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The Art of Dying: Living Fully Into the Life to Come

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LIVING FULLY INTO THE LIFE TO COME

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WHEN DEATH ARRIVES

Our culture simply doesn't know what to think about death. Through medicine and science we know more about death and how to forestall it than ever before. Yet we know very little about caring for a dying person. We don't know what to expect or how to prepare for our own death. And we're often awkward at best when trying to comfort a friend in grief.

Our culture is fighting, and sometimes succeeding, to expand the so-called right to die. We hear stories of the compassion of family members and doctors who assist in the deaths of terminally ill patients. Yet our doctors and hospitals are astounding in their ability and passionate desire to rescue cancer sufferers, accident victims or heart-attack patients. We have come to expect medical breakthroughs, vaccines and wonder-working drugs.

There is no shortage of books, studies and experts ready to explain our culture's fear of death or our eagerness to avoid it. Yet some of our bestsellers—*Tuesdays with Morrie, The Last Lecture, 90 Minutes in Heaven*—feature stories about people dying, or nearly so, and the lessons they discovered at the end of life. Celebrities give a whole society the opportunity to follow along in

the struggle with a terminal disease and publicly, at least on TV, mourn their deaths.

Having volunteered with hospice patients and worked with grieving families at a funeral home, I've seen the results of this confusion firsthand. Interviewing families, doctors and hospice workers, it's clear that our paradoxical approach to death is largely due to the fact that we are strangers to death—despite it being ever present. Caring for elderly parents is typically our first prolonged and engaged confrontation with death. Even then, however, doctors and nurses often guide us through the experience. It's not unusual for children to care for their parents from a distance, calling doctors or arranging transportation and nursing care, further removing us from face-to-face interaction with death and dying.

Death is all around us, however. Our movies are filled with violent deaths. Daily news reports feature wars that may involve our own neighbors, family members or church friends. We receive appeals from development agencies and news outlets to help ethnic groups, such as those in Darfur, targeted for violence by more powerful neighbors. We are asked to support relief workers caring for people struck by famine, natural disasters or epidemics.

I remember my first experience, after college, in a group that met weekly for prayer. I was amazed that, unlike my college experiences praying with friends, more than half of our prayer requests were for health issues. Often we prayed for people with potentially life-threatening illnesses. Some acquaintances at work went on leave as they received chemotherapy, and some of them never recovered. Often we prayed, as colleagues awaited test results, "Lord, let it turn out to be nothing at all."

Even at a young age, we are around death. A friend from my

high school youth group killed herself. Another friend from college died one summer in a car accident. My brother's youth group volunteer was murdered at a highway rest stop. Facebook friends fill their updates with information on ailing relatives.

Tragic as these incidents are, however, they are not the same as a sustained face-to-face encounter with a loved one on his deathbed. They don't affect our lives in the same way. Prayer requests and Facebook updates do not breed familiarity. While they can and should lead us to reflect on our own death and encourage us to live in the light of our mortality, often our busy lives don't allow this reflection. Death, while ever present, is ever more removed from our firsthand experience.

The average American's first intimate encounter with death might not occur until she is well beyond middle age. "Until their loved ones lie in the last light," author Stephen Kiernan says, "families today do not know mortality."[1] In fact, as people routinely live into their nineties, it is now not unusual to have elderly children taking care of their even more elderly parents.

When we are finally called on to be with a dying loved one, we must learn what to do and how to behave on the fly. This is a drastic change from the days when dying was a more familiar, if an equally unwelcome, presence. "All the things that once prepared us for death," writes journalist Virginia Morris, "regular experience with illness and death, public grief and mourning, a culture and philosophy of death, interaction with the elderly, as well as the visibility of our own aging—are virtually gone from our lives."[2]

For most of the last century, death has moved steadily away from view. Over the course of the first half of the twentieth century, the site of death moved from the home to the hospital. In 1908, 14 percent of all deaths occurred in an institutional set-

ting, either a hospital, nursing home or other facility. Just six years later the figure had jumped to 25 percent.[3] By the end of the century it was nearly 80 percent.[4]

As the place of death moved to the hospital, people became less familiar with the sights and sounds of the very ill. Medical personnel took over the intimate care of the patient, often simply because their expertise was required. These changes allowed patients to survive—at least temporarily—diseases that would have killed them. But through those exchanges, we forgot what death looks like, and we lost something. We now keep death at a distance. The dying, says historian Phillipe Aries, are pushed out of sight because society cannot endure their presence. While it was once common for friends, family and even strangers to pay respects to someone on her deathbed, Aries says,

> It is no longer acceptable for strangers to come into a room that smells of urine, sweat, and gangrene, and where the sheets are soiled. Access to this room must be forbidden, except to a few intimates capable of overcoming their disgust, or to those indispensable persons who provide certain services.[5]

We have forgotten how to behave as caregivers or simply family and friends. We act clumsily and awkwardly around the grieving, often complicating their mourning. We're clueless about what to say to a person on his deathbed. We ourselves are left feeling confused and uncertain about death's meaning and its affect on our faith and our lives.

But our behavior, it turns out, is rather common and understandable, if still inappropriate to the occasion. "Nowadays, very few of us actually witness the deaths of those we love," writes surgeon and author Sherwin Nuland. "Not many people die at

home anymore, and those who do are usually the victims of drawn-out diseases or chronic degenerative conditions in which drugging and narcosis effectively hide the biological events that are occurring."[6] In other words, even those few who have first-hand experience being with someone dying do not fully experience the event—at least not in the way every other society and every other generation throughout history would have.

Living far from our elderly loved ones also removes us from their declining years as well as from their medical care. Adult children find themselves on conference calls with their parents' doctors. They fret about their loved ones' safety when their home is no longer a safe place to live or when driving becomes dangerous. They fly a thousand miles for a surgery, never quite knowing what is happening and if this trip will be the last. And, in interview after interview, I've learned that relatives who live far away have a much stronger tendency to advocate for aggressive therapy, prompting family conflicts when other members, including the dying person, are opposed.

Not only can our unfamiliarity with death make us incompetent when visiting socially with the ill or grieving, we may also make decisions opposed to the best interests of the people we love. A doctor told me recently of a patient who had lived well for two years after deciding to discontinue her chemotherapy treatment.[7] For much of those two years, this woman enjoyed life. She was able to garden, take walks, spend time with her husband and accomplish some final goals she had set for herself. Her mental powers had declined, however. She regularly offered the same joke to her doctor. "Old age is not for cowards," she chuckled, each time thinking it was an original thought.

But eventually she began doing much worse. She was bleeding extensively, and the doctor could not determine where she was

bleeding from. Her short-term memory was failing, and she no longer wanted to eat, as happens to dying people.

"What do we do?" the doctor said to me the day after discussing the issue with the woman's husband.

> Do we say, "We're not quite sure what the bleeding is from, but we know she's got lung cancer. We know she's going to die from the lung cancer. She's comfortable. She's weak, but she's not in pain. She's breathing okay, and she's quite content." Do we put her in the hospital, transfuse her, see if this is correctable, and then let her die of the lung cancer, which could be a much more painful death than what she's experiencing now?

She had already lived more than eighteen months longer than she was told she would after refusing chemotherapy.

It is a complicated issue, even for a doctor accustomed to dealing with it. But invariably, the decision becomes more complex once out-of-state relatives are involved. The doctor continued,

> Rarely do I have any dissension when am I talking to people. The dissension comes from those who weren't there. I fully expect when I get to the office this afternoon to have a phone call from the daughter saying, "Why aren't you doing this? Why aren't you doing that?" And I have to go through the whole discussion all over again. Then it will be the son from Arizona.

Confronted by these challenges, we aren't always able to cope. Sherwin Nuland recounts an Alzheimer's patient who had moved from New York to Florida for his retirement. When he was diagnosed with the disease, all his children were still in New York. His wife spent every day with him in the nursing home, and she

lovingly cared for him during the remaining years of his life. But his children only visited once. Rather than watching a slow decline, the man's out-of-state children saw one massive drop in their father's health. Horrified, they never visited him again.[8] Their mother supported her children's decision, saying she didn't want them to remember their father this way. This extreme instance illustrates a more general truth: unfamiliarity with death can discourage us from fulfilling our familial responsibilities.

A hospice social worker from the Chicago suburbs told me that the most difficult part of his job is finding people to care for his hospice patients. Typically, they don't require twenty-four-hour nursing care. But often dying people need help using the bathroom, cooking and eating or keeping clean. For many patients, he said, finding someone willing and able to help is nearly impossible.

Though it was a problem in the affluent Chicago suburbs, it was no trouble to find caregivers among the poor communities of Miami, where he used to work. My friend said many impoverished families didn't have material things, but when a loved one was dying, they would drop everything to care for that person. "They knew what was important," he says. These families were much better at caring for their families. Still, such devotion is no longer the norm.

Ethics Versus Values

I began writing this book at a time when end-of-life ethics was being hotly debated in the press. Not long before, the doctors for Terri Schiavo, a woman who had been in a persistent vegetative state for roughly fifteen years, had been ordered by a judge to remove a feeding tube and other medical treatment that had been keeping her alive. Her husband and her family had spent years in

court trying to gain, or to prevent, such a decision from a judge. Congress became involved and tried to intervene.

While the legal process and the decision reached caused great commotion among the Christian community, as well as the rest of the country, I found few satisfactory answers to the dilemma. While most pastors, theologians and ethicists agreed that it was permissible to withdraw medical treatment, Schiavo's dilemma was more difficult. She only needed food, water and minimal care. Yet her food and water, delivered through a feeding tube, required medical professionals to perform the delicate maneuver to insert the tube. The contents of her food were scientifically and medically determined. She wasn't simply fed pureed pork chops. Even if Schiavo was so ill that removing a feeding tube was ethically defensible, Christians were rightly furious that anyone would be left alone, without care and human comfort, to die. Yet in my own conversations with doctors, theologians and church leaders, they suggested privately that they would never want to be kept alive artificially (even with just food and water) for fifteen years.

I was unsatisfied with Christian responses that either required the prolonging of life—no matter the physical, mental, relational or financial suffering involved—or that pinpointed what treatments might be appropriate under what circumstances. Instead, I wanted to find a Christian response to these issues that would be useful under any medical circumstance, that upheld the value of life and the dignity of the person.

What I discovered was the Christian tradition of the good death. While the particulars of medical technology in the twenty-first century are unique, every age has challenged Christians with difficult questions of how to die well. And every age, including our own, has wrestled with how to teach fellow Chris-

tians the meaning of death and the ways they could practice it faithfully. Each age recognized that how a culture approaches death precisely reflects what it believes and how it approaches life. While this is true for any culture, Christians must also reconcile their approach to death with Jesus, the Son of God, whose death and resurrection provides a very specific example of how to die and offers the hope to all Christians of a bodily resurrection in the last day. If we Christians really do enjoy the life of God, who is victorious over death, our life on earth is therefore cast in a very different light.

Century after century Christians rehearsed and applied their beliefs about death; throughout their lives they envisioned dying so that at the moment of death they would be prepared. They sought to die reconciled to God and their human brothers and sisters. They gave evidence of their faith in the life to come, either by professing it or by describing their deathbed visions of the heavenly places, often both. They offered comfort to surviving loved ones who desired to hear the last words of the dying who were so close to the eternal enjoyment of life with God.

Death, Christians believed, was not just a medical battle to be fought, though they did use medicine for healing. Nor was death simply about the loss of precious relationships to be mourned. Instead, this was a spiritual event that required preparation. The dying performed it in public as evidence of their faith and to provide instruction to others. Rather than waiting for illness to overtake them, these Christians were actively involved in their own dying, in control—to the extent possible—of the dying process. Injured at the death of a fellow Christian, the church community then rallied together to grieve and to express once again their faith and knit themselves together in a new way.

As dying in the late twentieth century became a drawn out

process, I also discovered an immense opportunity to relearn and reteach these values. While the question of when or whether to withdraw a feeding tube is still difficult to answer, there are at least certain values we can apply. As we assist others through the process of treating a terminal illness or as we contemplate our own answers to such questions, we can seek to perform these elements of the good death. Whatever the medical decisions made, under any circumstances we can express our faith in God, our love for one another, our hope in the resurrection. Having done this, we will have been faithful, in the eyes of fellow believers throughout history, to God and our neighbor. In the culmination of our lives, we will have said and done what was most important.

Aunt Eileen

My own first personal encounter with death came when I was twenty-seven years old. My wife and I went to visit my great aunt who was dying of cancer.

My aunt lived alone after her sister died fifteen years earlier. Aunt Eileen lived on the fifth floor of an apartment building on the 1300 block of north Lake Shore Drive. I remembered as a child staring through her window at the city below. Now, as I looked out her window, I thought about those visits when her apartment seemed as if it were set in the clouds. Neither Aunt Eileen nor her sister married. Their nieces and nephews, and their children, were her only family nearby. She lived by herself, but she wouldn't die that way. A few family members, particularly my mom, began regularly visiting her.

For years Aunt Eileen kept her cancer a secret. Even as she neared her eighties, she told no one about her trips across the park that straddled the distance between her apartment building and the hospital, just a few miles north of Chicago's Loop. She

walked, not wanting to spend the money on a taxi or ask a family member for a lift to the hospital for chemotherapy. I had visited Eileen seldom in the years before she died. When she'd been sick, she didn't allow visitors. On her deathbed, however, she changed her mind.

I only learned of her illness around the time Eileen entered hospice a few months before her death. Her doctor had urged her to undergo more treatments, but she declined. Having seen hospice at work when her sister died of breast cancer, Eileen preferred to die at home in peace. My mother, who had taken over much of her care, began making dozens of trips to North Lake Shore Drive.

I had made no effort to see her until my mother encouraged me to visit Aunt Eileen. I assumed there was nothing I could do for her, and it never occurred to me to simply drop by to see my dying aunt. When we entered her apartment, the hospice nurse directed us into her bedroom. My aunt lay on the hospital bed brought in by hospice. The only other object in the room was a dresser, and on it stood a mirror. Into the frame, my aunt inserted pictures of saints, Jesus, Mary and Pope John Paul II. A devout Catholic, Aunt Eileen was calling on her spiritual resources as she lay dying in the same one-bedroom apartment she had lived in for decades.

I tried talking to Aunt Eileen, but her speech was slurred and sometimes inaudible. She moaned and attempted to respond to my small talk. Curled on the bed, as if withdrawing into herself, she tugged at the clothes that lay loosely across her body, while the hospice nurse tried to maintain my aunt's modesty. The hospital gown she wore had the back cut off, apparently because the clothes at which she constantly pulled were irritating. She was covered by the partial gown and her sheets, with her knees curled

up toward her chest. She would die in only a week, and yet I was eager to get out of this room. My mind raced as I tried to think of something to say.

My wife is an easier conversationalist. She told Aunt Eileen about the recent snowfall. "But I'm used to it," she said while my aunt mustered an inaudible reply, "I grew up in New Hampshire."

I looked around her bedroom and wondered what to do. I'd never tried to make conversation with a dying person. The chit-chat I usually engaged in with my aunt seemed inappropriate, but other topics (How are you feeling?) seemed uncomfortably loaded with the suggestion of her death.

It was the second time my wife and I had visited my aunt since she entered hospice, and each time I stood uncomfortably, said little, and left as soon as I felt it appropriate. I felt awful for Aunt Eileen. I was afraid of this disease that had shriveled her up and left her twisted on the hospital bed in her apartment. I was, to some degree and to my shame, repulsed by my aunt's shrunken figure on that bed. Yet I'd never talked to a dying person before. I had no experience comforting, and certainly not ministering to, people on their deathbeds.

On this final visit, I fell into old routes of conversation. My wife and I talked of old show tunes and movie stars—Fred Astaire and Ginger Rogers. We reminisced about Aunt Eileen's days as a dance instructor, decades before I was born. We read the psalms, yet nothing we could do or say measured up to the gravity of the situation. Eventually, we left, saddened by her impending death, yet feeling helpless to provide her any comfort.

Aunt Eileen died the following week. In some ways her death was good. She gave a few final requests to my mother—instructions for her memorial service (she wanted no funeral) and requests for her favorite food, Dove ice cream bars. And my mom saw that

they were completed. Our family visited, and though she was alone during much of her final years, she was not entirely alone at the end. She had her church and the hospice chaplain to care for her spiritually. Her death was good also because it was a mercy, a farewell to the affliction visited upon her. Eileen's sickness had been a great evil. She suffered badly and over a long period.

I believe that Aunt Eileen appreciated our visit, so it had done some good. Yet I felt inadequate to the moment. It was an important event, but I talked about the weather and Ginger Rogers and waited for the first opportunity to leave. I felt that I'd failed in what seemed like a basic responsibility, to comfort a dying family member. Still, I didn't know what I'd done wrong or could have offered or said instead. I, like most Americans, grew up knowing nothing about the end of life. I never watched death's slow advance, as someone gradually loses the ability to drive, to clean windows and then to cook dinner or use the bathroom. I never saw someone's grip on life weaken, and his hopes turn away from this life as he faced the next.

Given the sacredness of such an event, I felt the need to offer more to assist my aunt. How should I care for a loved one on her deathbed? What do you say when no words can be sufficient? I had no idea.

I was bothered by these thoughts long after her memorial. I knew as I grew older these were skills I would need again. But I also realized that I had given almost no thought to this most essential truth of life: I will one day die. What should I think of that, and how should I prepare myself? And how could I help someone near death if I haven't spent time considering my own mortality?

Evil and Death

While dying well is often a matter of living well, to live well we

must come to grips with our death. It is difficult, but it can also be invigorating. "It is only by facing and accepting the reality of my coming death that I can become authentically alive," says the Orthodox bishop Kallistos Ware.

We avoid death or even fear it because death is an evil, the horrible rending of a person from her body, from loved ones, from the ability to be fully in God's image. "Death is not part of God's primary purpose for his creation," writes Ware. "He created us, not in order that we should die, but in order that we should live."[9] Jesus wept at Lazarus's death. The apostle Paul called death the last enemy. Death is indeed evil.

Yet death is also a mercy; it is the final affliction of life's miseries. It is the entrance to life with God. Life's passing can be a beautiful gift of God. This riddle of death's evil and its blessing is not difficult to solve. We enact it every Good Friday as we recall the evil of Christ's death to be followed on Easter Sunday with the joy of his resurrection. We do not rejoice in Christ's death or Judas's betrayal. Yet there is no evil so great that God cannot bring joy and goodness from it. That is why death deserves our attention in life. Because we instinctively want to avoid it, to turn our face away, it is good to look death in the eye and constantly remind ourselves that our hope is in God, who defeated death.

Meditating on one's death has been practiced throughout Christian history. St. Isaac the Syrian instructed,

> Prepare your heart for your departure. If you are wise, you will expect it every hour. . . . And when the time of departure comes, go joyfully to meet it, saying, "come in peace. I knew you would come, and I have not neglected anything that could help me on the journey."[10]