## It's Better Than the Alternative, Isn't It?

have a conversation with the eighty-six-year-old mother of a friend who, when she hears I'm writing a book about the golden years not being so golden, exclaims, "Oh, I don't know about that. I think these are good years."

"Tell me," I ask, "what makes these years good for you?"

The question stops her for a moment as she looks for words, then frowning and looking uncomfortable, she half mumbles: "Well, maybe they're not *golden*, but at least I still have my mate; most of my friends don't." Then she brightens and without missing a beat adds, "The best years of life are the fifties and sixties; I really loved that time. Those were the golden years. These years now, what can I say, what choice do you have? You make the best of them because it's better than the alternative, isn't it?"

It's a phrase everyone knows, one most of us say, but it tugs at me each time I hear it spoken so unquestioningly, makes me want to ask: "Is it?" Often I do; almost always it brings a confused and startled response: "You mean you think it's better to die."

It isn't that I'm so eager to die, but I can't help thinking about how destructive our fear of death is, how it compels us to live, even when "living" is little more than breathing, how we have made living, just to be alive, the unqualified objective.

Death, in earlier times, was an integrated part of life, a natural progression from one state to another, feared perhaps, but not denied, not hidden. People could see it, smell it, touch it; they knew its messiness, its meanness, its ugliness—and also its prospect of peace and release. As late as the mid-twentieth century, only 50 percent of Americans died in the hospital; the rest died at home. A mere twenty years later, the figure had jumped to 70 percent, and today it's up to 80 percent and still climbing.¹ Consequently, most Americans have never stood in the presence of death, never watched its awesome power and majesty as it took a loved one's last breath.

The whole untidy process of dying is now the province of medical experts who, with their technology, aid and abet our denial of death. It comes back to us as part of a ritual—a wake, a funeral—where we see only the embalmed, beautified body or the closed casket hiding it away. It's like listening to a story about death, a tale of a medical failure. "What a shame," people will say at a funeral. "They tried everything and nothing worked." Implying that there should be something that "works," some machine, something, that will confound death.

Long before her death, Susan Sontag, a brilliant, accomplished woman whose words were always brimming with clarity and unflinching honesty, wrote of death as "the obscene mystery, the ultimate affront, the thing that cannot be controlled. It can only be denied." A belief she lived out to the last moments of her life.

In a moving article, Ms. Sontag's son, David Rieff, pays homage to his mother's courage as she fought and won, temporarily at least, two previous cancer assaults before the last one ended in her death.

My mother was determined to try to live no matter how terrible her suffering...[Her doctor] offered her the option of treatment with a drug... which gave many M.D.S. patients some months during which they felt relatively well. But the drug did little to prolong life. My mother replied with tremendous passion, "I am not interested in the quality of my life."

Tears stung my eyes when I read it, tears for this woman I had so admired who, despite the warnings from doctors that more aggressive treatment was "medically futile," willingly submitted herself to torture just to live for another day, another week, another month.

I thought about my response for a long time, torn between whether I saw her as courageous or in the grip of fear and denial. Where's the line between the two? Is there one, or do they inevitably coexist? After all, she battled death to a temporary standstill twice before. Why shouldn't she try to do it again? How much of a chance justifies continuing the fight: 5 percent? I percent? At what point is the chance so small that it's medically irresponsible, even unethical as some physicians argue?

I have no answers; only more questions. I say firmly now that I want no part of a diminished life or one filled with pain, that death in such a condition would be an easy choice for me. But at what point will I decide that my life is diminished enough? Can I know now what will *feel* sufficiently impaired to me? Or will I find, when I'm actually walking down that path, that each crossroad I come to doesn't feel quite bad enough until, as has happened to so many others, I've crossed over the line to that place where I'm no longer capable of making the decision?

I write to a friend with whom I've been discussing these issues for some time and who's more on the side of fighting for every day of life than I am.

"I don't think I'd ever give up the fight to live," he writes. "It's either that or nothingness, and who can tolerate nothingness? I simply can't imagine myself not *being*, it's impossible to conceive. It isn't just denial of death, it's an affirmation of life."

His reply puzzles me. How can it be an affirmation of life when someone is in intolerable and incurable pain, when the mind is no longer fully functional, when the body can't do for itself the basic things necessary to sustain life? Is it affirming life or fearing death that drives people to fight for every breath?

"I actually don't understand what you're talking about," I write back. "Doesn't the quality of life mean something? If I'm tired and weak and worn out and hurt, why would the idea of nothingness fill me with such anxiety? Why wouldn't it feel like a blessing?"

He replies, "Okay, so for you the quality of life is what counts. But where do you draw the line? How terrible does life have to be to exchange it for eternal nothingness? If you can deal with that nothingness, you're a better man (pardon the gender confusion) than I am."

Then, in a postscript later that day, he writes, "I've been thinking about our conversation and, to tell you the truth, I think I'd change places with you if I could. Yours seems the easier road."

Which is easier, which harder? I don't know. What I do know is that life is full of potential, of possibilities, of promises that we're loath to give up, and that so long as we're alive we can tell ourselves we're the agents of that life, believe in the illusion that we're in control. I know, too, that death is the great unknown, the mystery we'll never solve and which, if we dare to look it in the face, offers only the terrifying realization of our helplessness. It signals the end—the end of possibility, the end of promise, the end of our very physical being—and leaves behind only a vast unknowable emptiness.

Does this make life worth living at any cost? Is it living when we're so incapacitated that we're incapable of caring for our most personal and fundamental needs? Most people say no, adding that their deepest wish is for "a good death," by which they mean one that's quick and painless. Tell any seventy-year-old that someone died of a heart attack in his sleep and it will strike both fear and hope in his heart—fear that he could be next; hope that if he is, death will come as quickly and painlessly. The worst possibility, far more frightening than dying itself, they say, is a lingering death, where pain is unremitting and they're hooked up to machines that keep them alive to no purpose. I have no doubt they mean what they say, but ambivalence reigns in death as well as in life, and when the question arises, so do the fears and the conflicting feelings.

"I know what I want and what I don't want," asserts a seventy-eight-year-old man suffering from heart disease. "I've told my family and my doctors: I want them to do what they can, but if they have to put me on machines to keep me alive, I don't want it. I don't want to be in a coma and a vegetable or anything like that unless there's a chance that I could come around and be normal again [emphasis mine]."

And in that "unless" we see his ambivalence. He wants to take control of his death, but how can he be sure he or anyone else will know when it's the right moment? So he hesitates, says "unless" as he tries to foreclose any mistakes, which leaves his doctors without a mandate and his relatives, already wishing to forestall his death, hesitant about making the decision to pull the plug. For who can know with absolute certainty that he'll never "come around and be normal again"?

True, there are differences among people. On hearing that there's one last-chance experimental procedure for a cancer that has metastasized beyond the reach of tested therapies, one seventy-five-year-old pleads, "Do whatever it takes, just save my life," while another says, "No, I'll take the months I have and live them." But even when people make the decision to forgo treatment, it's almost never without mixed feelings—conflict that's fed by a medical establishment for whom any death is a failure and by a family that wants to hold on for just a little longer.

More than a few of the people I met in the course of doing this book—some who were ill and infirm, some who were not—spoke with a compelling and authentic voice about being weary of living, saying that "life is just too long," that they're "tired and ready to go," that they want "to lay down and rest." "It's like God forgot about me. What's he waiting for?" demanded an eighty-nine-year-old woman who can no longer care for herself.

I was moved by their words, knew that part of them meant what they said, but the other part, the side that resists death, was plain for anyone who would look to see. All were in assisted-living facilities that are dedicated to saving their lives; all, in the year or two before we met, had some medical procedure that promised—a promise often unfulfilled—either to make them feel better or to extend their lives a bit. When I remarked upon the incongruence between their words and deeds, some said their doctors convinced them to do it, others explained that they gave in to pressure from family members, and a few acknowledged that at the last moment they were too afraid not to do it.

Would they have been able to forgo these treatments if they hadn't had pressure from others? They can't know, nor can we. What we can know is that the fear of death, the terror the very idea inspires, is a near-natural consequence of a society so committed to its denial that the alternatives that might allow for a different choice don't get much serious consideration, either by the medical establishment, the family, or the patient. As one eighty-eight-year-old man puts it, "When I came right up to it, I guess I was too scared not to try to put it off."

"Would you do it again?" I ask about the surgery from which

he had not yet fully recovered and that arguably left him no better than he was before.

"I sure hope not," he says with as much certainty as he can muster.

We say we want to die with dignity and mean it, but we're so frightened of death that we submit to often painful and undignified medical procedures in the often vain hope of putting off our meeting with it just a little longer. We say we want to control our death, but hope triumphs over reality, and we give over both life and death to the technicians' machines and the surgeons' knives.

But what about people who are deeply religious, who believe in an afterlife in which they'll be reunited with loved ones? Wouldn't they go more readily into death than those who don't hold that faith?

I'm certain their belief helps them through difficult times, and I have sometimes envied the comfort religious people find in their faith. I have no doubt, either, that there are women and men who believe that their impending death is God's will, that they'll find the peace and joy in death that escaped them in life, and who go as calmly and peacefully as possible into that better life.

"I had a brother who died in a motorcycle accident when he was sixteen, and my mother never was the same after that," says a fifty-nine-year-old woman, speaking about her mother's death. "She was very religious, so she believed God had some reason for taking him, but it didn't really make it easier for her to live with it. She got very emotional and was depressed most of the time after Robbie died." She heaves a sad sigh as she remembers. "It changed our lives. I don't think she ever had a happy day from the time he died until she did. When she knew she was dying, she kept thanking God for taking her so she could be with her son again, and when she finally left us, she looked... what do you call it... euphoric."

But at least from the stories I heard from others about their parents' death, most believers generally don't seem any more eager to rush off to death than those lacking in faith.

"My father died five years ago and after that my mother always talked about wanting to die so she could join my father up there and live in eternity with him," says a fifty-seven-year-old woman. "But it's funny, because when the doctors told us she had maybe a month to live, she wouldn't sign the DNR [Do Not Resuscitate] order, so she spent six months hooked up to machines."

"What do you make of that?" I ask.

"I'm not sure. I never understood why she didn't just sign it or later on, when she was still conscious, why she didn't let them turn off the machines. It was what she said she wanted the whole time after my father died, but when the time came, she couldn't do it. She said things like, 'It's God's will; he'll know when.' I have to admit, I wondered if God hadn't already told her and she just couldn't hear him, because otherwise why would she be so sick and dying. But I didn't feel like I could say anything. Anyhow, it wasn't God who finally turned off the machines, it was the doctors."

She's quiet for a moment, thoughtful, then says with a sigh, "I guess it's never easy to die, even though you believe you're going to a better place. When it comes right down to it, how do you know?"

I left her thinking about my mother, who in the years before she died complained endlessly that she had lived too long, that she'd had enough, that there was no pleasure and no reason to keep on.

"Why doesn't God take me?" she'd ask plaintively before she slipped over the edge and couldn't ask anything anymore.

After hearing the same wish every time I visited, I decided she must mean it, and asked, "Mom, would you like me to help you die?" She looked at me angrily. "What, you want to kill me?"

"No, I want you to live or die as you see fit, and you keep telling me you want to die. All I'm asking is if you want me to help."

"God doesn't need your help; he'll know when it's my time."

In fact, he didn't. She died of pneumonia, the disease caretakers call "the old people's friend," but not before I told her doctor to keep her comfortable but not to medicate her. Would she have died right then anyway? Her doctor thought she would, but when I asked for guidance, the best he could say was, "I think it's the right decision, but we can never be sure."

Some people talked actively about suicide as a means of taking control of both their lives and their deaths. Several told me that they had given clear instructions to their families not to interfere when they decided the time was right. Brave words. But despite suffering serious infirmities, they were still alive, still engaged enough to agree to talk to me, still not ready to take that final step.

"I'm waiting for the right time to do it," says a very frail ninety-one-year-old woman, explaining how she's saving pills.

"Do you have some idea when that time might be?" I ask.

"My body may be weak, but up here [pointing to her head], this works fine. So I guess the right time will be when that begins to go." She pauses a moment, looks at me with a rueful smile, and says, "I know, everyone says that, then they wait too long and can't make the decision anymore. I see it around here all the time."

A recent report from Oregon's Department of Human Services, the only state in the union that has legalized physician-assisted suicide, is instructive.<sup>5</sup> Despite the fears of those who opposed the law because they believed the state would be swamped with suicides, only sixty-four prescriptions were written for death-dealing drugs in 2005. Of those, only thirty-two people

actually chose to die and took the medication. Fifteen of the remaining thirty-two died naturally of their illnesses, seventeen were still alive at the end of the year, and six people who had been given prescriptions in 2004 took the medication and died in 2005, making a total of thirty-eight physician-assisted deaths that year. Statistics that tell us a good deal about the complexity of our relationship with death, even when we think we want it.

We can't know without asking them why people who had prescriptions would choose to wait for death without offering it a helping hand. The reasons, I'm sure, are complicated and probably weighted differently for each of them. But the one common factor was the knowledge that living or dying was in their control, that they could act when they decided the time was right. Given that so much of our anxiety about death is the uncertainty with which it makes its appearance, the pills in hand offered the assurance of certainty that made it possible to put off acting. This, the issue of control, the power to decide when it's enough, is what fuels the right-to-die movement, a movement that I expect will grow rapidly as the baby boomers, who have demanded and won control of their lives in other arenas, move into this next stage.

It's hard to imagine a time when the end-of-life decision, whether the patient chooses to make it or the family is forced to, won't be filled with conflict and ambivalence. But when, as is true in this country, there's neither public policy nor community agreement to support the decision to end a life, the field is wide open to the kind of acrimony we saw in the national furor over the Terry Schiavo case, where the courts were forced to decide whether or not to keep the machines pumping.

Ask anyone who has had to make the decision, and you'll hear stories about how hard it is, even from people who are true believers. Ask any physician, and you'll hear tales of family conflict that testify to the difficulty. Speaking of a seventy-four-year-

old woman with a long history of diabetes and all the problems that attend that disease, a doctor explains:

"Her heart finally was giving out; it happens; there's not much we can do about it at that stage. We brought her back a couple of times, had her on life support, but it was pretty clear she wasn't going to make it, and I told the family so. It's a hard time for a family, even if they're together on the decision-making, but when there's a difference, it can break your heart and theirs. In this case, the husband came in two days later and said he was ready to pull the plug but wanted to wait for the daughter to arrive from out of town.

"They were all there when I came in that evening, but the daughter had told her father she'd never forgive him if he gave the order. Everyone was in tears; the poor man didn't know what to do; the daughter was crying hysterically, saying, 'You can't kill Mom; I won't let you.' He was saying, 'She's already dead; this is what she wanted.' The two other kids were trying to calm the others down, but weren't even getting to first base. They just have to work it out, or the person who has the power has to make the decision and take the consequences. It's not easy."

As I listen, my anger rises: Who is this daughter doing this for? Her mother or herself and whatever unfinished business she thinks they may have? What right does she have to threaten her father when she'll go home to her life and family, while he's consigned to what could be a long nightmare? Thoughts that are followed almost immediately by a cautionary voice that reminds me to be careful, that I have no right to judge how a person responds in such circumstances. The emotional temperature in a family, never fully stable, flares quickly when confronted with hard decisions, none more difficult or painful than the one that asks us to have a hand in the death of a loved one.

We question our own motivations, look uncertainly at what prompts others who want to make a different choice. Simmering rivalries, long-buried conflicts, all the angers, regrets, and disappointments that are the almost inevitable accompaniment of family life—all these rise to the surface as a family confronts the questions: Is death inevitable? Is this the time? Should we wait? Our own fears of death step in, denial strengthens: There could be a miracle; it's happened before.

"What role can a doctor play in such wrenching conflicts?" I ask.

"It depends on the doctor. I believe that making a person as comfortable as possible and not extending life beyond what's reasonable is the most ethical way. But there's a lot of discussion and controversy about that right now, and different physicians make different choices. We're trained to save a life at all costs; that's what we do; that's what we swore to when we took the Hippocratic oath, so these decisions aren't easy for us either. All we have to go on is experience and the best reading of the scientific evidence. But in the end, it's art that tells you when to make the decision, not science. A doctor can only advise.

"In this case, there was another sister and a brother who played a mediating role and a couple of days later convinced their sister to go along with the program. Unfortunately," he concludes with a heavy sigh, "it doesn't always work that way and the hard feelings sometimes aren't ever resolved."

In an article titled "The Last Word on the Last Breath," Jan Hoffman raises the issue of who should have the last word: the medical experts or the patient's family? It's not an easy argument to settle, since there's something to be said for both sides.

In the decades before the upheavals of the 1960s questioned all authority, from the highest office in the land to the family doctor, decisions about life or death, if one was to be made, were the province of the physician. The doctor knew best. He (and it was nearly always a "he" then) was held in near-God-like esteem, the expert, the wise man who cared only for his patients' welfare, the

man to whom people turned for advice, who held their lives in his hands, who knew their bodies better than they knew them themselves. The patient's need to know was at the physician's discretion. Rarely were patients told the truth about their condition, especially if it were serious enough to suggest the possibility of death. Death and dying were ruled out of patient-doctor discourse; euphemism and false promises were the mode of the day.

Since then, the doctor has been flung from his lofty perch, replaced by medical technology, and the patient or an appointed surrogate rules. We demand the truth; we have laws requiring informed consent, make living wills to instruct our physicians about what we expect in our dying days, and resort to lawsuits to enforce those wishes when they are violated. A threat that weighs heavily on every doctor who's called upon to make the tough decisions.

Read what doctors write, listen to what they say, and you'll hear tales of decisions made, not on their best medical judgment but on their fears of a lawsuit. They may know in their hearts that there's nothing left to be done: the patient has been intubated, injected, studded with electrodes, shocked, and had a central line inserted into his groin. But when the patient's relatives insist it's not enough, visions of a malpractice suit and censure by the hospital's ethics committee own the day. Medical judgment is set aside, action takes over, even though they know it's not just futile but brutal. "One way or another," writes Sherwin Nuland, "the rescue credo of high-tech medicine wins out, as it almost always does."

"Kneeling on that bed, doing CPR, felt not only pointless, but like I was administering final blows to someone who had already had a hard enough life," said a young physician, recalling his first such experience. "Why was I forced to crack this person's ribs? Why couldn't we let the patient die in peace?"

I'm not advocating for a return to the doctor-knows-best days,

only for some balance, for something that looks more like a partnership where a doctor respects our needs and wishes and we respect his expertise, where we trust her best judgment at least enough to look inside ourselves, to examine our motives carefully and ask: Is our pain at losing a loved one combined with our fear and denial of death running the show?

"My father was in a coma and brain-dead; he was being kept alive by machines. I knew we had to turn them off, but my mother just couldn't let go," says a fifty-eight-year-old woman, tears flowing down her cheeks as she lived once again the impossible bind she found herself in. "She kept saying we didn't know, miracles happen, she couldn't kill him. The doctor tried to talk to her; he knew we had to end it, but she wouldn't listen.

"At one point, I asked the doctor if he just couldn't do it when we weren't there, but he couldn't; he said it was illegal because my father hadn't left any DNR instructions. But how could he? One minute he was fine, the next he was out of it, gone away before he had a chance. I know some doctors do things like that, like help out people in the end, but this guy wouldn't, and my mother just wasn't going to do it no matter what anyone said. She just sat there day after day insisting that some miracle would bring him back." She pauses, trying to contain the anger she still feels, then sighs. "My dad lived on those damn machines for eight more months before he finally died. What a waste!"

Multiply this story by the thousands and we see enormous waste—emotional waste, waste of social resources, waste of medical expertise. What is it that compels us to spend billions of dollars to keep people alive—no, not alive, breathing—while we let children go hungry?

In *The Denial of Death*, Ernest Becker's classic on death and dying, he argues that we are haunted by an "all-consuming terror" of death, "that it is a fear that is natural and is present in everyone, that it is the basic fear that influences all others, a fear

from which no one is immune, no matter how disguised it may be." But I wonder.

It may be true that death is a feared and alien monster in all modern Western societies, that we Americans are not unique in our insistent denial of death, in how much it is hidden away from common view, in our reluctance to even speak the word, crouching instead behind tired euphemisms like "passing" and "going over to the other side." But is it, as Becker asserts, a universal fear, "natural and present in everyone?" Or is our denial of death a product of a society that has the hubris to believe it can defeat it?

There's no evidence that the old in preliterate societies, who sometimes are left to die when the tribe must move on, fear death as we do. Quite the opposite. It's what they expect, probably have prepared for as part of the social compact to ensure the tribe's survival. Nor do most Eastern beliefs about death suggest the kind of pervasive fear we know.

"In India it's very different, not at all the same as it is here," explains an India-born man in his mid-sixties. "People prepare for death. That's what the last twenty years of life is supposed to be about, preparing to withdraw from worldly attachments. I don't mean people don't take care of their responsibilities, but while they're doing that, they're also in an active process of withdrawing from maya, which means this world, and moving toward the spiritual world. The idea is that an attachment to life, maya, prevents us from entering the spiritual world, which, for us, is the real world."

"Yes," I remark, "but isn't it also easier to accept death because you believe in reincarnation, that you'll come back one day, even if as something else? That doesn't feel as frightening as the nothingness we in the West fear."

"No," he says with a laugh, "you've got it all wrong. I remember a cautionary tale I heard from my mother when I was a child: A dying man saw a fly land on an apple and lick it, and he

thought: I wish I were a fly. He died and came back as a fly. That's what happens when you're not fully detached from maya; you come back and have to continue to suffer life's disappointments and pains. Being reborn is being condemned to maya; that's just what you don't want. You want to detach yourself so much that your soul will not come back. You want to attain nirvana, a state of non-being, or moksa, which is another word for the same thing."

They search for nothingness, for non-being, the very thing that frightens us most—the difference, it would seem, between Western materialism and Eastern spiritualism.

The Belgian poet Maurice Maeterlinck writes, "We deliver death into the dim hands of instinct, and we grant it not one hour of our intelligence." Perhaps we instinctively recoil from death; certainly Ernest Becker thought so. But it seems to me that the terror with which we approach death is at least partly learned, born of the reverence we give to the corporeal body, the primacy of the material self, rather than the spirit. Given those fears, it's true that reason too often is replaced by anxiety in our contemplation of death.

Yet reason doesn't always give us the answers we seek. So, much as I value reason, I can't help wondering how it happens that some people manage to outwit death, even if only briefly. A friend, whose mother had been on a respirator for some years, told me recently that she died only after he "gave her permission to go."

"I told her that I loved her very much, that she'd been a wonderful mother and I'd never forget her, and that I'd miss her. And I also assured her that my brother and I would be fine, and if she wanted to die, we'd be right there with her. Within minutes after I finished saying what I had to say, she heaved her last breath."

We've all heard such stories: people who hang on to life with amazing tenacity just until they can witness some long-awaited event—a daughter's wedding, a grandchild's Communion, a son's bar mitzvah, a prodigal child's return to the family, or in this case, a son's reassurance that he didn't need her to live—then die almost immediately afterward. No one knows how people manage to defer death in these situations. Will plays a part, certainly, but if will alone could do it, no one would die.

Death is a mystery with its own pace and its own time frame. It's the ultimate unknowable, the only act of life besides birth against which we are totally helpless. Our defense has been to deny it, to obliterate it from consciousness. We're like a small child playing peekaboo. She covers her eyes, shuts out the world, and believes it can't see her. But the world sees her, just as death finds us no matter where we hide.

In his foreword to *The Denial of Death*, Sam Keen observes that if we have the courage to face it, "the contemplation of the horror of our inevitable death is, paradoxically, the tincture that adds sweetness to mortality." When we shrink from the inevitable, when we capitulate to fear and denial, we forfeit some of the pleasure of living for the illusion of immortality and cheat ourselves of what it means to be fully alive.

When I started this book, I thought that these lines from Dylan Thomas's famous poem would be its epigram:

Do not go gentle into that good night, Old age should burn and rave at close of day; Rage, rage against the dying of the light.

I've always admired these words, always thought they were dead-on, the perfect expression of my own feelings about old age. But whatever anyone learns from reading a book, the author learns more from writing it.

I know now that it's one thing to "burn and rave" at old age, another to do so "against the dying light." I understand for the

first time how much our fight against the "good night" costs, how our fear of death imprisons us, how it invades, no, contaminates, our life, how our denial of it closes us off from the full affirmation of the life we could be living.

To live and die with dignity means to give up our denial of death, to accept it as part of life, linked to it as inevitably as the night follows day. Only then can we leave behind the fear and confusion that now assaults us and that deprives us of the full appreciation of the mystery of both life and death. As Sherwin Nuland writes so pithily, "The dignity that we seek in dying must be found in the dignity with which we have lived our lives.... The art of dying is the art of living." 12