, but because we deserve to die."
Paul Tillich

WESTERN ATTITUDES TOWARD DEATH: A HISTORICAL REVIEW

BASIC PARADIGM

I. From early Middle Ages to the 16th century.

-world-view may be called holistic: there is Oneness, the Whole.

-there is unity of culture

-the world is there for you—you can take that for granted

-had a living tradition: you lived inside a tradition that nurtured/supported you in every way

-had a social world that supported you in every way

-took for granted a moral universe, essentially a Christian moral universe with a fully articulated social-political morality for whole society.

II. From 16th century leading to first part of 20th century:

There emerged a scientific paradigm which may be called Cartesian, Newtonian or Baconian, since its main characteristics were formulated by Nicolus Copernicus (1473-1543), Rene Descartes (1596-1650), Newton (1642-1727) and Francis Bacon (1561-1626).

Its basic assumption: everything is separate; hence the dynamics of the whole could only be understood from the properties of the parts.

III. From the second half of the 20th century:

May be called holistic, ecological, or systemic, but none of these adjectives characterizes it completely.

What are its basic assumption about "Reality"?

One: there is the whole, the ONE

Two: Within the Whole, there is the inseparable web of relationships. In the new paradigm, the relationship between the parts and the whole is reversed. The properties of the parts can be understood only from the dynamics of the whole.

Three: Relations are dynamic and transformative.

Things are put together in an evermore synergistic, meaningful pattern.

We tried to close her jaw before we left, but it wouldn't shut. I continued whispering pith sayings to her, then we all left the room.

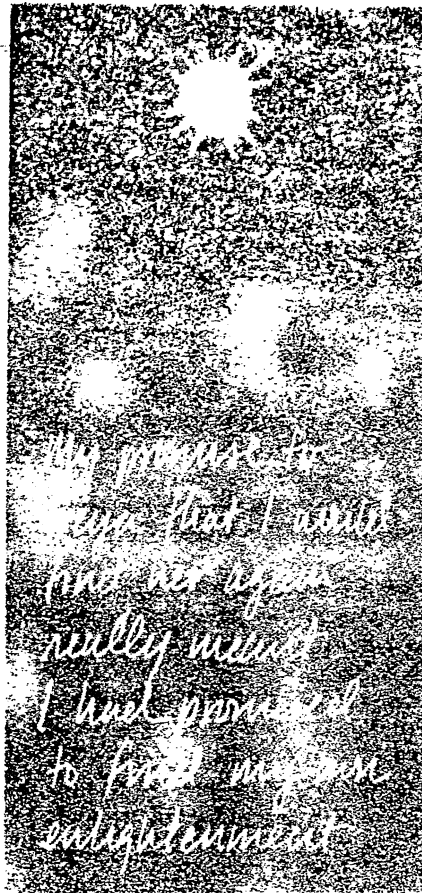
About forty-five minutes later, we went back into the room, only to be met with a stunning vision: Treya had closed her mouth, and there appeared on her face instead an extraordinary smile, a smile of utter contentment, peace, fulfillment, release. Nor was it a standard "rigor smile"—the lines were entirely and totally different. She looked exactly like a beautiful Buddha statue, smiling the smile of complete release. The lines that had been deeply etched on her face—lines of suffering and exhaustion and discomfort—had all completely disappeared. Her face was pure, smooth, without wrinkles or lines of any sort, radiant, glowing. It was so profound that we were all taken aback. But there she was, smiling, glowing, radiant, content. I found myself saying, "Treya, look at you. Treya, honey, look at you."

That smile of contentment and release remained on her face for the entire twenty-four-hour period that she was left in her bed. Her body was finally moved, but I think that smile is etched on her soul for eternity.

Everybody went up and said good-bye to her that evening. I stayed up that night and read to her until three in the morning. I read her favorite religious passages (Suzuki Roshi, Ramana Maharshi, Kalu, Saint Teresa, Saint John, Norbu, Trungpa, the Course). I performed her favorite *sadhana* or spiritual practice ("the saint of compassion"). And, most of all, I read to her the essential pointing-out instructions from the *Book of the Dead*.

These instructions I read to her forty-nine times. Their essence is this (to put it in Western terms): The time of death is the time when you shed your physical body and individual ego and become one with absolute Spirit or God. Recognizing the radiance and luminosity that naturally dawns at the time of death is thus to recognize your own awareness as eternally enlightened, or one with Godhead. You simply repeat these instructions to the person who has died, over and over again, with the very likely assumption that his or her soul can still hear you. And so this I did.

I may be imagining all of this, but I swear that, on the third reading of the essential instructions for recognizing that one's soul is one with God, something clicked audibly in the room. I actually ducked. I had the distinct and palpable feeling, at that utterly dark two o'clock hour in the morning, that Treya directly recognized her own true nature and



burned clean. In other words, she acknowledged, upon hearing it, the great liberation or enlightenment that had always been hers.

I don't know, maybe I'm imagining this. But, knowing Treya, maybe I'm not.

STAYED IN TREYA'S ROOM that night. When I finally fell asleep, I had a dream. But it wasn't a dream, it was more of a simple image: A rain-drop fell into the ocean, thus becoming one with the All. At first I thought this meant Treya had become enlightened, that Treya was the drop that had become one with the ocean of enlightenment. And that made sense.

But then I realized that it was more profound than that: I was the drop, and Treya the ocean. She had not been released—she was always so. Rather, it was I who had been released, by the simple virtue of serving her, the only dakini I have ever known.

And there it was: That was exactly why she had so insistently asked me to promise that I would find her—again, and again, and again. It wasn't that she needed me to find her; it was that, through my promise to her, she would therefore find me and help me, yet again, and again, and again. She was given to this soul that grace may abound, again and again, as long as it took for me to awaken, as long as it took for me to acknowledge, as long as it took for me to realize the Spirit that she had come so clearly to announce. And by no means had she

come for just me: Treya came for all her friends, for her family, and especially for those stricken with terrible illness. For all of this, Treya was present.

Twenty-four hours later, I kissed her forehead, and we all said good-bye. Treya, still smiling, was taken for cremation. But "good-bye" is the wrong word. Perhaps "aloha"—"till we meet again"—would be better.

DON'T THINK ANY OF US will ever actually meet Treya again. I don't think it works that way. That's much too concrete and literal. Rather, it is my own deepest feeling that every time you and I and any who knew her act from a position of integrity, and honesty, and strength, and compassion—every time we do that, now and forever, we unmistakably will meet again the mind and soul of the star dakini Treya.

That is my final feeling: If you miss Treya, and want to meet her again, then act with integrity, and honesty, and dignity. And every single time you do that, *every single time*, then your own awareness, simple and direct, is one with Treya's.

You can meet Treya again, from now to eternity, any time you want.

So my promise to Treya, the only promise that she made me repeat over and over, my promise that I would find her again—really meant that I had promised to find my own enlightened heart.

And I know, in those last six months, that I did so. I know that I found the mythic cave of enlightenment, where I was married, by grace, and where I died, by grace. This was the change that had come over me that Treya had noticed, and about which she kept saying, "What is it?" The fact is, she knew exactly what it was. She simply wanted to know if I did.

And I know, in those last few moments of death itself, and during the night that followed, when Treya's luminosity overwhelmed my soul and outshone the finite world forever, that it all became perfectly clear to me. There are no lies left in my soul, because of Treya. And Treya, honey—dear, sweet Treya—I promise to find you forever and forever and forever in my heart, as the simple awareness of what is.

"You promise?" she whispers yet again to me.

"I promise, my dearest Treya."

I promise.

To obtain an unabridged version of Ken W. ber's eulogy to his wife or to find out more about the Cancer Support Community, contact CSC, 401 Laurel St., San Francisco CA 94118, (415) 929-7400.