

*The*  
GOOD  
DEATH



AN EXPLORATION  
OF  
DYING IN AMERICA

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Ann Neumann

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Ann Neumann

Beacon Press  
Boston

*For my sister, of course.*

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# Contents

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CHAPTER ONE  
Terminal Restlessness

CHAPTER TWO  
Mortality Parade

CHAPTER THREE  
Priceless Days

CHAPTER FOUR  
Double Effect

CHAPTER FIVE  
Hunger and Thirst

CHAPTER SIX  
A Small but Significant Minority

CHAPTER SEVEN  
The Most Vulnerable

CHAPTER EIGHT  
Dying Inside

CHAPTER NINE  
A Good Death

ACKNOWLEDGMENTS

WORKS CITED

INDEX

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# Terminal Restlessness

I placed the tiny, white pill on the US Army spoon my father had used to eat cereal for nearly forty years. From a white plastic bottle, about the size and shape of a small flask, I extracted five drops of pink liquid morphine. I released each drop one by one onto the spoon and used the tip of the dropper to push the Ativan in slow circles until it dissolved. Then I sucked the mixture back up into the dropper. *Morphine takes your pain away. Ativan calms you down.* I wanted to lick the spoon.

From where I stood, I could hear him move on the vinyl hospital mattress in the next room. He was only shifting, dropping his stiff, pinched hands onto the sheet beside him. Not trying to get out of bed. He had complained about the mattress until four days before, when he stopped complaining about anything. My bare feet on the cold tile in the hallway, the dropper in my hand, the acrid smell of stale coffee coming from the kitchen behind me, I stood listening to the empty house.

Perfectly cured, twenty-four-inch oak logs my father had cut, split, and stacked the previous spring now shifted with an ashy thump in the woodstove down the hall. I looked out the window to the birch feeder he had made twenty years ago. It stood firmly planted in the frozen ground. Juncos and phoebe chattered and picked at the seeds in the tray and then flitted and disappeared into the gray pines behind them.

I could not see his face, only his thin, white feet against the simulated wood grain of the footboard. The blanket had slipped to one side. He moved his right foot up and toward his body, then back to the footboard in a slow, kicking motion, trying to get the blanket back over his toes. He was awake. I looked at the watch on my left wrist, which I'd set to military time when dusk had begun to blur into dawn. It now read: 15:57.

Lifting my shoulders and working a smile into my eyes, I stepped from the hallway into his daughter's room.

The toilet in the downstairs bathroom wouldn't flush. My younger sister, Mindy, called the man who pumps septic systems to come clean out our tank. She and I took turns searching for the cap in the yard—another bit of necessary information we could no longer ask our father for. One of us kicked the frozen sod, while the other tried to keep him from getting out of bed.

Terminal restlessness, the hospice doctor had told us. At the end of life, organs begin to shut down. Old ladies who hadn't left their beds in years suddenly rise up with unimaginable strength to move furniture. Frail, aged men who have been silent for months grow angry and yell profanity at anyone who passes by. They are agitated, violent. They want to go. Our father wanted to go home, and he was sure this was not it. I tried citing the evidence to the contrary. I pointed out the ceiling he had hung, the walls he had painted, and the carpet he had laid. I showed him photos of the house he was in, the same stone house we had built together three decades before, mixing mortar and gathering stone as a family. The same house in which he wanted to die and to which I had returned to help him do so. But he did not believe me.

When a nurse from hospice arrived, my sister and I cried with relief and exhaustion. We couldn't

keep him calm. We hadn't slept in days. He kicked at us and swung his twisted arms—at us, his daughters, as if he didn't know us anymore. Even the house was against us, its plumbing gurgling and sputtering. We wanted the nurse to tell us what to do. We wanted more drugs, other drugs that would keep him calm. She insisted that we could no longer keep my father at home, even with regular visits from the hospice staff. We had to take him to the hospice facility thirty minutes away, where drugs stronger than our pink flask of morphine could be administered. We were his advocates, the ones charged with his final wish, to die at home, and we had failed. When the ambulance arrived, the septic pump truck was blocking the driveway. The EMT backed across the frozen yard as the workman searched for the tank cap with a metal rod. He stopped to watch us load our father into the ambulance, an extra in our family drama, then went back to stabbing the turf.

In the ambulance, I gripped the rail of the stretcher, feeling the familiar rise and fall and bend of the road to town. I imagined the hospice facility to be exactly what my father didn't want: rows of withering patients lined up along pastel walls, whispering middle-aged nurses, strangers in plain uniforms, their faces full of pity. My father's eyes rolled deep in his head. He struggled to get his right hand out from under the straps and turned his face away from me as I brushed the hair from his forehead.

The young EMT asked, "How was your Thanksgiving?" I looked at him without answering. For days before, we had cooked a Thanksgiving turkey but not eaten it. The day before, I had passed my thirty-seventh birthday in my pajamas, with sleeplessness, dirty bedclothes, and the responsibility of giving care I wasn't sure I had in me. And now we had failed to let our father die at home. It felt like the greatest failure, and yet I no longer knew what I was doing any more than my father in his thrashing delirium did.

Hospice nurses ran to the back doors of the ambulance when we arrived. He was awake again, moaning and struggling against the straps of the stretcher. I followed them as they rushed the stretcher down the hallway and into a private room. He fought them; they jammed needles full of heavy doses of Haldol or Thorazine, hospice drugs of choice, deep into the waning muscle of his thighs to calm him. As he slipped into quiet, I understood that he was no longer my charge. I was no longer responsible for that body. The schedule that had kept me listening and feeding and dosing and restraining for three months was over, my responsibilities usurped by the uniformed and capable. That night, as I lay on the sofa at the foot of his bed, nurses came and went with syringes and incontinence pads in two-hour intervals. Then, after ten years of eating away at his body like a gluttonous parasite, his cancer finally destroyed them both.

In the lobby, family who had come to spend a moment with him, to touch the cooling skin on his hand, to whisper last thoughts to his deaf corpse, now sat silently with their spouses. Their coats smelled of cold winter air. Their eyes reflected the deaths of the past eight months: my grandfather, ninety-four, of old age; my cousin, thirty-seven, of Hodgkin's lymphoma; and now my father, sixty, of non-Hodgkin's lymphoma.

"What do we do now?" I asked my sister. She gave the exit door at the end of the hallway a faraway look; it opened onto the stubble of a sheared winter cornfield. Quietly, a mortician opened the door and pushed a stretcher inside. Another extra, like the septic tank man, came to clean up our mess. Without looking at us, he steered into our room with a wide turn.

The mortician unfolded a square of clear plastic—the stiff, heavy kind that painters use to protect floors. Nurses straightened my father's arms and legs and then, with a sheet, lifted his body onto the stretcher. "This is my Dad," I told the mortician as he wrapped the plastic, first over Dad's legs and then his arms and hands, taping the protective layers. The plastic crinkled like a tent. In less than two days, gases in my father's body would push fluids, fecal matter, and urine out of his orifice. Morticians call it the surge. Then, when his name or number came up in the queue, they would push

his body into a furnace and reduce it to four pounds of ash in a white box that my sister would pick up and place in the corner of the rec room, where my father had always sat.

The mortician lifted Dad's head and removed our pillow, covered with green-and-brown wood ducks in flight, and handed it to me. "It's still warm," I said.

I came undone. The things that had once held me together now seemed unimportant. When a leave absence couldn't be extended long enough to see my father through his illness, I had quit my job. I finally had to acknowledge the end of my marriage, which had been dissolving for a few years like paint under solvent. Nothing else—my friends, my flat in New York City, my own ambitions—could measure up to the rugged emotional pinnacles I'd just dragged myself across. Of course I was happy to be alive, as I was courteously and knowingly told that caring for the dying should make us. But how hell, I'd seen *death*, and it was close and permanent. Final. What was I supposed to do with that?

For the first two weeks, I didn't leave my father's house, my memory-infested childhood home. I ate the canned beets he had purchased from the scratch-and-dent store, burned the wood he had neatly cut, and slept in his bed with a view of the bird feeder. I watched back-to-back reruns of *CSI*, a crime procedural that always concluded with a comforting definitive answer. Everyone brought food and left it on the porch; I didn't answer their knocks or calls. I returned their cookie tins, Pyrex dishes, and Tupperware at odd hours so I wouldn't have to see these dear neighbors and friends on their front porches in the daylight. What would I say?

Caring for my father before he died was no easier than caring for myself after. I was still lost. With haste, I knew I had to get myself up and out. I had to counter the shock of grief with the shock of change. I renewed my passport, handed the house over to my sister, raided my retirement accounts (what was I saving it for?), and booked a ticket to Japan. For a year and a half, I hurtled around the globe, from shabby guest house to broken-down bus, through Russia, down the Adriatic coast, across Cyprus, Egypt, and the rest of Africa. I was careless, reckless even, and haunted—barely dodging wild elephants, Russian crooks, thieves, thugs, and disorientation. Grief, I learned, is a journey.

Grief for a parent is also often terrifyingly messy. I spent three hours on the tiled balcony of a ramshackle hotel outside Nakuru, Kenya, comforting a middle-aged man from Baltimore. When I had told him I'd lost my father, he launched into his own story, the heartbreaking kind that chronicles the labor of caretaking because the work of mourning is easier to explain than the emotion of it. "The solemnest of industries," Emily Dickinson called it, "the sweeping up the heart." Only hours and tea into our conversation did I ask when his father had died. "Ten years ago," he told me. Ten years. I realized that I was in a club: those who knew what it was like to see the death of a loved one up close. We could almost recognize each other on the street.

It was something visceral that had sent us into a tailspin, something that had to do with caring for our loved ones' bodies. The way we watched, so closely and with such patient horror, as they fell apart—not just the dandruff and draping skin and sagging face, but the saliva and puke and soiled bedsheets. "Our brains light up in weird and remarkable ways at the sight of blood or fecal matter as these weren't, in fact, perfectly mundane," wrote Florence Williams. My brain was lit up and I wanted to know why.

While my father and I had never seen eye to eye, we were close; we'd spent years together, working and hiking. I knew what he smelled like; I was used to his body. But caring for him, bathing him, brushing his teeth, and holding the basin for him as he vomited—those were altogether different acts. I'd never asked anyone else to do those things for me, and I could only imagine what it felt like for him to give up so much physical privacy. Loss of dignity is what the hospice people called it, the loss of the ability to physically care for yourself. He was slowly being evicted from his body; it wasn't his anymore. Whatever constituted him—his brain, his soul, call it what you want—was being pushed

the curb.

I had been in the examination room with my father when he told his doctor he didn't want to try the final experimental cancer treatment (a drug course with 5 percent efficacy and guaranteed nausea, shedding hair, disability, and depression). He just wanted to go home and die. What did I think was going to happen? Yet I had not imagined what was coming. I had never taken care of a dying person before. I had never even seen someone who was dying. Why didn't the hospice nurses, on their weekly visits to our home all those months, tell us what was happening? That dying is a process of function, like digestion and circulation, slowly slacking off the job? Because it's difficult to explain? Because they see it all the time? Because the body is unpredictable?

The way we talk about dying and the way we die are two very different things. Death fills our books and movies, our music and our language, just as it has in every other human era. What's different today is that our experience of death is a simulacrum, a myth, a romance where our loved one gives us a last meaningful look, then slips into a long sleep. By the romance of death, I mean what you find in the genre of movie or novel that depicts death as noble, beautiful, or peaceful, like the 2004 movie *The Notebook*, which I caught while in a hotel room in Windhoek, Namibia. The husband reads the story of their relationship to his wife who has Alzheimer's. They're both old now and their story is nostalgic, full of vintage cars, simpler times, and well-worn family dramas. He's reading from a notebook she kept throughout their life together. Because their love is so strong, when the story is finished, his memory briefly returns and they're able to crawl into bed together, hold hands, and die peacefully in their sleep. You can find this pretty rainbows-and-butterflies motif on posters covering hospital and hospice walls, at doctors' offices, in cancer centers, on support websites. It's the Hallmark ending, exactly what I was hoping to get with my father. He'd go home, I'd make soup, he would tell me he loved me and hold my hand, and then he would close his eyes to sweet death. Deep down, we all hope for this, but we also fear that's rarely how it happens.

Part of the reason we don't know how people die is because we no longer see it up close. Plague, basic infections, and childhood diseases have, for the most part, been eradicated. We've added an additional thirty years to the human life-span in the past century. In 1900, Americans could realistically expect to live to the age of forty-seven; by the 1930s, fifty-nine. By 2000, that age expectancy had reached nearly eighty. Infant mortality rates alone have dropped from fifty-six deaths per one thousand births in 1935 to seven per one thousand in 2000. This improvement in general health in the United States has prevented many of us from directly experiencing death in our homes the way it often used to occur. Today, 80 percent of Americans die in facilities—hospitals, nursing homes, clinics. When we do see the dying or the dead, it's most often during an abbreviated visit to a hospital ward where doctors and nurses are taking care of the drugging, changing, and bathing. We're visitors. The aspects of dying that are deemed unpleasant (or not made-for-the-movies acceptable) take place behind a curtain. Death has been put off and professionalized to the point where we no longer have to dirty our hands with it.

It hasn't always been this way. Little more than three generations ago, death made frequent household calls, particularly in rural areas. In some ways, the story of medicine in my native Lancaster County is told through the story of my family, Mennonite farmers who arrived about 170 years before the first hospital was founded. My grandfather's father, Enos Harnish, was the first in the family to drive a car. He was also the first in the family to die off the farm, in a hospital, although he stayed at home until shortly before his death, his legs filling up with fluids from dropsy, what we now call congestive heart failure. His daughter, Elizabeth, died the same way. Ninety-year-old Aunt Biz sat in the Mennonite home with her legs propped up on a stool, her wavy hair a little grayer, her cackling laugh the same as ever, refusing to take medicine for the swelling. She'd had a good run of it, she was sure.



But it's another Elizabeth I think of when I think of a peaceful home death. This Elizabeth, the granddaughter of Harnishes by marriage, lived on a farm with her husband, Martin F. Witmer, less than a mile from where I went to high school. From my extended family's surprisingly well-documented history comes this story, handed down orally, then recorded on page 902 of the *Biographical Annals of Lancaster County, Pennsylvania*, printed in 1903 by J. H. Beers & Company. "The family are all Mennonites, and as the Witmers are among the oldest residents of the township they are held in very high esteem by their neighbors." Elizabeth was Martin's second wife, the stepmother of two boys and the mother of three daughters, Mary, Fannie, and Lizzie. I imagine Elizabeth, eighty-two years and twenty-one days old, shuffling along the linoleum of the draft farmhouse kitchen before morning light, fetching water for coffee. A dozen jars of pickles she canned the day before sit evenly spaced on a cloth on the counter. Zinnias, pink, red, and yellow, from the July garden are in a milk glass vase on the table. Elizabeth pauses to look at them for a moment and then collapses in a stroke that sends the kettle clattering. Fannie and Lizzie, unmarried and still living at home in their sixties, come running. Elizabeth is unconscious when they find her. They carry her up the stairs and place her in her bed, still warm from when she left it. Mary, the oldest daughter, called from her home a mile away. The three daughters tend to their mother, a chore that is more emotional than physical. She never awakes. "She was sick but one day, having had a stroke or paralysis early in the morning," the *Biographical Annals* plainly states.

A doctor at the turn of the century, particularly a doctor in rural Lancaster County, was little more than a shaman, traveling from farm to farm on horseback with a rudimentary black leather bag lashed to his saddle. His tools were few and unproven; odd tinctures in small dark bottles, smelling salts, perhaps a flask of whiskey. While a vaccine for smallpox existed, along with various other treatments for scurvy or dropsy, antibiotics were still some sixty years away. Opium was recognized as a standard treatment for pain at the end of life in the mid- to late century, but its prevalence of use is hard to gauge. Elizabeth, because she was unconscious, most likely wasn't in pain. She was surrounded by her daughters and stepsons when she died. They laid her out in her best Sunday dress, and the next day they hauled her body to the grave.

Because of medical developments, we've gotten away from caring for our dying, from seeing death up close, just as we've gotten away from making our own pickles. Our contact with death has diminished so drastically since the turn of the nineteenth century that we desperately want to know more. As Michael Lesy writes in *The Forbidden Zone*, "The fictions we live [about death] only famish our craving." After my father's death, I was famished and I could tell by the questions friends asked that they wanted to know more too. I wasn't asked the metaphysical or religious questions—Where is he now? Did he believe in God?—but the concrete questions about dying—What did he die of? Was he sick for long? How did he know he was dying? And if I talked more about how his body changed, they listened intently, too abashed to ask their own specific questions about his organs, his skin, his last breath.

The only way for us to satisfy our shock or hurt, caused by the gaping disparity between what we say about death and how it actually arrives, is to spend more time with the dying. To know how death comes for others is to know how death could come for us. Knowing what death looks like strips away all the romance but makes it easier to understand and to live through. Yet the medical community's conduct around death continues to shield us from what we want to know—and what we would benefit from knowing.

Even in hospice settings, death is hushed. At an in-hospital hospice ward on Manhattan's Lower East Side, a sheet listing each of the patients is taped to the front counter for the nurses to keep track of who's alive and who's not. Names are frequently crossed out, with new ones scratched above.

pencil. The binder that volunteers write notes in—“Mrs. Smith ate two spoons of applesauce. Enjoyed talking about her family. Showed me pictures of her grandchildren.”—often contains a note from the hospice coordinator not to mention “hospice” to the patient or their family. Either they haven’t wanted to hear the terminal news or they haven’t been told what’s happening. This practice of shielding patients from knowing their fate is not new, but it is controversial and varies according to region, patient age, class, religion, and ethnicity. When someone dies on the hospice ward, all the room doors on a wing are closed so that no one inside can see the dead body as it’s rolled off the floor. Patient stays are short, a week or less, because until the time they’ve been moved to hospice, they’ve been on other wards of the hospital receiving treatments meant to cure, treatments that have nonetheless failed to cure.

To discuss dying with a patient is sad work. Doctors have to admit their inability to cure whatever disease is ending a patient’s life. Directly discussing hospice means discussing death, and many avoid doing so. Into this fray, between the dying patient and the mute medical community, falls a patient shamed for not wanting to try another experimental treatment; a patient under pressure from family and friends to “not go gentle,” to not give up the fight; or a family wrecked by incurable disease but too distressed or ill informed to ask the right questions or know their options.

Saying no to continued treatment, removing life support, regardless of its efficacy, can feel to a family like deciding to end their loved one’s life, like a betrayal. For patients, it can be understood as giving up, as being uncooperative or depressed, even suicidal. Yet the pain often caused by ineffective treatments can be debilitating, not to mention clinically depressing and bankrupting. If that’s a good way to go out, unconscious, sick from chemo poisons, or under the pump of a ventilator, patients have begun to ask, what’s the bad way?

For the first time in human history, the definition of death changed in the 1970s. Up until then, death had meant the almost simultaneous end of heartbeat, breathing, and brain function. But a revolution in medicine took place in that decade, developing innovations that could keep the lungs and heart functioning indefinitely. Respirators and defibrillators had winnowed the definition of death down to brain function alone. And nobody—not doctors, lawyers, patients, or families—knew what that meant. For centuries, the heart and its pulse had meant life and vitality; it was the rhythm of our cultures, our communities, our familial bonds. Ancient Egyptians removed all organs but the heart before mummification, thinking it was vital to the afterlife. In the 1600s, it was thought that the soul resided in the hollow muscle of the heart. William Blake depicted the heart as the “central-sun, the heart of the world.” We get to the heart of a matter; we know things in our heart; we take serious matters to heart. And it was clear: either the heart was beating and you were alive, or it wasn’t and you were dead.

The brain is a completely different matter, mysterious and complicated. It has three primary sections, each with unique and interdependent functions. How much brain function qualifies you as alive? The whole thing? What parts of the brain make you human, not just a body with biological properties? Where in the brain does your personality, your laugh, your ability to recognize your family reside? And how do you measure these things? These medical advances—coupled with cardiopulmonary resuscitation (CPR), 911 phone lines, and the population’s shift to urban living where an ambulance team could readily reach the stricken in their homes or on the street—saved countless lives. But they also created a new area of ethics that was unexplored. No one even had a map. Sometimes a heart can be started by shocking the patient or pounding him on the chest (compressions that frequently break the ribs of the frail or elderly) and the lungs can be reactivated by forcing air into them, but if the patient has been without oxygen for more than four minutes, the amount of damage to the brain is hard to measure and often irreparable. In these cases, when

technology had preserved “life,” death often becomes a conscious decision: to stop the respirator, the pacemaker, to remove the feeding tube, to end the treatment that delivers no results. In her 2011 article for the *New York Times Magazine*, “What Broke My Father’s Heart,” journalist Katy Butler wrote about the excruciating—and ultimately impossible—task her mother asked her to complete: shutting off her father’s pacemaker. He was eighty-five and had suffered dementia for several years, and his body was in full decline. “Sewn into a lump of skin and muscle below his right clavicle was the pacemaker that helped his heart outlive his brain,” she wrote. Living without a brain wasn’t living, Butler and her mother concluded. After fifty years of watching the definition of death be pulled apart by technology, society mostly agrees. Medicine and the law are another story.

A series of cases surrounding the shifting definition of death were brought before the public in the 1970s, including that of Karen Ann Quinlan. Quinlan was twenty-one when she collapsed after drinking alcohol and taking Valium. She had been unconscious and not breathing for more than fifteen minutes by the time paramedics arrived and resuscitated her. How much of her brain was still functioning was a mystery. After she had been kept alive on machines for a year, her parents “began to ask a question never really asked before in human experience: Should they turn off the respirator, which could not return their daughter to ‘living’ life, and allow their daughter, Karen Ann Quinlan, to die?” writes lawyer William H. Colby in *Unplugged: Reclaiming Our Right to Die in America*. The hospital feared homicide charges and refused. The Quinlan case, which flooded national and international headlines, was taken to the New Jersey Supreme Court, which side-stepped the “is Karen alive?” question. The court determined that a patient and her family had the right to privacy and could deny medical treatments, even if that denial meant certain death. Americans in their living rooms watched the media drama the Quinlan family lived through and en masse decided that being artificially kept alive on machines was not their idea of a good death.

In 1969, Elisabeth Kübler-Ross, a Swiss American, published a study on the five stages of grief, *On Death and Dying*. The book focused attention on patients at the end of their lives and began the grassroots movement to improve end-of-life care in the United States. The first modern hospice was opened here in 1971. Now, nearly 1.5 million deaths (out of a total of 2.5 million) occur in hospice each year. The number is misleading though. While patients can be admitted to a hospice program if they are diagnosed with six months or less to live, the average stay is less than two weeks. More than a third die after only seven days in hospice. One challenge is the requirement that patients’ end curative treatment before being admitted; some are not ready to give up the hope for recovery. While the focus of hospice is to keep dying patients as comfortable as possible, financial, familial, cultural, and ethnic variables continue to make the hospice experience different for every patient. Some have families with enough resources—money and time—to care for them as they die at home (Medicare typically only covers four hours of in-home care a day, not enough for those who are immobile or alone). Still others are moved to in-hospital hospice wards when they or their family finally acknowledge that the illness can’t be cured. Others finish out their days in an elder home, with a hospice nurse paying visits to the facility. There are also designated hospice facilities, like the one my father died in.

Alongside the growth of the hospice movement came the autonomy movement, which pursued another route in its search for a good death: the law. Forms such as advanced directives, medical proxies, and living wills have been developed to help us make our final decisions; laws have been enacted at the state and federal levels to protect those decisions. After my father’s death, I went straight to our family lawyer and had him draw up my own will and medical proxy. Everyone who knows me well knows where these documents are kept (in a manila envelope in the gray metal file box to the right of my desk, the numbers for my sister and my lawyer on a Post-it note stuck to the outside). Yet the existence of laws that protect my end-of-life wishes doesn’t mean I’ll get what

want should a bus hit me on the busy streets of Manhattan tomorrow. Routinely, law is thwarted in practice: an ambulance crew, say, that must resuscitate me and has no way of knowing what my living will says or even if I have one; an estranged relative showing up at my hospital bed to demand that everything be done to “save my life”; even my grieving family’s inability or unwillingness to request that life support be stopped.

Depending on what factions of the hospice and autonomy movements you look at, they’ve overlapped and learned much from one another over the last forty years. An emphasis on community and family relations imbues each with a focus on support structures and joint decision making. The well-being of the patient is rightly primary. Yet both movements are still without power in the face of endless medical advancements, uninformed legislators who shape end-of-life laws, “pro-life” activists who eschew choice for saving “life” at all costs, and general ignorance of what dying is like. Neither movement has fully grasped the meaning (and variability) of its own resounding principles: dignity and a good death. Dignity and a good death, just as death itself, continue to be terms that are not defined. They’re concepts that are unique for each one of us, depending on our age, culture, faith, interests, and a host of other factors. How can hospice, with its intentional and specific idea of a good death, and how can the autonomy movement, with stacks of legal documents, ever anticipate the variety of death experiences?

Furthermore, because of the institutionalization of death—our removal from it and our inability through experience, to know how it happens—and the numbing effects of grief, we often don’t so much make decisions as drift into passive indecision and acquiescence to authority, whether it be that of doctors or nurses or a hospital board. It’s what Joanne Lynn, a geriatrician at the College of Medicine at Ohio State University, called the “glide path.” Patients are encouraged by medical staff to comply with a phalanx of tests and treatments that bring hope but don’t improve their loved one’s health, and that often increase pain and suffering. The next thing they know, ninety-five-year-old grandma is prescribed a new drug for her Alzheimer’s (that costs the family’s savings and may or may not react with whatever drugs she’s already taking) or eighty-two-year-old Uncle Ben is headed in for surgery for a new knee, his stage-four cancer notwithstanding. Bereft families who are left feeling helpless look to medical staff to do something. It’s hard for them to know when there’s nothing beneficial left to do, particularly when hope is so often considered to have benefits of its own.

Hope is prayer’s second cousin, darkly dressed and hovering around the outside edge of the family photograph. If prayer is a plea to the Almighty for a precedented miracle—prayer’s memory is long—hope is a plea to nothing, to everything, to any possible refutation of the facts. It is tethered to the dreadful single-digit percentage, the medical equipment humming, the long sleepless night. Prayer can (or once could) deliver a miracle; hope can only give a body another week, maybe another month. Sometimes the dying can set goals and reach them: *just let me see my son get married, my granddaughter turn ten, my family carve into the Thanksgiving turkey*. Hope can outlast dress fitting, gift wrapping, and potato mashing, but it can’t deliver anything more. What hope does best is make plans. Sometimes those plans are to desperately avoid the worst.

Two years before he died, Dad mentioned that he was thinking of shooting himself or hanging himself out behind the shop. When things got bad, he hoped to find a painless way out. I was terrified I’d be the one to find him, his body swinging somewhere or bloody and mangled. I told this to a friend who brought me a copy of *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying*, the *New York Times* best seller first published by Derek Humphry in 1991. Humphry, a brusque and controversial figure, was a principle founder of the Hemlock Society in 1980. *Final Exit* outlines the ways in which a person can kill himself, without legal ramifications. I read it and read it again, then gave it to my father. I was certain that, if I ever had to make the decision to end my life, I knew exactly how I would do so (sleeping pills, turkey basting bag over the head, loose rubber band

around my neck to keep the carbon dioxide in), and my father would find his way, if he wanted to. I wanted him to know that whatever he decided, I supported him. Instead, he found death, good or not, in a hospice facility far from his beloved hollow.

When I finally left Africa for home, I quickly realized that all the hurt I thought I was working on on the road was still there, where I had left it. The divorce papers, the job search, the house that Dad built—my memory's catalog of images consistently fell open to the same one: my father, almost naked, pale, lean, and contorted. I realize that in many ways, my memory's recall of this image was my need for what Susan Sontag called, in her 2003 book *Regarding the Pain of Others*, "the pleasure of flinching." It's an easy memory to access because it hurts so much, but also because it made me feel close to him again. Yet it was crowding out all the good memories I had from our life together, like when we'd catch each other's eye some golden afternoon while cutting wood on the farm. Or the comforting intimacy of his voice when I'd call him out of the blue to talk about the rain. His twisted body, arranged in a way it never would have been had he been alive, was crowding out all the things I loved about him. I replayed the last hospice scenes in my head. Did everyone die this way, fighting with both arms and legs until the needles came? I wanted to know if his had been "a good death." And if so, might it come for me the same way?

It was clearly time for me to find another way to deal with my grief. Like my decision to get out of the country after he died. But this time, instead of running away from it, I had to get closer to it. I had been unmoored by my own grief for so long that I had no alternative but to finally make sense of it, wrestle it to the ground and know it. To function in the world again, I'd need to understand what had happened to my father, to my family, to me—to all of us. I didn't grasp the nature of this work at the time, but I was doing what Peter Trachtenberg describes in *The Book of Calamities*: I was launching myself into an investigation with all the raw energies and emotions I had put into grieving. "Before suffering people can form a coherent picture of their suffering," he writes, "they must first ask questions about it, or maybe of it. In doing so, they are performing the work of science and philosophy, interrogating their reality in order to derive a thesis about it."

Finding a good death seemed about as likely as finding the fountain of youth. What was good about dying? I had no idea where to begin, but since my reality of death began with hospice, I became a hospice volunteer. Most anyone can volunteer, and training is fairly brief, but hospice programs are constantly in need of more willing participants. Volunteers are warmly welcomed. I learned how to sit with other peoples' dying. And I kept going. I followed my pain-filled curiosity to conferences and clinics, to academic lectures and to grief sessions in church basements, to isolated prison cells and to pale-blue hospital wards where every hushed word could be the last. I didn't care if it was a morbid inquiry or a vain self-improvement project. I asked questions, yes, but mostly I listened to the stories of others who were close to death, their own or a loved one's. I pursued an expert's knowledge of how we human beings, in this time and country, slide into death or thrash at the end, and how those of us left behind stumble around in the absence. I told myself that this investigation was something that my father, who never let a loose chair leg or a broken appliance go unfixed, would have appreciated, if not encouraged. Something was rattling around, and I was going to set it right.

From my very first days as a hospice volunteer, I learned that I could help individuals to have better lives and deaths by doing little things like listening, being present, and understanding their experiences. But I also quickly found that improving deaths was not simply a matter of telling patients what their options were and letting them choose. Improving deaths involved more than the little things. Educating doctors to talk to patients about their ends is vital, yes, and so is educating patients on what to expect, but doing so will not better the way all people die, just the ones that message reaches. Helping one family to remove an unwanted ventilator wasn't going to prevent the next from having to make the same decision, nor was it going to change a process that had developed over time to default

to ventilators. It wasn't going to address the complicated needs of a vast number of elders approaching end of life in the next few decades, an elder population we aren't prepared to care for. It wasn't going to correct the desperate financial challenges that individuals and the country face, that particular demographic groups—economic and financial minorities, for instance—struggle with every day. And it wasn't going to answer the question of how we got here, to a place and time where the dying are misunderstood, ignored, underserved, and ill informed.

A larger understanding was necessary: of *why* we die the way we do today; of the development of medicine and concepts of choice, autonomy, informed consent; of how hospice and hospital cultures were formed and perpetuated; and of what our regard for the dying has become in broader society. Too, the laws that regulate what is available to the dying had to be considered, along with their purpose and origin. As well, the financial systems that had locked us into the untenable way we currently die. Religious and other cultural forces also play a role in how we die. I had to ask myself how all of these interactions influenced end-of-life care. By focusing on individual lives and deaths, it became clear to me that changing the way we die would be a project of depth and breadth, one that involved loving care for patients as well as a fearless examination of the social, legal, and institutional systems that governed the end of our lives.

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# Mortality Parade

Avenue House is a tidy, nondescript brick building on the Lower East Side of Manhattan. A large ramp sloping left and right from the elevated front door takes up most of the facade, but otherwise Avenue House blends in with food distributors, apartment buildings, and delis. Fresh out of hospice volunteer training, I thought I'd find myself in an elder home, quiet graying folks with the distance in their eyes. What I found was a cross between a hospital and a halfway house, filled with busy, lively people of all ages whose life experiences were completely unlike my own. Avenue House was an education behind glass doors. I was sent there by my hospice organization because a patient named Marshall was depressed and lonely. I knew he was dying because I was sent to see him, but I knew nothing else.

I found him in a tidy two-person room, in the bed closest to the door. He was wearing forest-green sweats, tops and bottoms, and a baseball cap. Mets. He was a small black man, lean and wiry, with graying, close-cropped hair. He didn't look particularly sick. More worn out than deathly. His sweats were about two sizes too big. His eyes were heavy and slow. Marshall was watching a small TV on a long adjustable arm that reached from the wall behind his head. Judge Judy was dressing down a pimply-faced kid in an ill-fitting sports jacket. "I hear you might like some company," I said after introducing myself, carefully leaving "hospice" out of my bio as I was told to do. Sometimes patients prefer to look at their mortality askance. Marshall nodded shyly. "Can I watch *Judge Judy* with you?" He pointed to a stained chair at the foot of his bed. A ruffle of get-well cards covered the wall behind it. Families aren't always able to accept that their loved one is dying, the cards reminded me, or they think that doing anything other than hoping for a miracle is the same as giving up.

Marshall shared a room with a man named Timothy who, unlike Marshall, was always talking and always a little dirty, and a little strung out. More than once I watched Timothy trade food items that he had hoarded from the cafeteria on his own facility-wide black market. Cups of dry cereal, cookies in cellophane. Residents of Avenue House came and went, poking their heads inside the door and then moving into Marshall's line of sight to wave hello and ask how he was doing. They came to see Marshall as much as they came to see Timothy. Room 210 was a popular stop on their social rounds.

People of all ages, genders, and colors moved around me as I sat at Marshall's side. Children and visitors waddled in the halls, shabby down-and-outers sat in wheelchairs, relentless years showing on their hollowed-out faces. Staff in stain-resistant uniforms, solid colors, and comfortable shoes. I was pushing forty, and I thought I was living, but here, where everybody was sick and some were dying, it was a bustling life I had otherwise never had access to.

I sat beside Marshall for two hours that first visit, trying to talk about the weather and the plaintiff, showing deference to TV judges, before I realized that company didn't mean conversation. Getting to know Marshall was going to take time. Just being next to him was what mattered.

That evening I went home to my computer to learn more about Avenue House. Why were all these people, young and old, *living* there? Avenue House, I quickly discovered, is an all-HIV facility. A panic hit me. Hospice training had taught me to be a good hand-washer before and after visits, but I

taken a sip of Marshall's orange soda out of his cup, I'd shaken his hand and removed his shoes, I used the toilet in the room. Wasn't my hospice coordinator obligated to tell me my new patient was dying of AIDS? In a flash I knew that my fear was totally irrational. I was of the generation being educated about AIDS prevention. I was aware of the ways in which HIV patients were wrongly shunned as dirty, not to be touched, contagious. There are only two primary ways that one can contract HIV, the virus that causes AIDS: from use of dirty needles and from unprotected sex. My little ripple of fear was nonsensical. But there it was. And in that moment, for the first time, the stigma of disease was suddenly real to me.

Hospice volunteer. Whoever the patient is, whatever her illness, whatever she needs, you give. There's something satisfying in that, in having a purpose that involves little negotiation of boundaries. I've fetched flowers, Twinkies, and magazines. I've wiped butts and pushed wheelchairs, watched Timothy and held hands, dialed estranged daughters and read the entire Psalms. Hospice work asks that you care without condition—personality traits, life choices, diagnosis, physical appearance, race, class—everything is irrelevant. There's a person in front of you who is dying. And you're going to fetch an arm of love, then lose and hurt.

A preacher and some Avenue House patients would periodically come by Marshall's room to lay hands on him and pray. I would move away from the bed and stand with my back against the wall. They would encircle Marshall, their hands in the air or on his legs and feet, shoulders and head. They would speak in tongues and entreat God to make Marshall walk again, to take away his illness, to make him whole. A second preacher came, dapper, clad head to toe in purple, from his brimmed hat with a purple band to his purple pinstriped suit and purple handkerchief, to his metallic purple shoes with purple laces. He swayed and bobbed and growled out God's love. He told Marshall about God's bosom and right hand, and I saw that Marshall relaxed when he heard this. I imagine it's not that I thought his sins were absolved, but that he was worthy, despite them. I wanted the man in the purple suit to lay a hand and a prayer on me.

Marshall had "accepted the Lord into his life" two weeks before I met him. Much as the care of his body had been placed in the hands of the nurses of Avenue House, the care of his soul was in the hands of the Lord. And it calmed him. I could see he was still scared to die—he hovered somewhere between wide-eyed shock and drowsy depression—but he clutched his tiny Bible and embraced his new praying friends. His wife and adult son lived in New Jersey and seldom visited. But Avenue House gave Marshall a friendly, accepting community. If he felt abandoned, he also felt adopted. They were a comfort to him. In a very different way, I learned how to keep Marshall comfortable too. He was ashamed of his pain, too timid to tell the nurses what he was feeling. He would tell me what his pain was—he couldn't go to the bathroom, his stomach was distended, he couldn't sleep—but when the nurses came around, he would force a smile for them, for their authority. He didn't like taking medications of any kind. He also had excruciating breakthrough pain, the kind that comes when one dose of medication wears off before the scheduled next dose. For the hospice office, I kept a notebook. On Friday, April 9, I wrote:

Oh a horrible day of pain. As soon as I walked into his room, I knew it had been a rough day so far. M was literally doubled over in pain—an expression I didn't fully understand until seeing him—with his head on the railing of his bed. The room was in disarray, a large sticky mark was on the floor by his bed; his nightstand littered with overturned cups and cans. Timothy, M's roommate, greeted me when I walked in with, "I'm glad you're here. He needs you. They threatened to kick me out today for getting him pain meds at the drugstore." It seems that he's been in pain for some time. He tells me that the meds last two hours and that the nurses tell him he can't have more for another two so he lies awake, calls his wife to tell her to call the doctor or



he sends Timothy out for Advil.

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“I just want to die,” he whispered to me. I asked the nurses to come, to bring the doctor with them. The obstacles to making him comfortable were many: the nurses had directions they had to follow. Marshall wasn’t explicit about how he was feeling; he once told them he didn’t like being drugged out; and he didn’t like to take the Maalox for constipation because it tasted bad. His hands were cold and I held them, rubbed his head as he rested it on the railing, told him the doctor and nurses were coming, that he was going to feel better soon. We both watched the clock.

A second time I pleadingly told the nurses at the front desk that we needed help. I stayed with Marshall until the doctor, the floor manager, and the primary nurse finally came to the foot of his bed. They spoke about him, not with him. They discussed what the challenges were and what new course of medication they could prescribe. After much resistance, they discussed switching him to Methadone, a drug that carried a particular stigma in Avenue House. It’s a junkie drug, what heroin addicts take to get off heroin. “Well,” the nurse said, “Methadone is highly addictive.” “He’s dying,” I whispered to them, an impatient tone in my voice. I listened to everything the doctor and staff said, then bent down to hold Marshall’s hand and tell him the translation: “You have to tell them when you hurt. Making pain go away takes some trial and error. They want to try Methadone, but you may have some side effects like constipation and feeling groggy, but do you agree that that’s better than being in pain?” He nodded his head.

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Cicely Saunders, a British nurse who founded the first modern hospice in the United Kingdom in 1967, often claimed that her program (and philosophy) was directly descended from the shelters set up by monks across Europe in the Middle Ages. Monks cared for soldiers returning from the Crusades, for travelers, and for the poor and sick.

How Saunders came to develop the modern idea of hospice is famous among hospice workers, particularly volunteers. It’s a love story, really. Saunders was a nurse in a cancer ward during the mid-1940s when she met a patient, a Polish Jew named David Tasma, who was dying from inoperable cancer. Saunders had recently converted to Evangelical Protestantism and was looking for a way to live her faith, to “say thank you and serve,” write Fran Smith and Sheila Himmel in *Changing the Way We Die*. Saunders and Tasma talked for long hours about faith and mortality. He made Saunders aware of how abandoned and lonely dying patients were. Saunders read two Psalms to Tasma, hoping to comfort him. Write Smith and Himmel: “I only want what is in your mind and your heart,” he replied. That simple desire came to represent everything she believed hospice should offer: the best therapy the mind could conceive along with the kindness, attention, and friendship of the human heart.

Saunders conceived of hospice as a way to address all the suffering a person was experiencing as he or she faced death, not just the physical pain but the emotional pain, the discomfort of being in a bed for so long, the loneliness, and the loss of control of one’s body, environment, and future. She completed medical school and later founded St. Christopher’s Hospice in London. Saunders was commanding, over six feet tall and able to speak passionately about end-of-life care. Her ideas, and her ability to captivate an audience, directly influenced American hospice development. Saunders’ relationships with Elisabeth Kübler-Ross, author of the classic *On Death and Dying*, and Florence Wald, a nurse who opened the first US hospice, in Connecticut, inspired the birth of hospice care in the United States in 1974.

Saunders, later made *Dame* Cicely Saunders by Queen Elizabeth II for her hospice work, is a compelling figure in the hospice movement, but her philosophy owed much to another early founder, an American with surprisingly literary roots. Rose Hawthorne Lathrop, daughter of the author of *The*

*Scarlet Letter*, Nathaniel Hawthorne, married young and traveled in a distinctly literary circle. Her husband, ~~George Parsons Lathrop~~, later became editor of the *Atlantic Monthly*, and Lathrop had his own literary ambitions. She published short stories, poetry, and a book, *Along the Shore*. She and her husband converted to Catholicism together, but after the death of their infant son, slowly drifted apart.

Lathrop became a nurse at New York Cancer Hospital in the late 1890s when she was forty-five. She saw the horrible deaths of the poor from cancer and decided to open Sister Rose's Free Care. "I set my whole being to endeavor to bring consolation to the cancerous poor," she wrote in her diary, write Smith and Himmel. She took up residence in the Lower East Side of Manhattan, buying a tenement to house the sick and dying. She was later encouraged by a Dominican priest to establish an order of nuns and, in 1900, became Mother Alphonsa in the new order Dominican Sisters of Hawthorne.

In photos taken after joining the order, Lathrop is wearing a large black-and-white wimple that sits high off her head and drapes broadly across her shoulders and down her back. Her face is broad and she wears large glasses that make her look stern. "Lathrop forbade proselytizing and welcomed patients of all religions, or none," write Smith and Himmel in *Changing the Way We Die*, "but she believed that she was preaching the gospel through nursing, and she rejoiced when someone came to the faith."

In 2003, Cardinal Edward M. Egan proposed Mother Alphonsa for sainthood. In March 2011, according to the Dominican Sisters of Hawthorne website, the "Decree of Validity for the Diocesan Acts in the Cause of Mother Rose Hawthorne" was signed by the Vatican. The next step toward beatification requires a miracle. The Dominican Sisters of Hawthorne ask that if you experience a miracle when praying to Mother Alphonsa, you contact them immediately.

The day after Marshall started Methadone, I stopped to say hello to the desk nurse on my way to his room. She told me that Marshall had been nauseous all morning, most likely from acclimation to the new drug. When I got to his room, he looked resigned to discomfort, no longer fighting against doubling pain. I let him know that it would take a while to adjust the dosage and that some of the side effects might not be pleasant, but that at least the pain was under control. The change in him was striking and wonderful. We watched TV for a while. I cleaned up his nightstand. He commented in a low tone that he had lost his voice, and I said that he didn't need to talk. I was happy to sit with him quietly. "But I want to talk," he croaked. In my journal, I wrote:

When I was preparing to leave and arranging with him for my next visit, he hanged his head and again apologized. "I'm sorry I've been so much trouble for you." I made small of it, saying that he needn't apologize to me ever again and that that's what we do—I was saying it to myself as much as I was to Marshall—we rely on others sometimes and there's no need to feel badly about it. On my way out, I spoke with his nurses—he's apparently had no breakthrough pain since they started the Methadone last night. He was set to have his next Methadone dose at 2 and still he was comfortable without breakthrough pain.

The change was almost unbelievable. Marshall and I began spending our time together talking about his life, his career as a welder, his family. As the weeks passed, I got to know him. We looked at photos of his family and watched his favorite movies, action flicks with heroes and bad guys and happy conclusions. I brought him whatever foods he was craving. Sometimes Marshall couldn't feel his feet. He could feel when I touched them, but he couldn't move them. He had the wide-eyed look of sedation, and I wondered at the inexact science of balancing his pain with medication.

After that week, I began visiting Marshall almost every day, far more than my hospice schedule

required. I enjoyed sitting with him, hand in hand. We'd fallen into a routine. We'd watch TV, my head on the railing: *Judge Mathis* or *House of Payne*, daytime shows that I had never seen before. My coming and going became common on the second floor. I'd say hello to the regulars—the woman in the pink nightgown who first called me into her room to show me pictures of her new niece; the young black man who sat by the elevators staring at the doors; the old Latina woman who would doze in her wheelchair in the hallway, her head on her left shoulder; the nurses chattering at the front desk. Once on the street, at the bottom of the ramps, I would take a deep breath of the city's air. I could still smell Marshall on me, a mix of cocoa butter and the sour scent of a rotting body, an institutionalized, dying body.

Marshall's decline was obvious now. He no longer dressed in his sweats. He was constantly in a blue-and-white hospital gown. He never left his bed, and the nurses had put his small brown feet in special slippers to take the pressure off his heels. They rotated him from side to side to prevent bedsores. The room was quiet now; even Marshall's roommate Timothy kept himself away or read on his bed behind the curtain.

On my last visit, Marshall was in and out of lucidity. He would turn his head toward me and gripe, then his dry lips would slacken and he would doze into sleep. He moved very little and the skin of his body seemed to have sunk into the bed, his bones a simple collection of small bumps under the smooth sheet. The nurses hovered around us for the hours that I was there; their knowing watchfulness alerted me. He was going. "Read him the Psalms," one nurse told me. I picked up Marshall's Bible and started at the beginning, "Blessed is the man that walketh not in the counsel of the ungodly, nor standeth in the way of sinners, nor sitteth in the seat of the scornful." And chapter 77: "I cried unto God with my voice, even unto God with my voice; and he gave ear unto me. In the day of my trouble I sought the Lord: my sore ran in the night, and ceased not: my soul refused to be comforted. Periodically, Marshall would wake up and look at me, then through me. He pulled his shaking hand out from under the sheet and pointed to a dim corner of the room over my shoulder. He saw his mother there, his wife, other friendly faces. By chapter 86—"Bow down thine ear, O Lord, hear me: for I am poor and needy. Preserve my soul."—Marshall was asleep.

That night I couldn't sleep. At 3:30 a.m., I was hanging out my kitchen window staring at the moon. It was so pregnant with light that the typically opaque New York sky was perforated with even fewer stars than usual. My area of Brooklyn was balmy, still and salty from the nearby open water, from the hum of air conditioners and eight million people breathing rhythmically in their sleep. I had a stiff neck. I was as weary as the heavy humidity, with a leaden anticipation of a sad blow. I was grieving. It was a familiar feeling, like an echo of the waves I'd ridden over the past five years, the wake from my father's death and dying. Hospice called the next morning to tell me Marshall had died.

I had completed hospice volunteer training a few short weeks before I met Marshall. When I walked into my first class, held in the middle floors of an office building a stone's throw from Wall Street, I was surprised to find more than two dozen people, ages nineteen to seventy-five. I expected a handful of dainty ladies, sitting with their ankles crossed. Women have always been the domestic caretakers of the dying. I was aware that my new volunteerism was gendered work—even volunteering we view it as gendered—something that men are too busy to do, something that holds a particular stigma. Women do the work. Hospice has changed drastically since the days of Rose Hawthorne Lathrop—it wasn't just for the poor, for instance, and it had become hypermedicalized—but the room still held a majority of women. Some volunteers, like a tall young man about twenty-two years old, had come to help prepare themselves for medical or nursing school. One young woman in a floral dress, perfect makeup, and platinum hair said she had time on her hands—"And I thought, why not volunteer for hospice?" A veteran of the AIDS epidemic in a bohemian skirt who had "lost too many friends" felt that hospice

work made her a better person. "It makes me thankful I'm alive." One of the oldest women in the room, sitting primly on my left, was paying a debt. Jean had the puckered hands of a septuagenarian and full dark cups of skin below her eyes. She was mannered but feisty, like she was still every age she had ever been. Hospice had helped her care for her husband, Michael, when he died. That was twenty-five years ago. Her voice cracked. She finally felt ready to help others die.

Help others die. It's a weird phrase. It betrays our long-held standard of encouraging others to "not go gentle," to fight to the end, to never give up. On the one hand, helping others die acknowledges the limits of medicine and contradicts the denial of death prevalent in our culture. On the other, it embraces an ethic of charity and care that reaches back to religious orders like the Dominican Sisters of Hawthorne.

However secular we think our society, religion continues to be most overt at the deathbed. Which is why contemporary hospice teams include chaplains among the social workers, nurses, and volunteers. American spirituality is the new nature of faith among hospice programs. Interfaith and all-inclusiveness are the tone of hospice today, a reflection of the changing religious landscape in the country.



I did not want to meet Mr. Cortez. Marshall had died only three weeks before. But hospice couldn't find anyone to sit with him while his wife attended Mass on Saturday nights. Who wants to hold hands with the dying on Saturday night? I didn't, but I said yes anyway, maybe to wipe Marshall out of my thoughts. Mr. Cortez would be my rebound patient. It was the middle of a heat wave. Lower Manhattan was the kind of July hot and humid that makes you angry, but too breathless to do anything about it.

The Cortezes lived in the projects below the Manhattan Bridge. Inside the main door, I found graffiti and trash, urine on the floor of the elevator. The hallway was dark after the bright summer sun. Would it be safe for me to come here in the dark, when the days were shorter, I wondered? I had no idea what Mr. Cortez was dying of or how long it would take.

Mrs. Cortez, a plump Latina woman with short hair and glasses, showed me into the bedroom where Mr. Cortez took up little space on a hospital bed. "I'll be back after Mass," she said in a heavy Puerto Rican accent and slipped out the door, locking it behind her. Immediately Mr. Cortez came to life, as if the sound of the lock woke him up. I watched the lower half of his face, collapsed and nearly toothless, as he gummed words that I couldn't understand. He was bird-thin and active, fluttering his hands as if to take flight or to stir the thick air in the room. Our first task was to survey the collection of tweezers he had in the pocket of his pajamas, one, two, three, four, five. Each taken out, held before me, then displayed across the bedsheet in a row. "A tweezer for every occasion," I said. He smiled and clumsily gathered them up and put them back in his pocket. Mr. Cortez's motor skills were florid and unpredictable, a hand striking several places before it did what his brain told it to. I couldn't make any sense of what he was trying to tell me, half pantomime, half garbled sounds from an uncooperative mouth. Mr. Cortez was insistent. We were going to communicate! Frustrated, we both sat back and took a breath.

I decided to try asking yes-or-no questions, a sort of game that could help us make sense. "Do you want something?" I asked. With the most subtle of gestures, a slight blink of his eyes, he touched his chin to his chest. A yes. I had just caught it in the midst of other shakes, shifts, rhythms, and twitches. "Is it in this room?" Yes. With a pointing, jabbing arm, he accused the top dresser drawer. I touched it. Another yes. As I opened the drawer, Mr. Cortez chopped his flat right hand up and down in the air. I mimicked him and finally understood that he wanted me to find something in the front of the drawer, vertical, between the clothing and the drawer face. It was a red vinyl folder of papers. I brought it back

to the bed for us to look at. Inside were Mr. Cortez's retirement papers from the city, his commendations for driving a limousine for seventeen years, a photo of his father, who had served in the military. Mr. Cortez didn't want me to see him as this frantic, birdlike person on the bed; he wanted me to know how he saw himself. As a person, not a patient. As a man who had had a rich life and a full history of accomplishments, not this waning body. He was proud. I put the file back in the drawer as Mr. Cortez closed his eyes and finally became still.

The next time I visited, I found Mr. Cortez sitting up in a chair in the living room, next to the white plastic-covered sofa, with a TV tray in front of him. He was feeding himself with a spoon. Oatmeal, applesauce, and a blueberry muffin. His arms were all over the place, as though he were swatting flies or trying to get food into his own mouth by playing airplane, as we do with toddlers. Mr. Cortez was showing off for me, performing eating. He was smacking his lips as muffin crumbs flew, waving his spoon like he was conducting the Philharmonic, and slapping his gums at his juice cup. *Smack, smack, smack*, like he was going to eat the cup. Food crumbs floated in the juice and clogged the straw. It was a performance of pure joy in motion and sound—and impossible etiquette. He couldn't stop the shakes and tremors, but he could make them a flourish, a rhythmic show of remaining skill.

If he could use a spoon, I reasoned, he could write. Our frustrating charades could use a break. I pulled out a notepad from my purse and held it in the air as if it were a question. Mr. Cortez paused, then swooped it from me. He struggled to synchronize the tremors of his left hand with the tablet and the tremors of his right with the pen. I couldn't imagine what he'd first write to me.

"I used to play a Spanish instrument. I can't play it now because the bridge is broken." "Do you think you could play it now if it were repaired?" I asked. Yes, he nodded. He reached over to the little cassette player on the coffee table. The *la-chicka-chicka* of a happy Latin song filled the little room. We both smiled and danced in our seats.

In 1978, according to the history page of the National Hospice and Palliative Care Organization website, the US Department of Health, Education, and Welfare task force wrote that "the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support." In 1982, Congress created the Medicare Hospice Benefit, allowing the terminally ill to receive federal coverage for end-of-life care, a development particularly important to those reliant on Medicare for their needs. While the Medicare Hospice Benefit will provide twenty-four hour crisis care when necessary, the burden of daily care—cooking, cleaning, bathroom assistance, bathing, sorting medications, bills—falls to the families of those still at home, or to staff for patients in facilities. For those who fall in the gap—between full coverage (the poorest of the poor in state-funded elder homes or places like Avenue House, where Marshall died) and those who can afford full-time caregivers at home—hospice isn't always enough. Four hours of care a day can leave many stranded and isolated for the other twenty hours.

The Medicare Hospice Benefit covers equipment, doctor and nurse visits, and medication, limiting the cost that a hospice can charge Medicare for a drug copayment to five dollars. Congress saw hospice as a way to keep end-of-life care costs in check, already a concern to the national budget in the 1980s. To ensure that savings, it required that anyone entering hospice end all curative treatment. Chemotherapy and other drug courses that aimed to cure cancer or another illness were no longer accessible to hospice patients. The reasoning was that those who need hospice, who are actively dying, have come to terms with dying. The provision fails to acknowledge the emotional challenges, for patients and their families, to accept that death is inevitable. Medicare coverage also limits the program to six months. It wasn't an arbitrary time frame, but it did ignore the inconsistency

diagnoses and the strength of the human will and body.

Multiple studies have shown that hospice patients can live up to two months longer than their peers who remain in standard (curative, hospital) care. That's two more months to get your finances in order and to make peace with estranged family members, two more months of birthdays, anniversaries, weddings, and births. A lot can happen in two months, even when you're dying.

From the days of Mother Alphonsa and Cicely Saunders, hospice was intended for those dying of cancer, but hospice has seen a large increase in other types of patients, such as Alzheimer's patients and Parkinson's patients, who can live for years with a diagnosis. Their deaths often come more slowly, a drama of physical decline and increasing frailty that plays out over years, even decades.

On the next visit, I found Mr. Cortez in the living room again. As soon as his wife closed the door behind her, he pointed to a walker in the corner. "Do you usually get around on your own?" I asked. He was so frail, his legs so thin, I couldn't imagine they would carry him. But he nodded his head yes, and, using the technique I learned from Marshall, I spread my feet to bear the weight of another person and lifted him from under his arms. Every volunteer with a mobile patient fears a fall. One out of three seniors falls, and falls are the leading cause of senior injuries, fatal and nonfatal. I held Mr. Cortez so tightly I feared bruising his arms. But we were upright, embracing like family members or lovers, when I caught him looking at me closely. Not like an old man about to die, not like someone with flakes of skin clogging up the hair at his scalp, with brown and white spots mottling his hands and arms, but like his toothless, smacking mouth warranted kisses. "You're a devil!" I said, and he grinned ear to ear.

"Bedroom," he said with a cackle. Of course. "Pot," he said when we arrived. I maneuvered him to the pot, a sort of chair with a bucket for a seat and, when he pointed at his pajama pants, I pulled them down. Then his adult diaper. He had no butt, nothing but skin and bones. I was a little jarred by how comfortable it was for him to be naked in front of me, or rather how awkward his nakedness made me.

Now seated, Mr. Cortez shook his pointing finger at the dresser again. This time he wanted a vinyl folder of photos. He on the pot, me at his elbow on the bed, we began to look at snapshots taken decades ago. Family in Puerto Rico, panoramas of the island's countryside, then a photo of himself with friends standing in front of a white car, perhaps here in the parking lot by the projects. He pointed to a handsome man, late twenties or early thirties, with a bouffant hairdo and rolled-up shirt sleeve. There's a sexy jaunt to his pose against the car. The photo is black-and-white; it's the 1960s.

"Who is this?" I asked trying to conceal my disbelief. Mr. Cortez jabbed his index finger into his chest. "This is you, Mr. Cortez? You're handsome!" I meant it. He was stunning, filled with bravado and brashness. A thin mustache lined his upper lip, a full double chin, a thick torso. The photo breathed machismo. I pulled out another one, him with his band, holding his little guitar like a beloved dance partner. And then another, a series of three black-and-white images taken in a photo booth of Mr. and Mrs. Cortez, obviously in love, their heads together. I could feel the happiness. Full and ripe and proud. I was mesmerized by the photos—and haunted by them. These beautiful, swaggering, sexy people were now old. My eyes moved from the image of a full and vibrant, young and proud Mr. Cortez embracing his young wife, to the wasted and dying man on the pot a few inches from me, showing me not who he was but who he is.

After we got him off the pot (I'd never wiped another adult's butt before), dressed and into bed, Mr. Cortez shook his arm to a place beside the dresser. An instrument case. When I opened it, I found the same instrument, a *cuatro*, worn along the strings from years of use, that I had seen in the photos. The bridge was missing, the neck was loose, it had no strings, but Mr. Cortez took it from me and cradled it in his arms. "Strings," he said.

The next time I arrived I chirped, "Hello, Mr. Cortez." He was on the pot again and Mrs. Cortez was

preparing to leave as if for a date, not Saturday night Mass. She preened in the hall mirror.

“He’s been writing on a tablet for me because I can’t understand what he’s saying.”

“Sometimes I can’t either,” she said and I felt better.

“He’s also asked me to get strings for his instrument.”

“Oh,” she waved her hand. “He can’t play anyway.” We both knew she was right. “What illness does he have,” I asked.

“Parkinson’s. Twenty-five years.” I shuddered at the patience and devotion of twenty-five years watching your husband’s physical and mental decline, getting away only a few hours each morning to work as a crossing guard. And on Saturday evenings to go to Mass.

Mr. Cortez pointed to my hair when I entered the bedroom. He was balanced on the portable pot, oblivious to the smell or any kind of embarrassment either of us might have. I looked in the mirror—the house was full of mirrors, floor-length ones in the hallway, two on dressers in the bedroom, a horizontal mirror in the living room—to see what he was pointing to. He looked into the mirror, to see at himself, studying his own face, slicking back his hair with a fluttering hand. Yes, my hair was still wet. “I rode my bicycle to the subway,” I said. “I got caught in a downpour.”

He took up our notebook and slowly wrote, *One of my sons died from a bicycle accident. Under the bridge. He pointed out the window to the bridge that passed over the edge of Manhattan a block away. He was 41.*

“I’m so sorry. That’s too young. I’m forty-one.”

*You don’t look that old*, he wrote, and I was flattered.

*I was born 1.15.36.*

“So you’re,” I paused to do the math, “seventy-four?”

He nodded.

“You don’t look that old,” I said, echoing his compliment. His eyes twinkled, and he glanced at the mirror again, smoothing his long gray hair back over his scalp. He pointed to the picture of his father on the wall opposite his bed. *I don’t want institution. My father in. He was 97 when he died. More math. Twenty-three years to go*, I thought.

When we got Mr. Cortez up from the pot, he demanded his walker and led me to a door in the hallway that was always closed. Inside, the walls were haphazardly painted red, with excess flicks of paint along the ceiling. A futon was against the left wall, and a few items of men’s clothing were neatly folded and stacked on it. Not Mr. Cortez’s clothes. On one side of the window, a small pair of nunchucks was hooked over the abandoned curtain rod bracket. A Slinky was hanging from the other side.

Mr. Cortez shuffled to a tall dresser where a boom box filled the top surface area. The screen flashed a pattern of colors until he pressed the play button. The screen rolled through a colorful display, then flashed, *GOODBYE*. He lifted a plastic frame from a shelf. In it a man about my age was smiling and holding a four-year-old girl, her hair in braids.

“This is your son?” I asked Mr. Cortez. He hit his closed fist on his chest. A row of men’s shoes—sneakers, boots, dress shoes—was at the foot of the dresser. On a shelf, there were a TV and DVD player, a few bottles of the pills that bodybuilders take, a clock, some knickknacks and books—Aristotle, Algebra, Business Math. Now I understood. For three years, this room, his son Johnny’s room, had sat this way, virtually unchanged. Mr. Cortez pressed the boom-box panel again. *GOODBYE*, and opened the top dresser drawer.

Its contents were jumbled and messy, like a kitchen junk drawer, but Mr. Cortez fingered each item lovingly—wrinkled pay stubs, an overnight case full of condoms (the kind handed out free and marked with colorful designs), pictures of Johnny with his buddies and with women. Mr. Cortez worked his shaking fingers into the back left corner of the drawer and dug a folded letter out of a tin. I thought how little privacy the dead have. *GOODBYE*. The letter was written on yellow lined paper, folded like

a high school note. Mr. Cortez handed it to me.

~~“Do you want me to read this,” I asked, uncomfortable because I was snooping through a de-~~ man’s possessions. He nodded his head, and as I began to read, I realized that it was to Johnny from a friend. It was a letter from prison. I read out loud to share with Mr. Cortez the guilt of this invasion of privacy. The slang sounded silly in my voice, in the abandoned, unchanging room.

*Hey bro what up?* Louis tells Johnny that he had better keep his head down and stay in school. Before they know it, Johnny will have his AA, his associate’s degree. Working out is good, being healthy and getting ripped, Louis writes, but a degree is better. *Watch your step*, he writes, because any violation of parole will end with Johnny right back inside. Like an expert, Louis lists the years that Johnny will get for various parole violations. Then he tells Johnny to send more pictures. But not Polaroids, because they aren’t allowed in prison (it’s too easy to hide drugs between the photo layers). *It’s lonely in here at night*, he writes. *Get me some photos of hot girls to keep my mind busy.* I folded up the letter and handed it back to Mr. Cortez, still unsure why he wanted me to read it. I pushed it deep down into the papers and condoms and photos in the drawer like he was planting a seed. A seed with no chance of growing. He closed the drawer and again pushed the button on the boom box. **GOODBYE.**

The fall leaves had begun to turn as I walked down the street to Mr. Cortez’s building. I’d finally found the right strings for his cuatro. He was in bed when I arrived, his blue-striped pajamas askew, a handful of crumpled paper towels shoved into the chest pocket. As had become our habit, I bent down in front of him to catch his eye and touched his chin with my hand.

“Hello, Mr. C,” I said smiling. He raised his own shaking, fluttering hand to my chin to acknowledge me. He was no longer able to keep his mouth closed, his lower jaw hanging and wet with saliva. I pulled my other hand from behind my back to show him the strings. He clapped his hands with joy and pointed to the instrument case beside the dresser. I pulled out the cuatro and handed him a coiled guitar string. With one motion, so fluid, smooth, and practiced that it surprised me, he rolled the coil between his two index fingers until it opened into a long line. Mr. Cortez died the next week, two hours before Saturday night Mass.

I’ve known Evelyn Livingston for four years. Every Friday evening, I enter the finely restored de- lobby of her building on Central Park West. The doorman and I exchange friendly greetings; the man behind the desk hands me a white key card for the elevator without having to ask where I’m going. I’ve made a habit of noticing the fresh flowers that adorn the desk and the interior lobby, dramatic arrangements of protea and greens in the winter, allium and lilies in the spring. These days, Evelyn is a permanent resident of the white divan in her front room. It’s a long and wide mass of furniture taken up with magazines and medical journals, a burgundy vest for when it’s cold, a basin for when her nausea is uncontrollable, and linen-covered pillows of various sizes that she uses to keep herself comfortable, an endless task. She used to use a walker to slowly go to the bathroom or back to her bedroom at night to sleep, but she’s now sleeping on the divan. A portable toilet like Mr. Cortez’s sits in the corner, covered with an elegant batik cloth. She hasn’t left the front room in months. After washing my hands—the immune system of homebound patients often can’t fight the germs picked up on the subway—I used to come into the room and greet her with a kiss on her papery right cheek, but we’ve begun to worry about my germs as well. I now touch her knee; I tell her it’s for our good luck.

One-and-a-half-million patients, about the total number of residents in the state of Idaho, die in hospice care each year. Although the program is for patients with six months or less to live, one-third die or leave the program after only seven days. Mr. Cortez was in hospice for three-and-a-half months, likely because his family acknowledged that he was dying years—even decades—before. Evelyn is an anomaly. Four years is an eternity in hospice time. Every handful of months, a doctor comes around



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