Awakening to Mortality: End-of-life as Rite of Passage and Pathway to Transformation

Joan S. Grey

A Thesis in the Field of Religion
for the Degree of Master of Liberal Arts in Extension Studies

Harvard University
May 2019
Abstract

Many view death as catastrophe, resulting from a cascading failure of biological systems. Fear, denial or unconsciousness results in a medicalized, often institutionalized, approach to end-of-life care. Is dying predominantly a medical event or can it be something more? What would it take to approach end-of-life with intentionality, dignity, and integrity, consistent with beliefs and values? Is healing possible when curing disease is no longer an option? Given the embeddedness of the scientific model in our culture, my thesis “Awakening to Mortality: End-of-life as Rite of Passage and Pathway to Transformation” uses medical terminology for chapter headings -- diagnosis, prognosis and treatment -- as a structure to examine end-of-life.

End-of-life is universal and personal, diverse and dynamic. Everyone dies, although each will follow a unique glide path, a personal wheel of fortune.¹ We tend to operate with “heads in the sand” until there is a crisis. My thesis probes the death illiteracy embedded in our culture, where the common approach is flight or fight, ignoring death until symptoms, disease or disaster overtakes us. When forced to face the reality, patients cede authority to doctors who control access to medicine’s vast arsenal of drugs, treatments, and tests and who default towards “always something more.”

¹ CDC recognizes four acute diagnoses that account for the deaths of about 10 percent of people over the age of sixty-five. These are unintentional injury (falls), influenza and pneumonia, nephritis, and septicemia. Six chronic diseases (congestive heart failure 34%, cancer 28%, chronic obstructive pulmonary disease 9%, stroke 8%, dementia 6%, and diabetes 4%) are responsible for 90 percent of the deaths among Americans over the age of sixty-five. Harrington, 71-72.
If humans are more than physical entities, death is a threshold into eternity, rather than an exit into nothingness. Religious belief stems from awareness that there is something greater than us, a force that animates. This spiritual essence pre-dates birth and will persist after bodies expire, although not dissectible during autopsy or observable on radiologic scans. Facing the certainty of death can help transform it. Acceptance doesn't mean death goes away, but acknowledgement of finitude helps clarify and orient how we spend our time. Whether we face and accept mortality, death eventually comes. With courage we can formulate a parting gift, a love letter that lasts and marks the transition from fleeing and fighting to acknowledging and transcending death. Embracing the paradox of mystery and certainty allows more choices over the finale. By acknowledging and preparing, end-of-life can be a time for transformation and blessings, in contrast to the current default: death as ambush, with dying viewed as biological failure, dominated by crisis interventions, and managed by medical professionals.
Frontispiece

© Kris Casey, “The Threshold,” April 2016
Biography

Joan Grey graduated from West Point in the first class with women and was commissioned in the Army. She served as a logistics officer in the US and Germany until a parachute accident ended her military career. As her husband continued to serve in the Army, frequent moves resulted in an eclectic career path including employment as hospital chaplain, environmental educator, fundraiser, social media coordinator, facilitator, and numerous volunteer positions. She currently collaborates on a blog, coordinates a number of groups, and hopes to distill her thesis research into a series of *ICE-teas: Preparation before Expiration* workshops.

Through her research and writing, Joan tries to emphasize the personal and cultural importance of death, with its guaranteed arrival, despite the uncertainty about when, where, or how. After three death-defying episodes in recent years (stranded on a DC metro train during an electrical fire; having a tree fall in front of the car while driving on the NJ Turnpike, and getting hit by a bus while biking), Joan decided to stalk the reaper and befriend the angel of death. She is committed to finishing her thesis and getting her affairs in order because “Life is what happens while you are busy making other plans.”2 During the writing of this thesis, she has had opportunities to act as an existential coach for family members and friends who were facing end-of-life situations.

---

2 John Lennon’s “Beautiful Boy” dedicated to his 5-year-old son the year Lennon was murdered at age 40.
Dedicated to:

Awakening on the journey:
To eternity and beyond
∞
Acknowledging with gratitude

Sincere appreciation to my Thesis Director Dr. Cheryl Giles, for her willingness to guide and support me throughout the thesis writing process. Thanks to Research Advisor Dr. Stephen Shoemaker, for suggestions in developing my proposal and providing match-making assistance and to Academic Advisor Sarah Powell who helped illuminate steps to completing the degree. For the wonderful Harvard Library HOLLIS.

To Dr. Diane Moore whose guidance influenced the formulation of this project

To Professors Pat Bellanca, Kevin Madigan, and Jason Silverstein who pushed me to clarify and express my thoughts and opened my eyes to new ideas

To members of my book group for their support, especially Jane, Lee, Marge, and Sue who helped with edits, suggestions, and encouragement and to Kris and Mary Kay from WISP (Writing as an Intentional Spiritual Practice) for their accountability: “Hands on keyboard, butt in chair."

To my Holy Angels friend and Index Card Cure collaborator: Jane

To physicians whom I have never met, but whose writing and insights inspired me on this journey of discovery: Atul Gawande, Paul Kalanithi, Arthur Kleinman, and Victoria Sweet

To Bill and Dan for their deep read and comments about the draft

With love and special thanks to Dan, Steven, Emily, Rachel, Allison, and Patrick: You always make me smile. Love you forever.

∞ Namaste ∞
Preface: “The Talk”

Attentive parents communicate with their children about where babies come from. Having “The Talk” about the facts of life is an essential discussion about the connection between sex and babies. For those who are pregnant What to Expect When You're Expecting is a bestselling guide. The book’s website promises to reveal “What to Expect, every step of the way… We’re all in this together.”3 There is no counterpart instructional manual for life’s terminus; no What to Expect at Life’s End or Dying for Dummies. While contraception can prevent birth, humankind has found no lasting death prophylaxis. Being born means that we will die. But, if we don’t face facts many may find themselves on “life” support in an intensive care unit. And even when the ending is unambiguous, loved ones and professionals hesitate to address this fact of life. Who are we fooling when we ignore and avoid life’s conclusion? Although the better question may be: who are we hurting?

In our culture, “dead” is the ultimate four-letter word, even as our lives run on death. In the course of a day, we consume and produce death, ranging from the foods we eat to the fuels that power vehicles and generate energy. For many, the only lives that count are human, with younger generally better. Aging and end-of-life are stages to avoid, with encroaching dissolution masked by makeup, hair dye and face lifts. We hold death at arm’s length; keeping the elderly institutionalized and dying segregated, as if by

3 https://www.whattoexpect.com/
ignoring expiration, we’ll be granted a personal exemption from the certainty of cessation. Death is the unwelcome elephant in the room, that which must not be named.

We can’t change the fact that life ends in death, but we can change how we approach “The End.” Medical science has made wondrous strides with diagnostic tools, antibiotics, vaccines, therapies, and surgery. And yet despite the discoveries, we still die. Many people live longer than ever, although the shadow side to longevity is that years are back-loaded, applied to the end-of-life span. We’re in this together. At birth, our countdown timer starts. While the outcome is certain, the timing and causes are unknown. Is dying a medical event, or is it something more? Currently, the healthcare system provides the singular framework for dying, employing default aggressions like cardio-pulmonary resuscitation (CPR) without consideration of underlying illnesses or cognitive capacity. Compressing, shocking, or cutting flesh may be appropriate measures when the goal of care is a bridge back to health and functioning. What about when someone is already in fragile shape? Patients and families buy into the conspiracy—“Don’t lose hope;” “It will be okay;” “Never say die;” “We want everything done.” Something has got to change. For that to happen, it will take a conversion experience that mindfully addresses life in its entirety, which includes the final phases of dying and death.

My thesis, “Awakening to Mortality: End-of-life as Rite of Passage and Pathway to Transformation” looks at what is, proposes what could be, and gives suggestions for how to transform the current approach. We don’t know how our world ends, only that it will. The time to consider dying and death is not during admission to an Emergency Department (ED) or Intensive Care Unit (ICU) or after receiving a terminal diagnosis. Facing facts means acknowledging mortality and preparing ourselves and our loved ones.
“Awakening to Mortality” reminds us to live fully so dying is metamorphosis, not catastrophe.

As people grapple with the existential challenge, some might think: “Why bother? Carpe diem. Work hard, die anyway.” But there’s another way to approach the certainty: by focusing on meaning, purpose, and legacy. Philosopher priest Teilhard de Chardin reminded: “We are not human beings having a spiritual experience. We are spiritual beings having a human experience.”\(^4\) We are more than physical bodies. Spiritual derives from a Latin root \textit{spiritus} meaning breath (also shared with words like inspiration and respiration). If we have breath, we have a spiritual core, whether or not we follow a particular religious tradition. End-of-life (EOL) is universal, but because it is feared, it is often neglected until we are right in its midst of crisis. We’ve created a medical express train—not always speedy but often technologically invasive. Patients and families may hop on this train, not realizing the pitfalls of treatments and the low probabilities of success. When you have received a diagnosis or are emergently admitted to the hospital, the medical system envelopes. Sometimes a patient is patched up and released to live another day. But there comes a time, where there is less return on the investment of more interventions. And, whatever the route, everyone eventually disembarks at the same terminus—destination death.

When we admit to its certainty, we can transform our expectations as death approaches. Acceptance doesn't mean death goes away, but acknowledgement of finitude helps clarify and orient how we occupy our time, the building blocks of life. If we accept mortality, we can review the life we have lived and discern what the future might hold.

\(^4\) \url{http://www.theclearingnw.com/blog/spiritual-beings-having-a-human-experience}
Rather than fighting and fleeing a perceived enemy, we can accept the inevitable and avoid a crisis-by-crisis succession of medical treatments. Awareness of death can precipitate awakening—that what matters in life is more than physical matter.
# Table of Contents

- Abstract ............................................................................... Error! Bookmark not defined.
- Frontispiece ........................................................................ Error! Bookmark not defined.
- Biographical Sketch ............................................................. Error! Bookmark not defined.
- Dedicated to: ........................................................................ Error! Bookmark not defined.
- Acknowledging with gratitude.............................................. Error! Bookmark not defined.
- List of Figures ....................................................................... Error! Bookmark not defined.
- Chapter 1 Introduction .......................................................... 1

## Chapter 2. Diagnosis ............................................................ 7

- Life versus death ..................................................................... 7
- Material versus spiritual ....................................................... 8
- Birth / death analogy ............................................................ 10
- Philosophical / ethical differences ....................................... 13
- Galtung violence ................................................................... 14
- Situatedness......................................................................... 15
- Humans versus “Econs” ....................................................... 16
- Expectations.......................................................................... 17
- Stakeholders perspective— “Don’t just sit there, do something” .......... 18
- PT: Patients ........................................................................... 19
- DR: Doctor............................................................................ 20
Jargon and inaccessible terminology ................................................................. 22
Granularity and fragmentation: allopathic treatment versus a holistic approach .24
SYSTEM ................................................................................................................ 25
Financial: Follow the money ................................................................................ 26
Legal ...................................................................................................................... 28
Religion: “Everybody wants to go to heaven, but nobody wants to die.” .......... 30
Technology: The Medicalization of all Maladies .............................................. 32
Conclusion ............................................................................................................. 33

Chapter 3. Prognosis: “We can run, but we can’t hide.” ........................................ 35
Illness versus disease .......................................................................................... 37
Charting the human lifespan ............................................................................... 39
Causes of death in US for ages 65+ ................................................................ 40
Peace and dignity in the midst of VUCA .............................................................. 44
Ethics: Individual Self-Determination ................................................................. 45
Bio-medical ethics: pursue benefits; avoid harm .............................................. 47
Personal and social costs ................................................................................... 51
Immortality .......................................................................................................... 51
Terror Management Theory (TMT) ................................................................. 52
Conclusion ............................................................................................................. 53

Chapter 4. Long-term Treatment: Memento Mori —Live with the end in mind ...... 55
Ars Essentia: art of the essential ....................................................................... 58
Proactive versus reactive ..................................................................................... 59
Connecting the dots ............................................................................................. 60
List of Figures

Figure 1: Kagan diagram of human lifespan

Figure 2: The wheel of fortune on how we die

Figure 3: Patterns of dying

Figure 4: Holistic Integrated Map (Model) to Health and Healing

Figure 5: Life’s through-line or Soul

Figure 6: Estimated success rates for CPR

Figure 7: Frontispiece from Wyer’s Ars Moriendi

Figure 8: Shneidman’s ten criteria for a good death
Chapter 1

Introduction

*Teach us to number our days that we may gain a heart of wisdom. Psalm 90:12*5

Every morning the sun rises and each evening it sets. Sunrise and sunset are natural. We expect the cycle and make concessions for darkness, such as using lights to continue working. Weather is also a force of nature; however, its variability causes us to pay attention to forecasts. If rain is predicted, prudence may dictate carrying an umbrella or wearing a raincoat. We anticipate and plan in order to deal with possibilities. Like the certainty of sunrise and sunset, all creatures that live will also die. Death is fact, although changeable like the weather. Elements of choice and chance, such as genetics, behaviors, and environment, influence its timing and cause. Dying may occur either soon or far in the future, but the outcome is certain.

Death surrounds us: featured on the news, depicted in movies, or possibly even interrupting our commute. Despite its ubiquity, paradoxically we manage to forget that someday it will be our turn. While some even refuse to mention the word, disparaging it as morbid and fearing it will somehow jinx them or their loved ones, death remains part of the human condition. Most view it as a catastrophic occurrence resulting from a cascading failure of biological systems. Humans exhibit higher order thinking processes, an evolved state that allows pretending that life does not include death. The formidable barrier against “that which must not be named” is a great delusion and a psychic energy

---

5 [https://www.biblegateway.com/passage/?search=Psalm+90%3A12&version=NIV](https://www.biblegateway.com/passage/?search=Psalm+90%3A12&version=NIV)
sink. Fear or denial results in a medicalized, often institutionalized, approach to end-of-life care. Humans are endowed with consciousness and fated for oblivion: we know that we will die. However, we equate dying with terror, trauma, pain, suffering, and separation. Our current cultural practice has delegated authority over dying to medical practitioners, prioritizing costly treatment of the body over a plan that anticipates and incorporates our final reality. When life is “saved” by procedures that rescue or extend, the fix is temporary. Even raised-from-the-dead Lazarus of Biblical renown\(^6\) ultimately died, although no record exists of his second foray into death. As the author of *When Breath Becomes Air* Paul Kalanithi reminds us, “Humans are organisms, subject to physical laws, including alas, the one that says entropy always increases.”\(^7\)

Given the embeddedness of the scientific model in our culture, my thesis, “Awakening to Mortality: End-of-life as Rite of Passage and Pathway to Transformation” uses medical terminology as chapter headings: diagnosis, prognosis and treatment. The Diagnosis chapter studies the current paradigm and presents factors that influence behaviors and stakeholders who are invested in the status quo. This chapter puzzles over the problem by looking at the symptoms, including the conspiracy of forces that have created customary health care practices. The Prognosis chapter forecasts the likely scenarios for disease progression at end-of-life and describes the conditional arguments that frame human existence, the if/then relationships. If we are born, then we will die: a conclusion that follows a hypothesis. What can we expect that process to look like? Two Treatment chapters, one long-range and one short-term, make suggestions and propose

\(^6\) John 11:38-44 NIV
solutions for healing the current approach. Having acknowledged the problems, how can we alleviate them? The scope of this research is limited to ages 65+ Medicare-eligible adults, and is primarily oriented toward Christianity, the predominant religious affiliation in the United States.8

We are finite creatures: “Our days may come to seventy years, or eighty, if our strength endures; yet … they quickly pass, and we fly away.”9 On some primal level, we understand that we will die but seem personally and culturally reluctant to address issues related to that eventuality. This blind spot results in ignorance about death, an illiteracy that incurs not only a physical toll, such subjecting bodies to violent and ultimately futile treatments, but also exacerbates emotional and spiritual suffering for the patient and loved ones.10 In the aftermath, survivors often cope with legal, financial, and administrative chaos compounded by bereavement. Promoting end-of-life literacy can ease the turmoil. Viewing the end as a natural and inevitable part of life requires intentionality. Facing this certainty realistically and holistically widens the aperture for approaching end-of-life mindfully.

The current medical system is reactive: bodies experience dysfunction that doctors try to fix. This bio-medical model appropriately responds to injuries or illness with attempts to cure or mitigate symptoms, but goes overboard in order to extend life indefinitely. A medicalized dying process reduces us to an assortment of aging parts subjected to painful treatments for diminishing returns. Focusing on physiological vital

---

8 Pew
9 Psalm 90:10 NIV
10 This pathway is also enormously expensive: “Spending on Medicare beneficiaries in their last year of life accounts for about 25% of total Medicare spending on beneficiaries age 65 or older.” https://www.kff.org/medicare/issue-brief/medicare-spending-at-the-end-of-life/
signs as the only measure of life neglects the profound human essence. If humans are more than just flesh, then why does the healthcare system act like dying is merely a physical event and pretend that administering the right treatments will “save” lives?

While sad, death is universal; only the circumstances are unique. Accepting that life ultimately ends allows for the necessary preparation and planning to ensure that chaos does not compound grief. Throughout life, people should reflect on what makes life worth living. What do I consider to be a quality life? Such a review often reveals that the body is just one facet of the whole. Medicine is intended as a bridge back to health, responsible for diagnosing disease, treating illnesses, managing symptoms, and fixing injuries. Medicine may postpone but cannot prevent death.

An integrated life includes spiritual, emotional, and social aspects that often receive short shrift in the bio-medical model. Awakening to mortality can bring more depth to life. Whether we identify with a particular religion or not, facing the reality of finitude, can catalyze spiritual awakening. When we come to terms with life ending, it brings clarity and a sense of urgency to live with passion, purpose, intention and awareness.

The time to explore dying is while reasonably healthy and mentally competent, when death seems remote and abstract. To prevent painful and futile procedures and minimize suffering, preparation is needed before experiencing an episode that requires an emergency department (ED) visit, admission to an intensive care unit (ICU), or after receiving a terminal diagnosis. Unfortunately, too many of us wait. When we have lived fully, dying may be heartbreaking, but this transition can be an opportunity for transformation. Acceptance may generate the strength and compassion needed to
accompany loved ones, a vicarious preparation for our eventual end. By embracing the whole of life, including death, our demise can evoke elements of transcendence rather than torture, with dying as a grace-filled transition more than a medical event.

Oliver Sacks speaks to the cultural default: “We have come to medicalize aging, frailty, and death, treating them as if they were just one more clinical problem to overcome. However, it is not only medicine that is needed in one’s declining years but life—a life with meaning.” Living a full life requires awareness, courage, and a more holistic approach. Dying well includes spiritual preparation for tasks such as mending relationships, reviewing life, and creating a legacy narrative. Whether we identify with a religious tradition or not, facing mortality, our ultimate reality is an existential endeavor with spiritual aspects. Dying well isn’t a matter of the right medicine, procedure, or doctor; a good death becomes more likely when one has lived a life of purpose and connection, acknowledging that physical bodies expire. It is time to resuscitate dying and rescue it from the domain of medicine. Giving credit to death as a natural boundary helps clarify what does and does not matter while we are still alive.

Religious belief stems from awareness that there is something greater than us, a universal force that animates, conceived as a spiritual essence, which some call soul, that pre-dates birth and will persist after bodies expire. If humans are more than physical entities, death is not so much an exit into oblivion as a passage into eternity. What would it take for life’s twilight to be a pathway to spiritual growth? Recognizing that earthly pursuits are transient encourages reflection on meaning, mortality, and mystery. Not everyone is religious, but as long as we breathe, we are spiritual: “We are not human

beings having a spiritual experience. We are spiritual beings having a human experience.”¹² Best-seller lists feature physician-written books recognizing problems with status quo health care and trying to spur revisions of end-of-life care. Their intentions are admirable, but the timeframe proposed—when the medical system has already transformed a person to a patient—is too late to make a difference. While in the prime of life, we need to consider and define what constitutes a good life, and thus a good death. A secret to a life well-lived embraces Memento Mori, remembering that we will die. Life is fleeting and fragile; finitude is certain. Pondering this certainty can guide each person to the realization of what matters most. My hope is that my thesis “Awakening to Mortality” will catalyze action and change the approach to dying. By acknowledging and preparing, end-of-life can be an opportunity for transformation and blessings, instead of the current default: death as ambush, with dying viewed as biological failure, dominated by crisis intervention, and managed primarily by medical professionals.

Chapter 2.

Diagnosis

In *The Bright Hour*, Nina Riggs (1977-2017) reflects: “A bus. A cough. A rusty nail: Death sits near each one of us at every turn. Sometimes we are too aware, but mostly we push it away. Sometimes it looks exactly like life.”\(^{13}\) Humans face intractable facts: nothing lasts and people die. In *The Consolations of Mortality*, Professor Andrew Stark claims:

> We know on the most abstract level that we will come to an end. But we do not—and maybe could not—live our lives in the full face of that knowledge. We’d be paralyzed with fear or a sense of meaninglessness. And so, we repress our awareness that extinguishment awaits us. We repress it also because it’s simply impossible to imagine our no longer existing. Freud saw death denial as a fact of our individual nature: At bottom no one believes in his own death… in the unconscious, every one of us is convinced of his own immortality.\(^{14}\)

Life versus death

An inevitable consequence of being human is death. We know and yet we avoid this knowledge. Humans aren’t born equipped with an owner’s manual, and there are limited guides to end-of-life and the dying process. Some religious devotees consult scripture\(^{15}\) as a quasi-handbook on what it means to be human and how to live life, although even believers recognize wisdom literature’s limitations: not only are divine revelations time and place specific, but they are heavy on allegory while light on details.

---

\(^{13}\) Riggs, 197-8.

\(^{14}\) Stark, 14.

\(^{15}\) Various acronym for BIBLE: *Basic Instructions Before Living Eternally* or *Believer's Instruction Before Leaving Earth* or *Basic Instruction Book for Living on Earth* or *Biblical Instruction Before Leaving Earth*
This chapter examines the issue of mortality, the forces at work, and the players in the game. Transforming life’s twilight to a path of spiritual growth requires looking at factors that have created the current culture. Even before probing end-of-life, it is necessary to define the terms. What is life? We use the words life and living reflexively, often triggering an emotional reaction, especially when it concerns a loved one, but what exactly does being alive mean? Is the body who I am or is the body something that I temporarily occupy? It seems analogous to how Supreme Court Justice Potter Stewart explained pornography: “I know it when I see it.” Since the advent of medical technology, multiple legal cases have attempted to answer the question of when does life end and to differentiate between ordinary versus extraordinary treatments. The law has attempted to delineate the life / death boundary regarding persistent vegetative state (PVS) patients. Clinical criteria continue to evolve in the face of existence-prolonging care. The medical domain primarily focuses on biological aspects to define life, judging the state of health numerically using vital signs such as blood pressure, urine output, temperature, respiration, and pulse. Outside of medicine, life is harder to define and thus most people would subscribe to Justice Potter’s criteria: “I know it when I see it.”

Material versus spiritual

_In you is the source of life and in your light, we see light. Psalm 36: 9._

A lamp is a mechanism for illumination; it requires an energy source, wiring, and a bulb. When the switch is turned off, the light disappears and the lamp loses its primary purpose of providing light. For human beings, the body is a mechanism. An animating

---

16 [http://corporate.findlaw.com/litigation-disputes/movie-day-at-the-supreme-court-or-i-know-it-when-i-see-it-a.html](http://corporate.findlaw.com/litigation-disputes/movie-day-at-the-supreme-court-or-i-know-it-when-i-see-it-a.html)
force, called by some soul or spirit, is like light—weightless but vital—housed in the body. Organs such as the brain and heart show up on scans and during autopsy, but mind, relationships, and soul are intangibles: “Not everything that counts can be counted.”17 A materialistic interpretation might propose that “I am my body;” while a spiritual approach might claim that “I have a body.” What life means continues to evolve in synch with scientific and medical advances or in dispute because of legal challenges. Defining life goes beyond biological facts to the realm of values; a topic many people do not consider until they are faced with the case of one specific person, which ramps up the emotional investment. In “Roadside Assistance for the Spiritual Traveler,” Rabbi Rami Shapiro clarifies:

Beliefs are unprovable propositions about reality; faith is trusting that those beliefs are true; and religion is a system of communal behavior designed to enforce and reinforce faith in the correctness of those beliefs. Beliefs should not be confused with facts or hypotheses. Facts and hypotheses are testable; beliefs are not. That is why you need to have faith in God but not in gravity. Because beliefs are not testable, they need not change. Beliefs only change when experience makes faith in them untenable.18

Even in the abstract, the binaries are elusive: life versus existence, having a body or being a person. The theoretical perspective fails in an ICU room when emotionally charged decisions affect the continued existence of a mortally ill loved one. With the current emphasis on staving off death, we have equated body with life, and possibly sacrificed the essence of who we are. Currently attention focuses on the mechanism / lamp / body, without consideration of whether the light will still function.

17 Quote often attributed to Einstein but original authorship is unclear.
Birth / death analogy

The counterpart life transition to death is birth. Not everyone will go to university, get married, or have a baby, but everyone who lives shares birth and death, the beginning and the end. We spend more time planning for college, weddings, and even vacations, than preparing for death. There are obvious differences between birth and death: a child’s arrival generally is celebrated, and a woman may experience multiple pregnancies. However, until the latter part of the twentieth century, “Childbirth was characterized by a hospital-dominated model of care to which pregnant women and their partners passively submitted. Women endured labor and delivery without preparation, they were separated from their husbands, and they often received general anesthesia.”¹⁹ Women have been giving birth as long as there have been humans. In times past, a woman might have a midwife or friend to help deliver the baby, but there were limited resources if a problem arose. The advent of medical technology altered the delivery process. Women labored in confinement with nursing support; doctors handled delivery; and fathers were exiled to await the pronouncement of good news.

Starting in the 1960s, women began reclaiming pregnancy from the medical profession and demanding more autonomy over childbirth. The ensuing cultural shift brought scores of instructional manuals to illuminate the process and the creation of special breathing techniques and birthing suites. The Baby Boom generation insisted on changes, leading to a more family-centered model. Now, women develop birth plans that outline goals covering holistic aspects of labor and delivery, addressing physical and

---

¹⁹ Quoted in Franklin Miller.
emotional preferences, and the support expected from caregivers. Hospitals and medical staff have adapted, paying attention to patient desires by providing expectant mothers more sovereignty and options.

Consider the differences between pregnancy and end-of-life preparation. A simple drugstore test can determine whether a woman is pregnant, subsequently confirmed with an ultrasound approximating a due date. The family expecting a baby has access to books and preparatory classes that provide guidance and orientation to the process of labor and delivery and eventually a familiarization tour of the birthing facility. Some parents outline desirable features for their birthing experience. The planning and preparation clarify what to expect at different stages of pregnancy, foundational for approaching birth with readiness and the right mindset. Expectant parents own the process and have time to embrace their new identity. While there is always the possibility for an emergency, which might require intervention, the pregnant woman usually feels in control of her experience. At the time of delivery, the mother will be treated as an honored guest, perhaps ensconced in a plush birthing suite and selecting a special menu for a post-delivery celebration. Preparation helps orchestrate inner and outer environments, with mind-set and setting contributing to a positive experience.20

On the opposite end of the lifespan is the transition called death. Granted, the dying time span usually exceeds that of pregnancy, with research indicating disability can affect a significant percentage of the lifespan:21

The average American male is debilitated for five years before he dies; the average American female for eight years before she dies. We live in the shadow

---

20 Pollan, 442
21 [https://www.sciencedaily.com/releases/2016/04/160415103502.htm](https://www.sciencedaily.com/releases/2016/04/160415103502.htm)
of death for a long time… And, given anticipated progress in medical science, all of these numbers will be larger by the time we reach the ends of our lives.22

All who have survived birth will experience “The End.” However, no definitive tests can confirm if a person is dying or give a predicted date. Even if suspected or known, a terminal outcome may be kept secret. Few guidebooks outline what someone might expect while dying, nor are mentors or preparatory classes available. A critically ill person may have tubes placed to monitor vital signs and to assist with breathing or urination. If a patient tries to relieve discomfort by tugging on tubes or wires, restraints may ensure safety. A cacophony of beeps and alarms, unrelenting light, frequent interruptions, and lack of privacy can contribute to a form of psychosis. With nutrition and hydration delivered via tube, there is no need for menus. And flowers are forbidden in ICUs due to the infectious potential. Setting and mindset can contribute to hell on earth. The patient is certainly the center of attention, usually with observant staff, but often with limited autonomy or awareness.

Before the trend towards medicalization, people were familiar with death because dying often happened at home. While the sick person languished, friends might visit to pass on regards and share stories. Death was sad, but it was an inescapable fact of life. Visiting an older cemetery hints at the prevalence of childbearing deaths where clusters of gravestones memorialize babies who didn’t live long enough to receive names. It was not a golden age, but it was a time of realism.

Today, few people have intimate experiences with death, such as holding hands as someone takes a last breath or sitting overnight with a body bathed and dressed by family and laid out at home before burial. Now, much of dying and death is professionalized. A

22 Hardwig, 4.
sick person is sequestered for care, and dying often happens surrounded by strangers. When a death occurs in a hospital, the body is bagged and inconspicuously wheeled to the basement morgue, often hidden behind an unmarked door. Evidence of perceived failure is whisked away and the mess is sanitized; a neat, clean and discreet façade is presented. Discomfort with death may lead to brutal episodes: serial CPR codes that break the frail ribs of a demented patient, families that insist on “everything” without understanding the torture they are encouraging, and futile treatments imposed by physicians who vowed to “do no harm.”

Philosophical / ethical differences

In *Overcoming Religious Illiteracy*, Harvard professor Diane Moore quotes Brazilian educator Paulo Freire: “Structures of oppression are reproduced unwittingly when critical thinking is not fostered.” Martin Luther King, Jr. put it more pointedly with his observation that “nothing in all the world is more dangerous than sincere ignorance and conscientious stupidity.” We operate with “heads in the sand” about dying and death until there is a crisis. Death illiteracy is embedded in our culture, where the common approach is flight or fight. We ignore death until symptoms, disease, or disaster overtakes us. When forced to face the possibility of dying, patients cede authority to doctors who exhibit “always something more” attitudes and control access to medicine’s arsenal of drugs, treatments and tests. Patients, families, and physicians pin hopes on measures that buy some time, until they don’t, emphasizing medical treatment over spiritual and emotional preparation.

23 Moore, 20.
Whether or not someone believes that death is the end, failing to talk about it inadvertently creates chaos for survivors through disheveled financial or legal affairs, uncertainty about medical interventions, and emotional strain for unprepared proxies. A lack of written guidance unnecessarily substitutes guessing for informed decision-making. Out of guilt or ignorance, loved ones may opt for “everything” without realizing the consequences: that they may be the ones responsible for bills or negotiating with insurance companies for reimbursement. Failing to plan sends a message to your relatives and friends that no matter what endearments you uttered, you left them with a mess to resolve and set them up for post-mortem post-traumatic stress (PTS). At least you know they will be thinking of you, just maybe not positively. Families have gained control of the birthing process at the start of life, but have yet to take charge of the dying process, continuing to leave this oversight of this momentous transition to strangers and chance.

Galtung violence

End-of-life is universal and personal, diverse and dynamic. People will die following their own unique path. Uncertainty, lack of knowledge, and fear contribute to imaginings of violent interventions, lack of control, and depersonalization. In his essay “Cultural Violence” from the Journal of Peace Research, peace activist Johan Galtung describes violence as “avoidable insults to basic human needs, and more generally to life.”\(^{24}\) He goes on to explain: “Direct violence is an event; structural violence is a process…and cultural violence is… ‘permanence.’”\(^{25}\) Galtung’s model is applicable to end-of-life care, where violence is often unintentionally pervasive and embedded. An

\(^{24}\) Galtung, 293.
\(^{25}\) Galtung, 294.
example of direct violence is CPR. While the in-hospital success rate varies, it is zero percent for people over age 89 (which translate to a 100% failure rate). And yet, CPR is the standard of care, if do-not-resuscitate (DNR) documentation is unavailable. Doctors’ medical specialty focus represents a form of structural violence, blinding them to systemic issues, emphasizing an ailing part, rather than seeing the whole person. An example of structural violence is the reimbursement system, with financial incentives that reward procedures and shortchange prevention. Violence can be self-perpetuating, with feedback loops that reinforce behaviors, influence beliefs, and mold the culture. An expectation that everything can be fixed leads to failure to plan for decline. Despite health care providers vowing to “do no harm,” medicalizing end-of-life fits Galtung’s violence model and unintentionally propagates harm in hopes of restored health.

Situatedness

Perspective shapes perception, and vice versa. People seeking or providing care see and act from situatedness, a term coined by social scientist Donna Haraway that “recognizes the subjective nature of all knowledge claims.” Thinking that truth is objective or transcendent is a “god trick” since individual viewpoints are filtered through the lens of identity and experiences. No one can be completely neutral; we see the world as we are, with our particular understandings and backgrounds. For example, completion of medical training turns students into physicians. Entry into the health care system transforms people into patients. When patients consult doctors, they enter a

26 Quoted in Moore, 56.
27 Quoted in Moore, 79.
system with an unequal power dynamic, with those who are sick seeking expertise and
deferring to white-coat wisdom.

Humans versus “Econs”

How can physicians better guide patients during challenging medical
circumstances, and how can patients collaborate in order to achieve desirable outcomes?
Richard Thaler and Cass Sunstein’s book Nudge: Improving Decisions about Health, Wealth, and Happiness explores decision making and examines factors and barriers that contribute to or hinder the process. The authors differentiate between humans and “econs,” short for “homo economicus or economic man—the notion that each of us thinks and chooses unfailingly well.”28 The authors of Nudge contend that “homo economicus can think like Albert Einstein, store as much memory as IBM’s Big Blue, and exercise the willpower of Mahatma Gandhi.”29 But, of course this idealized paragon differs from the real-life version. People are human. Emotions color facts, which sometimes contribute to making bad decisions. Thaler summarizes saying “Unlike Econs, Humans predictably err.”30 Those seeking health-care may not be in a rational state of mind, given the stresses of sickness and treatment decision making. Physician encounters with patients represent professional, business, and legal transactions—all highly rational endeavors. By virtue of training, doctors tilt towards being more rational econs; however, they are also human and bring their own values and biases to their medical practice.

28 Thaler, 6.
29 Thaler, 6.
30 Thaler, 7.
Physicians must learn how to deal with patients who present with seemingly irrational, odd, or even illegal\textsuperscript{31} religious or cultural preferences.

**Expectations**

End-of-life is universal, but because it is feared, few discuss it until crisis occurs. When a person receives a life-limiting diagnosis or is emergently admitted to a hospital, the medical system envelopes them.\textsuperscript{32} Often, a patient is patched up and released to live another day; other times, medical brinksmanship ensues. During an emergency, protocol dictates actions without consideration about whether interventions are burdensome or beneficial; rescue and resuscitation medicine dominates until a monitor’s flat-line definitively indicates “game over.” One might think of the current medical system like being ensconced on an express train—once on board, your autonomy is limited. The conveyance may be speedy, but it features limited stops. No matter whether a person is likely to recover from an illness or is on a decline which will result in death, the health care train is the default since our society has now designated medical science as conductor for monitoring and shepherding dying. Unless people have anticipated and chosen an alternate plan to bypass the system, they accept a ticket to ride the medical locomotive.

Patients expect miracles, with doctors considered saviors as they rush in to test and treat. The truth of mortality is distressing, so it is better to ignore by taking action instead. Patients and families step on the train without realizing that they have

\textsuperscript{31} Illegal practices might include female genital mutilation or a Christian Scientist parent refusing treatment for a minor

\textsuperscript{32} In a hospital where I worked as chaplain, trauma patients even received new names, a Doe persona, until identity could be verified.
relinquished control and the system hurtles ahead in an “always something more” frenzy. Empirical knowledge rules and diagnostic tests validate. If something doesn’t appear on a scan, its existence is suspect. Maintaining vital signs, physiological benchmarks, is differentiated from consciousness, a measure that incorporates awareness, emotion, and higher order processes. A body can seem alive, even if only because machines are ensuring life. Doctors recommend and patients pursue treatments without understanding the collateral tradeoffs: extended time but diminished life, possibly with remaining time spent tired, nauseated, depressed, or demented. Patients’ fear of death may convince them to pursue cures because the alternative is unpalatable. The cultural norm surrounding dying focuses on technological medicine and measurable metrics instead of acknowledging and honoring this transition as a sacred passage.

Stakeholders perspective— “Don’t just sit there, do something”

Whose health, life, and dying is it anyway? Multiple parties are involved with health care throughout life. Stakeholders include patients, doctors, and businesses, and also behind-the-scenes insurance and pharmaceutical companies. And, if situations get contentious, lawyers and courts weigh in. In addition to the involved parties, cultural, economic, and legal macro forces influence interactions. Given the realities, limitations, and values of humans, the various stakeholders have different motivations. Health care is more than a simple transaction between care giver and care receiver. The system is politically fraught and inclined to impose parameters on those who seek care. To draw an analogy with the theater, costumes and accoutrements help distinguish identities of the characters. The cast of the medical system dons costumes to represent their status in the hierarchy. Petitioners called patients, wearing gowns and wrist bands, pursue solutions
from experts clad in white coats or scrubs whose badges and stethoscopes symbolize authority. Somewhat anonymous individuals wearing business attire (“suits”) protect bottom-line profitability and represent covert power behind the care exchange. The “suits” have authority to deny or pay claims, or to price drugs so they are accessible or prohibitively expensive. Each stakeholder plays a role in the health care system and deserves an introduction.

PT: Patients

The noun patient has a Latin root and means one who “suffers.” The desire for restoration of health and the systems that attempt to fulfill that wish transform people into patients. For a patient, the encounter with a physician is foremost personal: her body is at stake. She seeks the doctor’s informed opinion on what is wrong and how to correct the problem. This special relationship allows intimacies, such as touching naked skin or probing orifices. Ultimately, the patient must live with the consequences of options available and choices made: a return to health, a state of disability, or death. Even well-educated patients may find themselves overwhelmed when confronted with a multifaceted illness. Sudden onset, complex diagnoses, medical jargon, and multiple treatment choices with uncertain individual responses and outcomes are intimidating and stressful. Because patients need help navigating unknown territory, they defer to physician authority and expertise, sometimes viewing doctors as miracle workers: white-coated acolytes who employ an array of techniques and medicines to save those who are suffering from maladies and the consequences of mortality and lifestyle excesses.

33 Neuberger, 1756. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1116090/
Patients submit to ministrations with hope and the expectation of a positive outcome or even a miracle.

DR: Doctor

The word *physician* has Greek and Latin roots and means "natural science and medicine." Various factors influence the physician persona including training, hierarchy, and granularity. Doctors are selected for scientific acumen, train as scientists, learn to diagnose ailments, and apply algorithms. Mary Shelly’s *Frankenstein* presents a physician blind to complexities and consequences, rescuing life from death in the creation of a monster. The physician / patient encounter is transactional with the physician employing diagnostic aptitude or surgical skill in an attempt to help. The professional barrier elevates status, conveys authority, and shields against questioning (“Where did you get your medical degree?”). The Medical Doctor (MD) designation implies a trusting relationship that sanctions intimacies that under different circumstances would qualify as criminal acts. Dr. Kalanithi speaks from professional and personal experiences about objectifying patients:

> All of medicine… trespasses into sacred spheres. Doctors invade the body in every way imaginable. They see people at their most vulnerable, their most scared, their most private. They escort them into the world, and then back out. Seeing the body as matter and mechanism is the flip side to easing the most profound human suffering.

Doctors may be referred to as healers, but in many cases they are technocrats, acting as specialized technicians. Training reinforces a singular narrative—people seen through the

---

lens of medical science, so “the most profound human suffering becomes a mere pedagogical tool.” Doctors face pressures including zero-defects mentality (We certainly don’t want new doctors learning on us), heavy patient loads, limited time, and surfeit of suffering. Personal survival requires compartmentalizing. Hefty tuition loans, exhausting schedules, and monetary compensation differentials steer doctors into lucrative sub-specialties.

A conspiracy of forces ensures continuation of a deception where doctors proceed as if death is not an option, and patients will not die, since physicians are in the business of fixing broken parts and saving lives. Physicians may exhibit Dr. Frankenstein’s hubris, treating without consideration for the suffering their actions can cause. Rather than view a patient’s situation and prognosis holistically, there is always another treatment to try to postpone the inevitable. Palliative care physician Dr. Ira Byock explains:

Modern doctors are taught to view sick patients through a lens that primarily sees their medical problems. The problem-based frameworks and clinical assessment procedures that are intended to streamline and focus doctors’ attention have become like horses’ blinders, keeping the focus straight ahead on diseases and their treatments.

In his book *At Peace*, Samuel Harrington details this tunnel vision:


If the only tool you have is a hammer, everything looks like a nail. While clinical expertise is more sophisticated than carpentry, physicians train extensively with a focus

---

36 Kalanithi, 49-50.
37 Byock 24-25.
38 Harrington, 220-21.
on their specialty, with limited areas, such as family practice, geriatrics, internal medicine, and palliative care, that take a holistic approach. These generalist specialties, while more comprehensive, are generally less highly compensated and less respected in the physician hierarchy. In additions, patients may view a primary care doctor visit as merely the gatekeeping step required by insurance companies in order to acquire referrals or potions. Many doctors, regardless of specialty, search for solutions to avoid the singularly unfortunate outcome of death. They are trained to save lives, not to cope with the alternative.

Jargon and inaccessible terminology

It’s called life insurance, but survivors collect money only after the insured party dies. Likewise, “Lifesaving” and “survival” are synonyms for “death postponing;” meaning a temporary reprieve, not a permanent solution to dying. Diagnostic medical tests do not save lives, despite ambiguous messaging. Following the recommended schedule for mammography or colonoscopy and early detection of a tumor means earlier treatment, which may extend life, but does not convey immortality. Language can build bridges or walls. I witnessed a doctor speaking to the family of a man with head trauma from a motorcycle accident. After completing an exam, the neurosurgeon reported, “The patient’s eyes are fixed.” Fixed and dilated pupils signal catastrophic brain injury, but the comment generated a palpable sense of relief for the patient’s loved ones. Apparently when the family heard the assessment, they understood “fixed” as repaired and good, not that the patient was an organ donation candidate. Telling someone something doesn’t

guarantee that the intended receiver has properly decoded the message. A key element of assisting informed decision making is communicating so that patients and families understand.

The unintended consequences of situatedness can cause problems with communication. The physician shares information using medical terminology in an attempt to convey findings clearly and accurately, perhaps not realizing that listeners may hear something different than intended. Profession-specific vocabulary may unintentionally mislead. Despite advanced diagnostic testing, medicine isn’t an exact science. Due to uncertainty such as “estimating survival accurately and the challenge of disclosing that information to the patient,” doctors sometimes present an overly optimistic prognosis. Even physicians err with determining when patients are actually dying and nothing more can be done. Dr. Gawande writes that, “Words like ‘respond’ and ‘long-term’ provide a reassuring gloss on a dire reality,” but if medical providers are unable to express the reality, who can patients trust? The doctor/patient power differential can inhibit patients and families from initiating conversations about when the end is near and how to prioritize treatment versus comfort care. Certain questions may reveal a patient’s essential nature: “What is one thing that is most important for this patient?” What makes her/his life worth living? Questions that focus on symptoms and treatment options can mask personhood.

40 SSCI E-121 Final Lecture (12.6.17 FINAL), slide 5.
41 Gawande, 151.
42 Appendix, Essential Questions
43 Gawande,
Granularity and fragmentation: allopathic treatment versus a holistic approach

The medical profession primarily fixates on fixing, assuming everything must be repaired without holistically assessing the implications of strenuous treatments on sick or aging bodies. The balkanization of medicine focuses on body parts. Becoming a doctor is expensive and requires a significant time and financial commitment for education and training. With the need to repay loans, and since certain specialties are better compensated with a less onerous schedule (more control and fewer emergencies), this may encourage physicians to specialize rather than choose primary care. As representatives of this system, doctors may forget or ignore the human behind the presenting symptoms: “Through the scientific reduction of the person to a specimen composed of systems, organs, cells, organelles, biochemical reactions, and a genome, medicine has made remarkable discoveries that have led to countless therapeutic advances.”44 Advances in healthcare have been a blessing. Innovations have increased survival and life expectancy. But, the shadow side is tunnel vision: a reductionist focus on specialized care that may lead to identifying patients solely as disease or injury. Many physicians focus on corporal survival rather than taking a systems approach and looking at the big picture. The emphasis on expertise over empathy makes some providers seem emotionally indifferent, which is perhaps understandable given the need for rational life-or-death decision making:

Learning to judge whose lives could be saved, whose couldn't be, and whose shouldn’t be requires an unattainable prognostic ability. …. Rushing a patient to the OR to save only enough brain that his heart beats but he can never speak, he eats through a tube, and he is condemned to an existence he would never want.45

45 Kalanithi, 80.
A patient may visit a primary care physician and depart the office with multiple specialist consultations. As doctors become more specialized, few look at the whole person to evaluate treatments holistically and inform patients and families about possibilities of side-effects. A treatment that focuses on one particular problem may create unintended consequences in an unrelated area—medical whack-a-mole. The lack of a holistic perspective permeates the health care system, from specialized training for doctors to a disconnection or ignorance about the impact of treatments on patients’ finances.

**SYSTEM**

External forces affect health care. A cure-all cultural mindset has raised expectations that any illness or injury can be overcome. Improved survival rates instill a belief that there’s always something more that can be done, which ignores the 100% certainty of mortality. In addition, increasingly narrow specialization brings discontinuities of care. No one has the expertise, time, funding, or incentive to coordinate care options, leaving the patient feeling like a set of depersonalized, discrete body parts. Money also factors into decision making. The fee-for-service system favors billable procedures over discussions about end-of-life options, although in 2016, Medicare began covering reimbursement for advanced care options. Money, the bottom line of profit, is often at the root of conflict between long-shot possibilities and costly treatments with uncertain or no benefits. Dr. Gawande commented: “The subject seems to reach national awareness mainly as a question of who should ‘win’ when the expensive decisions are made: the insurers and the taxpayers footing the bill or the patient battling for his or her

---

But mostly health care consumers are oblivious to costs and providers hid, obscure, or don’t know costs because someone else is paying. Another force is legal. In our litigious society, physicians are risk sensitive so they try to cover all bases with diagnostic tests to preclude the possibility of getting sued for not ordering tests, no matter how peripheral.

Financial: Follow the money

Who pays for care? Ultimately, we all do, whether directly or indirectly. Money is a major force responsible for how our current health care system operates. Is health care a commodity or a right? If you meet certain conditions, such as being a certain age, income level, or employed at a workplace that provides coverage, you get health care. A commodity means something of value that can be bought and sold, such as bread, milk, oil, or meat. Commodity is driven by the economic engine: “pay to play.” Obtaining care, especially during a hospital admission, is analogous to buying a car without knowing the amount owed. You sign papers and drive off the lot; only weeks later does an invoice arrive. Costs are hidden and vary depending on insurance providers. We want an all-you-can-eat buffet that someone else pays for. Without knowing costs, there is no incentive to reduce them. Correcting the current system will require answering the commodity versus right conundrum plus financial reform and overhauling the reimbursement process.

Hospitals and insurance and pharmaceutical companies operate as businesses with

---

48 After being hit by a bus, I went to the ER. Bills arrived weeks later (3 mile ambulance ride-- $460; 4 hours in the ER--$25,200. My insurance sent me to another ER the next day. I was hospitalized and had a 2nd surgery. My insurance covered this and I haven’t received bills. I don’t know how expensive the second ER visit, hospitalization, surgery, plus follow-up therapies are.
payment structures that are opaque even to those providing services. Insurance companies negotiate with hospitals and physicians for special rates. The US health care system evolved to compensate tangibles, such as procedures, supplies, and medicines. Treating aging and death as predominantly medical events generates lucrative compensation for hospitals, drug companies, and specialists. More aggressive care at end-of-life means costly payments, sometimes regardless of treatment suitability or effectiveness. The system is reactive and there is little money in prevention or “waiting and seeing.” Rather than addressing root causes, “Health professionals may tend to deal with the symptoms.”49 Diagnostic tests, surgeries, and medicines are substantial line items on invoices. With business offices segregated from clinical departments, patients and even providers are often unaware of what things cost.50 As Dr. Gawande writes, “Our medical system is excellent at trying to stave off death with $12,000-a-month chemotherapy, $4,000-a-day intensive care, $7,000-an-hour surgery. But, ultimately, death comes, and few are good at knowing when to stop.”51 Given the fragmentation of whether patient, doctor, or insurance adjuster determines what care is appropriate and/or reimbursable, the price tag for “doing everything” is some else’s problem.

The “suits” which includes insurance and pharmaceutical industries and hospital administrations, operate behind the scenes but with considerable power. Patient Dana Jennings writes, “In our modern health-care industrial complex… the emphasis is neither

50 For an ER visit in March 2017 after getting hit by a bus, my George Washington hospital bill for 4 hours was $25,200 not counting the $450 ambulance ride. The next day, I was admitted and stayed overnight for an additional surgery, not to mention follow-up appointments and physical and occupational therapy.
51 Gawande, 153-154.
on health nor care, but the bottom line.”52 Former New York Times health reporter Dr. Elisabeth Rosenthal describes the state of medicine in An American Sickness, “Chief complaint: hugely expensive medical care that doesn’t reliably deliver quality results,”53 while Dr. Steven Nissan judges, “When medicine became a business, we lost our moral compass.”54 Contemporary medicine exists because of machines and drugs; advances like respirators, dialysis machines, defibrillators, and vasopressor drugs have paved the way for postponing dying. These inventions truly can make a difference, when used at the appropriate time and circumstance. However, the health-care system is currently configured as a market economy. Dr. Rosenthal wryly deduced, “If the March of Dimes was operating according to today’s [medical] foundation models, we’d have iron lungs in five different colors controlled by iPhone apps, but we wouldn’t have a cheap polio vaccine.”55 There is little money in prevention. The system is based on supply and demand, responding to patients and families demanding “everything,” abetted by physicians who almost always have something more to try, and facilitated by a reimbursement system that financially benefits from “more” being done. “Do everything” has become expected, even when burdens and risks outweigh benefits. A capitalistic approach that incentivizes “more” has created a monster.

Legal

Many legal forces affect health care. HIPAA, the Health Insurance Portability and Accountability Act of 1996, governs patient confidentiality, safeguarding the privacy of

53 Rosenthal, 4.
54 Quoted in At Peace, 12.
55 Rosenthal, 189.
The proliferation of litigation and fears of being sued have resulted in ordering “just in case” comprehensive diagnostic tests to ensure that all possibilities are covered. With the unrealistic assumption of a zero-defects mentality that regards death as a mistake, families may blame health care providers and seek compensation for bad outcomes.

Determining when someone is dead would seem straightforward given the availability of medical devices such as stethoscopes. Victorians concocted safety coffins, equipped with bells as an alert system to allay fears of being buried alive. However, advances in medical technology have blurred the boundaries between living and dead. At one time when the heart or breathing stopped, biological death resulted and doctors declared death after confirming absence of heart or respiratory sounds. In 1981, the American Medical Association (AMA) and the American Bar Association (ABA) approved the Uniform Declaration of Death Act, establishing clinical criteria for determining brain death. Throughout the United States, there are un-dead patients who languish in long-term care facilities, minimally conscious or in a persistent vegetative state (PVS). How does one determine the quality of life of such patients? Are they suffering? Headline grabbing stories on PVS cases include Karen Ann Quinlan (1954–1975–1985) whose parents battled to have her ventilator disconnected after she lapsed

56 https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html
58 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4028548/
60 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2495105/
61 The unusual notation of three years is based on birth, death, and at peace dates, according to tombstones. See photos at Appendix 6.
into coma and then PVS; Nancy Cruzan\(^{62}\) (1957–1983–1990), whose parents fought to the Supreme Court over discontinuation of her tube feeding; and Terri Schiavo\(^{63}\) (1963–1990–2005) whose tube feeding became a matter of concern for the Florida governor, Congress, and the US President. These high-profile cases are just a sampling of individuals with minimal consciousness or PVS\(^{64}\) who reside in facilities through the United States, sharing a commonality: they did not document their wishes on an advanced directive. These individuals also raise concerns about life’s big questions: ethics, theology, human rights, and suffering.\(^{65,66}\) A silver lining from the Cruzan case was that it precipitated the 1991 Patient Self-Determination Act\(^{67}\) to inform patients about advance directives (AD) and honor their wishes for medical treatments. A patient’s AD extends autonomy and safeguards wishes, but alas, it is only as good as the availability of the document.

Religion: “Everybody wants to go to heaven, but nobody wants to die.”\(^{68}\)

For Americans, the First Amendment provides for Freedom of Religion with a proviso that government will neither control nor prohibit the free exercise of one’s religion. Even with separation of church and state, religion is culturally embedded\(^{69}\):

\[\text{\footnotesize \url{https://www.ncbi.nlm.nih.gov/pmc/articles/PMC557072/}}\]
\[\text{\footnotesize An accurate count of how many patients fit this designation is not available, but this article estimates as high as 25000 adults and 10000 children. \url{https://content.iospress.com/articles/neurorehabilitation/nre1387}}\]
\[\text{\footnotesize \url{https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1255938/}}\]
\[\text{\footnotesize \url{https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3678818/}}\]
\[\text{\footnotesize \url{https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self determination_act.html}}\]
\[\text{\footnotesize Unknown author, but sometimes attributed to boxer Joe Lewis}\]
\[\text{\footnotesize Harvard Religious Literacy Project \url{https://rlp.hds.harvard.edu/our-approach/four-principles}}\]
Christmas is a federal holiday; citizens recite “one nation under God” in the Pledge of Allegiance, "In God We Trust" appears on money, and elected officials and witnesses in a court of law often swear on a Bible. Religion plays a significant role in US culture. According to a Pew Research Center study, 80% of US adults believe in God, even if not the God described in the Bible. Most Americans are Christian, with at least 70% of us identifying as such. While religion seems to imply participation in communal practices, not all who claim to be Christian are affiliated with a church or observe their claimed denomination’s preferences. What is next after earthly existence: heaven, hell, or oblivion? According to the Pew Research Center’s 2014 Religious Landscape Study, around 72% of Americans believe in heaven and 58% believe in hell, with percentages even higher for Christians. So, while Americans are predominantly Christian and believe in an afterlife, they are reluctant to face dying, even though death means potential entry into the kingdom of heaven and eternal life. Staff ethicist at the National Catholic Bioethics Center John Di Camillo contends that, “We don’t give enough attention to people near the end-of-life because we’re afraid of the end-of-life and don’t want to come to grips with it.” Whether we identify with a religious tradition or not, facing mortality—our ultimate reality—is an existential endeavor with spiritual aspects. Dying well isn’t a matter of the right medicine, procedure, or doctor; a good death becomes more likely when one has lived a life of purpose and connection, acknowledging that physical bodies expire. The current norm primarily focuses on death of the body.

71 70.6% Christian, 23% unaffiliated, 6% non-Christian
74 http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/
However, death is a natural boundary that can offer clarity about what does and doesn’t matter.

The obsession with biological functioning and clinical outcomes overlooks the possibility of opening to our spiritual essence. In her book *With the End in Mind: Dying, Death and Wisdom in an Age of Denial*, Dr. Kathryn Mannix speaks to transcendence: “This transformation of world view is a spiritual transformation, whether theistic or not.”

Often, people operate on auto-pilot, forsaking delving into life’s big questions, until loss or trauma forces us to pay attention. At such times, recognizing a common spiritual bond can connect us with fellow seekers and catalyze changes. While not everyone embraces formal religion, the existential aspect of life is universal and implicitly religious, extending beyond discrete expressions of beliefs, rituals, and practices. Instead of religion, many now believe in healthcare, deifying doctors not only as medical authorities, but elevated to a priestly caste of miracle workers.

**Technology: The Medicalization of all Maladies**

Our culture worships a false idol: science as savior. The downside to the miracles of technology is determining when to stop, when actions are prolonging dying and torturing patients with limited benefits. The line between helping and hurting is unclear, even for professionals. Physicians learn to diagnose, treat, and release instead of confronting patients who not only exhibit complicating co-morbidities, but also limited inclination or ability to comply with treatment or prevention protocols. Death is our fate,

---

75 Mannix, 319.
but our tendency tilts toward ignoring rather than accepting. Despite the lurking reaper,
we forget that mortality applies to us and our loved ones, not just to others:

When there is no way of knowing exactly how long our skeins will run—and
when we imagine ourselves to have much more time than we do—our every
impulse is to fight, to die with chemo in our veins or a tube in our throats or fresh
sutures in our flesh. The fact that we may be shortening or worsening the time we
have left hardly seems to register. We imagine that we can wait until the doctors
tell us that there is nothing more they can do. But rarely is there nothing more that
doctors can do. They can give toxic drugs of unknown efficacy, operate to try to
remove part of the tumor, put in a feeding tube if a person can’t eat: there’s
always something. We want these choices. We don’t want anyone—certainly not
bureaucrats or the marketplace—to limit them. But that doesn’t mean we are
eager to make the choices ourselves. Instead, most often, we make no choice at
all. We fall back on the default, and the default is: Do Something. Fix something.
Is there any way out of this? 76

In the midst of overwhelm, what seems to be forgotten is that medical care exists as a
means, a bridge to restored functioning and health, not as an end in itself. By focusing on
continuing treatment of individual body parts, the patient may experience more suffering
in the hopes of a return to former vigor. Without honesty about risks, burdens, and the
likelihood for recovery, this cycle repeats mindlessly, ending only upon pronouncement
of death. After World War II, the United Nations drafted a “Universal Declaration of
Human Rights.” Article 5 states “No one shall be subjected to torture or to cruel,
inhuman or degrading treatment or punishment.”77 Hospital emergency response codes,
such as for cardiac arrest, that I’ve witnessed appear to violate this standard of protection.

Conclusion

Patients, identifiable in skimpy gowns, often demand “life-saving” procedures,
precipitated by denial of an illness’ severity, misinformation about prognosis, or

76 Gawande, Being Mortal, 173-74.
heartbreakingly, because they thought they had more time. A family may request secrecy about diagnosis because they don’t want to abridge the patient’s hope, even if it requires lying or prevaricating. And, if a patient has not identified a proxy decision-maker and is unconscious or incompetent, the family may request invasive and futile treatments out of ignorance of wishes. We can do better than this.
Chapter 3.

Prognosis: “We can run, but we can’t hide.”

“World Death Rate Holding Steady At 100 Percent” Onion Headline

Prognosis forecasts the likely course of an ailment or a situation. Although a consequence of being born is dying, Americans operate with a faulty expectation about life: they don’t expect to die; therefore, therefore many don’t think about end-of-life and thus fail to prepare. However, if an injury or illness requires health care, there is an ancillary expectation for cure as soon as possible. A message loops through consciousness, “Please stand by; normal service will be restored soon,” falsely leaving the impression that everything has a fix. However, biological vulnerabilities mean that normal functioning does not always return. If patients survive, they may linger in a state of minimal consciousness or significant impairment without hopes for recovery. Imprecise terminology like “life-saving” misleads, adding to misconceptions that death can be postponed infinitely. Humans fight the limits imposed by bodies with technology, employing brink-of-death care and defaulting to rescue and resuscitation (R&R) medicine without consideration for incurable conditions such as frailty or dementia. Medicine can’t fix all damage, but in the midst of emergency, the instinct for restoration of vital signs delays questioning over what is right—ethically and morally—until after the crisis resolves.

78 Quote attributed to boxer Joe Lewis. The Complete Annotated Grateful Dead Lyrics edited by David G. Dodd, Alan Trist. 353.
79 https://www.theonion.com/world-death-rate-holding-steady-at-100-percent-1819564171
In “The Summer Day,” poet Mary Oliver reflects, “Doesn’t everything die at last, and too soon?” Death is humanity’s common denominator, a great equalizer, and the clinical event everyone will experience. *The End* may be out of sight, out of mind, but it’s a reality that all encounter, whether predictably or precipitously. Everyone faces “the hour of our death.”

According to the Centers for Disease Control and Prevention (CDC), life expectancy in the United States is 78.6 years. For planning purposes, Americans can assume they will live approximately 80 years, although “actual mileage may vary” due to variables such as race, gender, and ethnicity. To estimate date of death, a person could add 80 to their birth year, a pragmatic calculation that potentially can rattle the psyche. The Social Security Administration’s Life Expectancy calculator gives a more accurate figure, although it bears remembering that people are individuals, not statistics, and life offers no guarantees.

Life expectancy expresses a binary: alive or dead, a situation that doesn’t account for health span. Health span is a continuum indicating the period of life during which a person is generally healthy and free from serious illness. Since quality of life correlates with health, the gap between lifespan and health span may lead to prolonged pain, suffering, or insentience before death. Advances in health care have led to life extension, but extra years come at the end, leading to longer lives with more debility. Considering what parents and grandparents died of, and at what ages, give clues to a person’s future,

---

80 Hail Mary prayer
81 Kochanek, 1.
83 [https://www.ssa.gov/planners/lifeexpectancy.html](https://www.ssa.gov/planners/lifeexpectancy.html)
although habits, occupation, and income also affect life expectancy.\textsuperscript{84} While controllable practices like exercise and caloric intake influence individual health, there are limits to how much a person can alter genetic inheritance. Eventually, the reaper appears. A common fate links humans and eventually funeral bells will toll,\textsuperscript{85} first for others but always hinting that everyone’s turn will come. However, except at Halloween, we tend to overlook “the skull beneath the skin,”\textsuperscript{86} pretending we can control impermanence.

Illness versus disease

Harvard Professor Arthur Kleinman explains the differences between disease and illness: “Modern physicians diagnose and treat diseases (abnormalities in the structure and function of body organs and systems), whereas patients suffer illnesses (experiences of disvalued changes in states of being and in social function; the human experience of sickness).”\textsuperscript{87} Concentrating on disease has its place, but there comes a time when \textit{something more} does not involve procedures or drugs. Dr. Gawande reminds:

Good medical care can influence which direction a person’s old age will take. Most of us in medicine, however, don’t know how to think about decline. We’re good at addressing specific, individual problems: colon cancer, high blood pressure, arthritic knees. Give us a disease, and we can do something about it.\textsuperscript{88}

Planning for aging requires balancing between spiritual and practical preparation, hope and realism, and knowing life has meaning even though it ends. Having faith that

\textsuperscript{84} Estimated that 20% of life will be spent dealing with health issues and disability \href{http://www.healthdata.org/news-release/life-expectancy-climbs-worldwide-people-spend-more-years-living-illness-and-disability}{http://www.healthdata.org/news-release/life-expectancy-climbs-worldwide-people-spend-more-years-living-illness-and-disability}
\textsuperscript{85} Donne, Devotions Upon Emergent Occasions, Meditation XVII “for whom the bells tolls; it tolls for thee" \href{https://www.phrases.org.uk/meanings/for-whom-the-bell-tolls.html}{https://www.phrases.org.uk/meanings/for-whom-the-bell-tolls.html}
\textsuperscript{87} Kleinman, et al., 355.
\textsuperscript{88} Gawande, New Yorker, 55.
something exists beyond the cessation of vital signs requires paying attention to past, present, and future; reviewing one’s life; completing essential tasks; and being confident that we will be okay, just as we were before we were born.

Healthcare would look different if practitioners followed Paul Kalanithi’s suggestion, “The physician’s duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence.”

Patients want “an honest reconciliation between her and her medical condition” by a knowledgeable, trustworthy guide who relieves symptoms and points out pitfalls, someone who takes time to care. There comes a time to recognize that the battle can't be won, that return to a meaningful life is not an option, and to promote measures that enhance quality over quantity of life. Doctor Gawande quotes chief geriatrician Juergen Bludau:

The job of any doctor…is to support quality of life, by which he meant two things: as much freedom from the ravages of disease as possible, and the retention of enough function for active engagement in the world. Most doctors treat disease, and figure that the rest will take care of itself.

---

89 Kalanithi, 166.
90 Mukherjee, 468-9.
91 Gawande, 41.
Yale Professor Shelly Kagan diagrammed an interpretation of the human lifespan. In his book, *Death*, he asks readers to consider what it means to be alive and whether death occurs when the person or the body stops functioning. As indicated in Figure 1, during the A, B, and D phases, the body functions, moving and breathing in addition to internal processes like circulation, digestion, and elimination. He differentiates higher-level cognitive functions as P—person functions. The drawing indicates how the timeline for Person and Body functioning diverge. Initially in phase A, “the brain simply isn’t sufficiently developed to engage in communication, rationality, creativity, self-consciousness.” Phase B diagrams the time of full personhood which continues until something happens at point *1*, possibly a near drowning incident resulting in a cerebral injury or perhaps anoxic trauma which interrupts cognitive functioning. In cases of minimal consciousness or vegetative state, a person lacks self- or other-awareness, but the brain stem preserves some reflexes such as breathing, movement, and the sleep-wake cycle.

---

92 Kagan,
cycle. At point *2, body functioning ceases and the individual is declared dead, a corpse as indicated by C.

What does it mean to be human? In phase D, the body functions, however “for all that, my personality has been destroyed. Nothing exists with my beliefs, memories, desires, fears, or ambitions.” Kagan suggests “Suppose that instead of asking whether I exist or not, we ask whether I’m alive? … My body is still alive in phase D. After all, it’s fully engaged in B functioning. But what about me? Am I alive?” Medical technology and advances in pharmaceuticals have blurred the line between existence, being alive, and death. Does death occur when the person ceases, or when the body stops functioning? Life “saving” technology has distorted the boundary. Under the current paradigm, individuals and society grapple with the life/death distinction because not only does lifespan often exceed health span, but there are times when the body continues operating though the resident has vacated the premises. People may be un-dead, having entered pre-mortem limbo, a state of being, affecting not only the person experiencing illness or dementia but also caregivers.

Causes of death in US for ages 65+

As the on-call chaplain, I answered a page to the neurological ICU to be with family as doctors reported unequivocal results of testing. The patient was brain dead and not going to survive the stroke that caused her hospitalization. Her distraught daughter cried, “It’s too soon!” The patient was 85 years old. Is there an age at which death is appropriate?

---

94 Kagan, 173
Forecasting the future is like spinning a wheel of fortune. In roulette, players bet where the ball will stop. It may not be possible to determine the particular slot, but there are limited possible outcomes. The predictability of post-age 65 aging likewise offers finite selections. Where will my ball stop? What will eventually kill me? Based on personal habits, family history, and an individual’s health weak link, the process isn’t completely random. Over a lifetime, the range of possibilities narrows as trends in mortality indicate:

There has been a shift in the past 100 years in the cause of mortality, from infectious disease to age-related chronic illnesses as the most common causes of death (e.g., cardiovascular disease, cancer, and stroke). There are some predictions that the gains made in average lifespan may be relinquished owing to obesity trends and the corresponding increases in diabetes.96,97

Biological functioning is multifaceted. Ultimately, failure of vital organs—heart, lungs, and / or brain—results in death. Among Americans over the age of sixty-five, more than

---

96 Depp et. al, 528.
97 Increases in opioid addiction and suicide rates is also shortening average life expectancy.
a third (34%) will die from heart ailments while another 28% succumb to cancer and its side-effects. Six chronic diseases (congestive heart failure 34%, cancer 28%, chronic obstructive pulmonary disease 9%, stroke 8%, dementia 6%, and diabetes 4%) account for 90 percent of the deaths for this age cohort.  

While there is usually no single cause for death, contributing factors include disease, genetics, and personal behaviors. For example, obesity can cause multiple, serious health complications such as heart disease, diabetes, and/or cancer. Dr. Gawande explains: “As the defects in a complex system increase, the time comes when just one more defect is enough to impair the whole.”

A facilitator opened a Death Café session with the icebreaker, “How do you want to die?” In most settings, a question like that would freeze rather than spark conversation given the superstitions attached to mentioning death (knock on wood). Those who responded expressed a preference for going to sleep and not waking up—sudden death. The term sudden generally refers to death resulting from trauma, a cardiopulmonary or neurologic event, systemic infection, or influenza. Sudden doesn’t mean unexpected. While in some cases the death occurs abruptly, after a certain age decline has set the stage for an acute episode from which a patient cannot recover.

---

99 http://www.newyorker.com/magazine/2007/04/30/the-way-we-age-now
100 Death Café’s objective is ‘to increase awareness of death with a view to helping people make the most of their (finite) lives’. https://deathcafe.com/
Figure 3: Patterns of dying

Figure 3 displays four patterns of dying, although individual debility could combine elements of each slope. After age 65, deaths correspond to the trajectories depicted. Most patients with progressive illnesses such as cancer, organ failure, frailty, or dementia follow typical trajectories. Cancer often involves a steep period of deterioration before death. Long term illnesses include progressive limitations aggravated by intermittent acute episodes. Heart failure and chronic obstructive pulmonary disease (COPD) gradually lead to unrecoverable organ failure. Someone may experience frailty, which manifests as prolonged dwindling as a result of brain trauma, cognitive incapacity, or multiple organ failure. Most people imagine that their death will follow the acute route, fully functioning until launched over a metaphorical waterfall, the “dying in sleep” scenario favored by Death Café participants. However, statistically only 10% of age 65+ adults die suddenly, as a result of trauma such as falls or from flu, pneumonia, kidney

disease, or infection. The more likely scenario is a gradual decline of function from underlying illnesses or co-morbidities of the heart, lungs, brain (stroke or dementia), or from cancer or diabetes.

It doesn’t take a crystal ball. At a certain age, the downward slope for 90% of us is gradual but inexorable. Unlike the waterfall scenario, dying often corresponds to a riptide, superficially benign while individually insignificant maladies accumulate to sweep us off our feet, resulting in less stamina, more medicines, and a dance card filled with doctor visits. Examining contributing factors such as disease, genetics, medications, and behaviors helps foretell the likely cause of death. Additionally, chronic ailments and limited mobility make people more susceptible to infections. In someone relatively young and reasonably healthy, treating with antibiotics to cure infection makes sense, so the person recovers and resumes full life. If illness has restricted capacity, such as for a person with end-stage dementia, it may be more humane to provide comfort care rather than trying to cure infection. The Harvard Health Letter cites Sir William Osler’s opinion about pneumonia as "'friend of the aged'…as a swift, relatively painless way to die." Knowing what we know about dying, and documenting our desires, can give a degree of autonomy over how the story ends.

Peace and dignity in the midst of VUCA

Most days, people wake up and go about business as usual. Perhaps one day, a person heads out and everything changes. In a second, predictable can morph into

---

102 Harrington, 71.
103 https://www.health.harvard.edu/newsletter_article/An_update_on_the_old_mans_friend
capricious, exposing the limits of fragile bodies and brains. Like a military unit, an Emergency Room (ER) faces a VUCA environment: volatile, uncertain, complex, and ambiguous. Crossing the threshold into a hospital is like entering an alien land, occupied by inhabitants wearing distinctive garb, displaying peculiar customs, and speaking a proprietary language. Mystifying and disconcerting, the situation is volatile because there is an unexpected interruption of normalcy. Chaos surrounds a trauma or a coding patient. An emergency hospitalization is complex, uncertain, and unpredictable, subjecting loved ones to an overwhelming volume of information. Because patient status is unstable with unknown potential for recovery, the duration of stay is indefinite. Not everyone gets a warning or has time or inclination to prepare. Even when faced with a diagnosis of terminal illness, many concentrate on the immediacy of treatment rather than focusing on the future. It takes bravery, emotional control, selflessness, and practicality to plan and prepare for death.

Ethics: Individual Self-Determination

Foundational human needs for autonomy, competence, and relatedness follow a normal distribution curve over the human lifespan. As people move from childhood to adulthood, they grow in the ability to fulfill these needs. Autonomy is the degree to which individuals feel a sense of agency and responsibility for their behaviors. Competence relates to feelings of effectiveness and being able to exhibit capabilities. Relatedness is a sense of belonging and connection to others. According to Deci and Ryan’s Self-Determination Theory (SDT) model, “people initiate and persist at behaviors

---

104 Moore, PSYC E-1770 lecture, Jan 2018.
Humans are naturally inclined to grow: “SDT suggests that it is part of the adaptive design of the human organism to engage in interesting activities, to exercise capacities, to pursue connectedness in social groups, and to integrate intrapsychic and interpersonal experiences into a relative unity.” Most likely as people age, there will be a downward arc with less autonomy, relatedness, and competence. Nursing homes residents may experience problems with self-determination in “environments that would be controlling, that would impose strict rules, and/or that would constrain self-expressivity would likely lead to non-self-determined motivation, and decreased need satisfaction.” How can we ensure self-determination in order to “reach his or her highest level of motivation, engagement, performance, persistence, and creativity” throughout the lifespan?

Autonomy is self-governance and capacity to act on one’s own motives. Essential to autonomy is informed consent, the ability to understand clinical information about treatment options, risks, benefits, and potential consequences that leads to intelligent decision making. The idea of patient autonomy in a medical setting is dynamic. Within several generations, childbirth has changed from a doctor-centered, mother-sedated, father-excluded medical event to a holistic experience where parents develop detailed birthing plans that customize preferences for labor and delivery. Expectations have changed from someone else deciding about mothers’ best interests to self-determination. Whose body, whose life, whose dying? The saying “my body, my choice” summarizes

---

105 Deci, 227.
106 Deci, 229
107 Ferrand, 105.
109 See comic representing informed consent in Appendix 6.
the core principle of patient autonomy. Dr. Gawande writes about the connection between aging and autonomy:

Decline remains our fate; death will come. But, until that last backup system inside each of us fails, decline can occur in two ways. One is early and precipitately, with an old age of enfeeblement and dependence, sustained primarily by nursing homes and hospitals. The other way is more gradual, preserving, for as long as possible, your ability to control your own life.

Patients have both rights and responsibilities. A patient’s failure to make decisions about their health care preferences undermines autonomy and places a burden on loved ones. People forget that in the event of sudden incapacitation, incompetence, or unconsciousness, someone else will need to express wishes regarding medical care. Who do you trust with your life? The 1991 Patient Self-Determination Act instituted advance directives (AD) to extend autonomy and safeguard wishes for health care. Patients have the right to decide about care, but this requires having documents prepared in advance, completed, and available when needed. An AD allows patients to indicate desires for pain control as well as interventions such as cardiopulmonary resuscitation (CPR), breathing tubes, tube feeding, or dialysis.

Bio-medical ethics: pursue benefits; avoid harm

Rooted in the Hippocratic Oath, physicians vow *primum non nocere—first, do no harm*,¹¹⁰ a promise to use training, diagnostic aptitude, and skills to help. Patients rely on health care providers’ professional judgment to understand and reconcile the benefits of treatment versus the burdens of pain, suffering, and futility. Doctors adhere to a code of ethics for the benefit of patients and society. They are obliged to maintain minimal

⁠¹¹⁰ The phrase “do no harm” is paraphrased from the modern version of the Hippocratic oath https://www.medicinenet.com/script/main/art.asp?articlekey=20909
standards of competence, beneficence, and non-maleficence, and to “provide competent medical care, with compassion and respect for human dignity and rights.” 111 Beneficence is an action taken, while non-maleficence is an action avoided. When a patient presents with breathing difficulties, bleeding, or broken bones, ER doctors immediately respond to the trauma. After the crisis resolves, other physicians may investigate patient preferences. Since many therapies have serious risks and side effects, determining whether potential benefits outweigh risks requires professional judgment, subject to perspectives and values. Treatments are often burdensome, invasive, painful, and costly. When these will definitively provide a bridge back to full functioning, enduring the short-term torment makes sense. Complications or conflict arises when a patient’s wishes are not written, retrievable, or followed.

In the current medicalized environment, science may trump healing, which Dr. Kleinman refers to as “contemporary medicine’s care giving paradox. The balance between science/technology and art has shifted so far towards the former that the latter is a pale shadow, a fragile remnant of what had for centuries been crucial to the work of the doctor.” 112 Patients and families pin hopes on science, optimistically and sometimes unrealistically blinded to knowing when there are no more options and it is time to say “enough.” Former Vice President Joe Biden referred to his family’s hope for the appearance of a timely silver bullet to cure his son’s illness, “We kept thinking the science would outrun the cancer, and we didn’t make it.” 113 From a physician’s perspective, “Discussing a fantasy was easier—less emotional, less explosive, less prone

111 https://www.ama-assn.org/delivering-care/ama-principles-medical-ethics
113 USA Today. “Biden on grief, and what might have been.” 16 Nov 21017.
to misunderstanding—than discussing what was happening before my eyes.”

Sustaining vital signs no matter what the cost or prognosis may violate the vow to “Do no harm.” Rev. Gerald Kelly suggests, “The treatment being considered should have a reasonable chance of offering a remedial effect, [which includes] the extent of improvement ... Not just any improvement justifies the treatment, but an improvement that fulfills the patient's reasonable expectations.”

Health care isn’t just about individual biology and personal healing, but includes social factors like access to care. One element of bio-medical ethics is the principle of justice, defined as fairness and implying equitable distribution. Distributive justice recognizes the reality of limited resources which require fair allocation. Who deserves care? Through government, society establishes criteria, with people receiving an equal share according to need, effort, contribution, and merit. In the US, Medicare is available to all citizens 65 and older, a category determined only by age. Social factors create disparities with health and access to care.

In the midst of rescue and resuscitation medicine, issues arise regarding ordinary (proportionate) and extraordinary (disproportionate) treatments. Ordinary refers to “those means of prolonging life which are available, offer a reasonable hope of benefit, and do not cause unbearable pain and suffering.” With extraordinary treatments, burdens, such as pain or cost, outweighs benefits. Ethicists contend:

Two important considerations are the effectiveness and benefit of the proposed treatment. An effective treatment is that which demonstrably alters the natural

114 Gawande, 169.
115 Tuohy, 77.
118 http://www.lifeissues.net/writers/mis/mis_01prolonginglife.html
history of an illness or alleviates an important symptom. A beneficial treatment is that which brings some good to the patient, not only medical benefit but also in terms of quality of life. Treatment may be effective but not beneficial by simply prolonging the life of a patient while at other times it might be both effective and beneficial. The key word here is benefit to the patient.\textsuperscript{119}

Disputes may arise because of religious or moral perspectives, especially regarding whether tube feeding is ordinary or extraordinary:

There are those who believe that respect for human life demands that we continue feeding seriously ill people, even artificially, and that includes people in irreversible comas, because feeding and hydration are part of the minimum care that compassion demands. On the other hand, there are theologians and philosophers who maintain that recourse to artificial nutrition and hydration does not involve the same moral obligation as the natural process of ingesting solids and liquids. This is a medical technique more akin to treatment than to everyday care.\textsuperscript{120}

The Roman Catholic Church has weighed in on the issue of life-prolonging treatments, proposing that, “excessive expense, excessive pain, excessive difficulty or other inconvenience, and no reasonable or 'proportionate' hope of benefit as criteria for deciding that a treatment is 'extraordinary' in the context of a particular patient in particular circumstances.”\textsuperscript{121} Just because we can, does not necessarily mean we should. Some insist that failing to insert tubes and provide artificial nutrition and hydration is akin to allowing someone to die of starvation and thirst. Because disputes can tear families apart, people need to make their desires known beforehand to reduce conflicts. Courts, with winners and losers, are an inappropriate forum for resolving family disputes.

Personal and social costs

Being sick is a wretched experience. Health affects how individuals feel, but health care impacts a country’s prosperity:

Good health is a personal and individual goal, but the broader effect of a nation’s health on its social and economic well-being should not be underestimated. The World Health Organization (WHO) states that good health is linked to economic growth through higher labor productivity, demographic changes and educational attainment.122

A nation wants healthy citizens. One might consider health care as analogous to public education: having a healthy, educated population is a common good. Who will pay for what care? Should staying alive at all costs be available for everyone? The US government pays for health care for the elderly, the disabled, those in end-stage kidney failure, and the impoverished. While many US citizens view socialism as bad, 60% of the mandatory spending in the federal budget includes socialistic programs like Medicare and Social Security. People age 65 and older account for approximately 14.9 percent of the total population and by 2050, the Census Bureau estimates 22.1 percent of the U.S. population will be 65 or older.123 In examining this issue, one needs to review not just direct costs related to care, but access to care and the caregiving burden.

Immortality

While death tends to be viewed as the enemy, would we really want to live forever? Unfortunately, or perhaps fortunately, immortality is mythical. In Jonathan Swift's novel Gulliver's Travels, certain humans, the Struldbrug, are eternal. While they

123 https://www.census.gov/newsroom/facts-for-features/2017/cb17-ff08.html
do not die, they continue aging.\textsuperscript{124} Fears about death would presume that immortality is preferable. But at a certain point, living has adverse side-effects such as declining vigor and increasing dependency. Kagan muses about immortality, “Is there a way of living forever that's attractive? I can't think of what it would look like. Immortality wouldn't be desirable. It would actually be a nightmare. Something you would long to free yourself from.”\textsuperscript{125} Living forever fits into the category of “be careful what you wish for,” but many would opt for any alternative to death. As John Milton wrote in \textit{Paradise Lost}, “The mind is its own place, and in itself can make a heaven of hell, a hell of heaven.”\textsuperscript{126}

\textbf{Terror Management Theory (TMT)}

We die and then what? Unmanaged terror about this unknown may keep people hurtling along the \textit{do everything} medical track. People trust \textit{here and now}, even with its difficulties and limitations. We prefer the devil we know over the unknown. There are no customer reviews on the after-life, peer-reviewed studies on heaven, or GPS for reaching that destination. The popular strategy for coping with the existential threat of death is to just deny and ignore.\textsuperscript{127} Social psychologists developed Terror Management Theory (TMT)\textsuperscript{128} to explain human’s deep-seated fear of death and offer strategies for dealing with overwhelm. According to TMT, death anxiety causes us to adopt worldviews that protect our sense of identity, worthiness, and self-esteem, allowing the belief that life has meaning. Needing to bolster distinctiveness may result in a sense of superiority and

\textsuperscript{124} Swift, Part 3, Chapter 10.
\textsuperscript{125} Kagan, 238.
\textsuperscript{126} Milton, \textit{Paradise Lost}.
\textsuperscript{127} This may contribute to lack of advance directives.
\textsuperscript{128} Martens, 223.
prejudice against the “Other.” This confirms the value of me and people like me, as well as insulating us from fears of vulnerability and insignificance: “TMT proposes that we are motivated to develop close relationships within our own cultural group in order to feel immortal, to convince ourselves that we will somehow live on—if only symbolically—after our inevitable death.”

Conclusion

Prognosis is dynamic, a matter of cause and effect. If we live, then we will die. After age 65, there are predictable, somewhat limited ways death occurs. A smoker is more likely to develop breathing ailments and possibly succumb to lung cancer. Metabolic syndrome is a side effect of obesity and can lead to diabetes and heart disease, chronic illnesses that can result in death. If people complete Advance Directives and have them available, they extend autonomy even if they are unconscious or incompetent. Someone who fails to declare treatment preferences will condemn loved ones to uncertainty, legal and administrative chaos, and potential bankruptcy. Even if a person believes death is the end, failing to plan guarantees a hellish afterlife for survivors, compounded by bereavement.

The course of diseases and the aging process have predictable elements, though individual realities vary and may diverge from expectations or statistics. The bottom line is that, “we can run but we can’t hide.” We must face the realities that humans have a deadline and all “saves” are temporary. Despite access to care and providers’ skills, death is inevitable. While this outcome remains fixed, there are ways to ensure peace and

dignity and minimize suffering. With grace, may we seek “serenity to accept the things we cannot change, the courage to change the things we can, and the wisdom to know the difference.”\textsuperscript{130}
Chapter 4.

Long-term Treatment: *Memento Mori* —Live with the end in mind

*Not exactly* Breaking News! Being alive is linked to death.

If you’ve hiked, you know that planning, including selecting an appropriate route and carrying the right equipment, makes the experience safer and more enjoyable. Sometimes preparation can mean the difference between survival or disaster. Unlike the possibility of a hiking accident, death is a sure thing that everyone will encounter, usually first with loved ones before we face our own. Despite the ubiquity, most people stumble into the dying process because, as Sallie Tisdale explains in *Advice for Future Corpses*, “One of the central ideas of our lives is that there will be a tomorrow.”131 Dying is universal but few learn how to prepare for end-of-life, spiritually or practically. Dying is not on the to-do list. If we consider it at all, we view death with repugnance and denigrate the topic as morbid. Because of a bias toward the present moment, Americans embrace “give us this day our daily bread”132 with the expectation that bread will miraculously appear when needed. We live for today without considering how death will impact us, our loved ones, and seven generations into the future. We assume life will extend endlessly, since no age is suitable for death. For most of life, death is a secret buried deep in our psyches, emerging only if a friend dies in a crash or a parent develops cancer. The catastrophic suddenness frightens and provokes lamentation. Underlying all the expectations for a long, vigorous life, we also realize there are no guarantees. When a health issue arises, the primary focus is medical. An ER visit or ICU admission may not

---

131 Tisdale, 11.
132 “Our Father” prayer
be wanted, but most people should reliably expect a medical emergency in their future. At that time, the health care team’s singular focus will be repairing the body and maintaining vital signs, emphasizing saving lives and restoring functioning. If efforts at recovery fail, few medical personnel have the necessary expertise to guide someone through dying. Except for referring to hospice, pronouncing death, or completing death certificates, the medical focus is on living. To counter cultural taboos about death, individuals must find the courage to become literate about a topic most people shy away from.

Death’s universality means we really are “all in this together.”\textsuperscript{133} However, unlike pregnancy, there are few incentives to prepare and limited handbooks that divulge “What to expect, every step of the way.”\textsuperscript{134} Failure to anticipate dying, and a lack of tools and guides to assist with the task, often results in needing to bushwhack a path, tripping over rocks, paradoxically predictable and yet unexpected, and laboriously dealing with thickets of information and chores. When death is a distant abstraction, preparation is an intellectual exercise, which makes it easy to ignore or defer. However, when death is imminent, the circumstances disorient as if a rogue wave has pummeled the person and loved ones. Given humanity’s common fate and health trajectories, documenting wishes and gathering information are pragmatic adult responsibilities. Death is unsolvable, but certain actions can alleviate symptoms. The Treatment chapter of my thesis \textit{Awakening to Mortality} discusses long-range preparations that can be completed ahead of time like \textit{set and forget} insurance policies. An ICE (In Case of Emergency) plan can bring peace of

\textsuperscript{133} https://www.whattoexpect.com/
\textsuperscript{134} https://www.whattoexpect.com/
mind. “I don’t expect to die, but just in case, this is what loved ones need to know about me and my wishes.” Planning goes a long way toward easing the way for those who will share your crisis. Documenting treatment parameters based on values, identifying contacts, and cataloguing assets are about taking care of your family. These answer emergency *what ifs*. What if you are hit by a bus, unconscious or killed, who needs to be alerted? What essentials does a proxy need to know to make informed decisions or resolve an estate? Treatment is an exercise of imagination, anticipating the future, knowing that after receiving a terminal diagnosis, in addition to physical and cognitive deficits, the dying person may experience less stamina and more pain and nausea. An end-of-life plan can minimize the pre- and post-mortem chaos that often surrounds dying. Making wishes known can assuage loved ones’ suffering because, at a certain age, the countdown ticking gets louder as a reminder that our hour will come. Given that death is one and done, if we don’t get it right, there will be no chance for do-overs.

This thesis includes two Treatment chapters focused on different timeframes, but intended to improve end-of-life literacy. The first chapter, “Long-term Treatment,” covers the time when life seems to stretch forward without end, while the “Nearing Death Treatment” chapter addresses the phase from diagnosis of a life-limiting illness until the end. This first Treatment chapter incorporates information on vision and practices. Vision means facing reality, acknowledging the end of health or life, and using this anticipated limit to optimize time. While existential questions are universal, answers are singular: What matters most? What gives my life meaning? What’s on my bucket list? The practices section lays out steps for ensuring the implementation of vision. Courage and pragmatism will enable a counter-cultural approach to the status quo of dying as a
medical problem with people reduced to a compilation of physical ailments. This path honors values and helps prioritize decisions, such as considering whether comfort and dignity are more important than longevity. Anticipating can assist in advancing a new paradigm of self-actualized or mindful dying.

Ars Essentia: art of the essential

*Teach us to number our days that we may gain a heart of wisdom. Psalm 90:12*

Psychologist Erik Erikson developed a model of psycho-social development, dividing the lifespan into eight stages between the bookends of birth and death. By middle adulthood (ages 40+), a stage which Erikson designates as generativity versus stagnation, people typically wonder about the impact of their lives, how they have given back and made a difference, and how their lives fit into the bigger picture. In the final stage of Erikson’s model (around ages 65+), adults must reconcile integrity versus despair. Integrity recognizes “the acceptance of one’s one and only life cycle as something that had to be.” During this phase, individuals seek “a sense of coherence and wholeness.” Discerning integrity is a lifelong task, predominating as time gets shorter. Unlike learning to drive, no process or ritual encourages contemplation of life’s meaning. No instructor urges pondering the question, what is my soul’s purpose for being in this lifetime? Conducting a life review can elicit a sense of perspective and purpose.

---


136 Quoted in McLeod from Erikson’s 1950 book, 268.

137 Quoted in McLeod from Erikson’s 1982 book, 65.
When we know that our lives have made a difference and contributed to the greater good, life’s end signals completion, not obliteration.

Proactive versus reactive

Stephen Covey’s book *The Seven Habits of Highly Effective People* differentiates between proactive and reactive mindsets. A reactive approach is passive and disempowered; a lack of goals lets events set the agenda. When something happens, it feels urgent and stressful and may lead to inefficient resource use. Many people orient reactively towards aging, illness, and dying, despite the identifiable benchmarks of developmental stages. At some tipping point, more time lies behind than ahead, an unknown, but always decreasing *Time Remaining* (TR) number. Proactivity allows the ability to respond instead of being surprised by predictable circumstances. Planning permits retention of autonomy by evaluating and documenting wishes while an individual is still capable of doing so. Personal choices can maximize health span and minimize time disabled. Since 90% of people over age 65 will face a decline scenario with incremental disabilities, anticipating this development gives the opportunity to take steps to minimize its impact. Being proactive requires commitment to clarifying values and deciding consciously, which Covey calls “response-ability: the ability to choose your response.”

Mindfulness about death and limited time can be a catalyst for living life to the fullest.

---

138 Covey, 71.
Connecting the dots

Sixty-five is a magical age. A study conducted by the World Bank determined that “you reach your maximum human potential if you…survive to age 65.” In the United States, many people retire from employment in their mid-60s, become eligible for a federal Social Security pension, and qualify for health care under Medicare. Longevity, health care, and income comprise a trifecta of opportunity. Few routinely celebrate winning this genetic and social lottery. The bonus years after 65 herald a passage into elderhood with release from the tyranny of schedules. Having time, health, and money present an occasion to explore fundamental questions: What matters most? What makes life worth living? What gives my life meaning? How do I want to spend my remaining time and energy? Am I living by heart or by accident? What do I value? How important are my self-determination needs for autonomy, competence, and relatedness? Is quantity or quality of life more important? To what extent am I willing to suffer to gain more time? How important is dignity? What do I believe life to be—for me? At this stage, a person has the time and resources to ponder life’s big questions and spend remaining time building legacies that will live beyond them.

Psychologist Carol D. Ryff studies aging and well-being. She has determined that “living longer does not necessarily translate to meaningful living.” In contrast to the medical emphasis on biological processes, Ryff determined that components of well-being include being “self-realized, fully functioning, [and] purposefully engaged.” In addition to meaning, purpose, and growth, healthy relationships contribute to realizing

---


140 Ryff, 244.

141 Ryff, 244.
full human potential. The World Health Organization expands the definition of health to include “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” 142 Well-being equates to quality of life. Psychologist Colin Depp’s “theoretical model of successful aging includes three components: (a) freedom from disability and disease, (b) high cognitive and physical functioning, and (c) social engagement (in terms of involvement both in social and productive activities).” 143 The US medical system’s core competency relates primarily to (a) on that model, eradicating illness and treating injuries. Becoming ever more specialized and expert, clinical medicine focuses on the body and its maladies, with an implied goal of longevity, aiming to ensure years of life with limited consideration for well-being, even while psychological studies argue that quality of life is more consequential than quantity. Since there is no one to advocate for full personhood, or manage the gap between vital signs and vitality, it is up to each person to anticipate and plan for the inevitable.

In medicine, we trust. Countering medical science’s granular approach must come from outside the clinical arena. People may assume that health care aims to balance quantity and quality of life, but providers aren’t necessarily concerned with whether patients feel a sense of purpose or have meaningful relationships. Their focus is reductionist: Break your hip; we’ll fix it. Run a fever; we’ll identify and treat the infection. Unlike Bhutan’s gross national happiness index, in the US, no guru or bureaucrat tracks vitality signs and ensures well-being or publishes a timetable that recommends updating ICE contacts, auditing friendships, or examining purpose.

142 http://www.who.int/suggestions/faq/en/
143 Depp, 529.
Monitoring autonomy, competence, and relatedness happens on an ad hoc basis. A social worker or occupational therapist might prescribe finding a hobby, pet, or friend, but only if a patient happens to get referred to that particular professional. People default to the health care system with the expectation that it serves their best interests, when the system’s interests serve the bottom line, which is generally financial. Individuals search for a good life and are motivated by more than the physiological base of Maslow’s hierarchy. Gawande posits: “What we [medicine] have lost sight of is that well-being for some people is bigger than health and survival.”

Healing versus curing

Often people use the words healing and curing interchangeably, but there is a difference. It is possible to heal without curing or to cure without healing. Healing comes from the Old English hǣlan and means “restore to sound health or make whole.” Cure has the Latin root curare, “take care of,” or “treat medically,” providing a substance or procedure that relieves a disease or condition. Generally, the word cure is specific, whereas healing is considered broader and holistic. A treatment administered may lead to a cure, from the outside in. By contrast, healing is transformational, working from the inside out and enhancing wholeness. Healing and curing must work together to eradicate illness. For example, unless a patient suffering the ravages of Type 2 diabetes also engages in healing activities, such as changing eating and exercise habits, the medicines

144 https://www.mdmag.com/conference-coverage/apa-2016/atul-gawande-conversation-is-powerful-medicine
145 Online Etymology Dictionary
146 Online Etymology Dictionary
are a Band-Aid. We consult health care worker for cures, while healing also requires involvement from the person who desires wholeness. The current system mostly absolves patients of responsibility to participate in their return to health.

This process is particularly evident at end-of-life. Involved parties are focused on curing the body, without considering the big picture and recognizing integrative aspects of being human, not only physical but also emotional, social, and spiritual. While hospice embraces a comprehensive approach to care, qualification rules limit patient enrollment. Someone who is debilitated or moribund may not benefit from the hospice-facilitated healing practices that can ease the transition for all.

Patient or person

Figure 4: Holistic Integrated Map (Model) to Health and Healing

---

147 https://www.alternative-doctor.com/love_and_sex/medical_model.pdf
We are more than physical bodies, although most physicians operate at the base of the Holistic Integrated Map to Health and Healing pyramid in Figure 4 (a full-size version is located in Appendix 5). The existing medical system is paradoxical, supposedly for the good of patients, but operating with doctors, treatments, and technology as lead actors in an unfolding medical drama where energy is directed towards curing without considering healing. Patients play bit parts as objects that something is being done to. But patients are complicit with the system; often going along without questioning. It takes courage to face the end and say, “Enough treatment.” If someone does not or cannot insist on being addressed in full personhood, the individual will continue to be viewed and treated as a collection of malfunctioning body parts. Medical schools do not currently teach evidence-based integrative care therapies.

Twentieth century inventions have increased the medicalization of end-of-life. While advances have been a boon, technology has assumed an outsized role in health care, particularly at end-of-life. Originally, machines were intended to provide temporary support while underlying disease resolved, such as iron lungs used by polio sufferers to be used while recovering from the virus. The pendulum has swung so that technological interventions are the default, regardless of efficacy. While hospitals and physicians profit, indiscriminate use of this high-tech approach may cause more suffering for patients and raises ethical questions regarding the intent of treatment:

We must look beyond numbers. Modern medicine has become dominated by a special kind of intellectual ritual, shaped and validated by instrumentation, quantification, replication, hard-edged activities that characterize the so-called “basic sciences.” Displaced by these steely disciplines are acts of empathy and of the imagination, which are…imagistic, whether verbal, pictorial, or conceptual, which have shadows and vanishing points, coiling ambiguities, which are, in short, the stuff of what it is to be human.148

148 Schneiderman, 9-10.
Illiteracy about aging and competing treatment goals may lead to violent interventions. Patients trust that their best interests motivate care givers and entertain faulty expectations about success rates for procedures. The health care system has mandated procedures like CPR, regardless of underlying conditions that would thwart successful outcomes. Prevalence presumes usefulness. Patients are inclined to follow physician recommendations, assuming its efficacy and validity.

For an alternative path, people must prepare ahead of time and weigh what is more important: to be a patient or person. Am I a body, or do I have body? Is curing more important than healing? While health is about more than ailments, and people are more than bodies, it is easier to fix a broken bone or track the alive/dead binary than determining, monitoring, or correcting well-being. So, the medical establishment often directs its resources at things that can be fixed or measured. Patients may not know enough to request caring which includes:

A commitment to protecting and enhancing the patient’s dignity. Effective caring goes beyond good intentions or simple kindness and includes physiological, philosophic or religious, and social components, taking into consideration the patient’s social context and specific goals.149

Many patients don’t ask; and physicians don’t tell. Patients assume that if a doctor recommends a treatment, it is in their best interests to accept that protocol. They acquiesce, without awareness of the full gamut of side effects, financial burden, risk, or whether they will even benefit. Dr. Gawande illustrates the rarity of prioritizing personhood as he describes a former patient who “was a person and not a patient in the last four months of his life,” which also has economic implications: “It was a fraction of

149 Schneiderman, 138.
the cost it would have been going down that other path.”

In taking a medical history, many physicians don’t ask about values and what things are most important to patients. Their responsibility ends with diagnosing and treating ailments. The health care system supports failing organs with medicine and technology, rather than ensuring patients’ well-being.

If people want autonomy and freedom to choose, they need to expect and plan for death. Failing to anticipate ensures riding the medical express train, sometimes to the end of the line. Determining preferences ahead of time and alerting others of those wishes reduces stress for decision makers if a patient cannot communicate. This also allows the health care team to concentrate appropriate resources based on an assessment of the whole picture.

Rites of passage

“All endings are also beginnings; we just don’t know it at the time.”

Loss is part of life. Even growth brings changes. When a crawling baby learns to walk, she leaves infancy behind for toddlerhood, with mobility bringing freedom but requiring enhanced safety precautions. Rites of passage indicate status changes, whether biological or cultural. People honor milestones and mark times of transition with celebrations such as birthday parties, graduations, or weddings. A marriage is an example of a social construct between two individuals who commit to a union “until death do us part.” Societies have devised ways to aid in transitions with rites of passage as a means of celebrating and understanding. Arnold Van Gennep’s schema explains rites as having

---

150 https://jamanetwork-com.ezp-prod1.hul.harvard.edu/journals/jama/fullarticle/2300598
151 Albom, 222.
three phases: separation, transition, and incorporation.152 In the separation phase, participants leave behind the familiar for new territory. The transition phase is a threshold where initiates prepare for new roles and routines, learning appropriate behaviors for the upcoming stage. Transformation occurs in liminal space, “the time between the ‘what was’ and the ‘next.’ It is a place of transition, waiting, and not knowing.”153 During the incorporation phase, ceremonies formalize inductees’ new status and help witnesses recognize those who have undergone the conversion experience. 

By its nature, the aging process brings changes, both physically and socially. During the post-employment years, individuals enter a new phase of life, leaving jobs and qualifying for Medicare and Social Security. However, people are on their own navigating this new terrain. Except for the lucky few who are honored at a retirement ceremony or with a party, no rite commemorates this passage. Written guides, mentors, or workshops provide instruction if someone is getting married or having a baby, but the elder years are uncharted and unaccompanied. With longer life, people may expect to live for decades from the conclusion of employment until death. Hope is not a method, but it seems to be our approach for the final stage of life’s journey. Planning for this threshold and developing a ritual helps acknowledge and honor the spiritual nature of this transition. We cannot rely on the health care system, with its emphasis on biological failure, to respond to psycho-social and spiritual needs.

152 Hockey, 212.
153 https://inaliminalspace.org/about-us/what-is-a-liminal-space/
Anointing

Christian churches consider ministry to the sick and dying as corporal works of mercy, compatible with Jesus’ teaching in Matthew 25. Different denominations approach this mandate differently, but anointing is a way of providing comfort. Before my mother died, a Protestant minister who was a family friend anointed her. The focus of this interaction was consolation of the grieving family. Decades later, when my father was in hospice, a Roman Catholic priest responded to a request for a chaplain visit. The priest arrived, left his coat on, donned a stole, anointed my father’s body, and departed, having administered what my brother called a “drive-by anointing.” The anointing of both my parents met the legalistic definition of care of the dying, but my mother’s also provided spiritual nourishment. Anointing is available for those who are sick, injured, or aging, not just for someone in danger of dying, but often a request is postponed until death is imminent. At one time, the Roman Catholic Church reserved the sacrament of Extreme Unction for the dying, a one-time heavenly EZ-Pass. Now, a dying Catholic who is conscious may receive Anointing of the Sick multiple times, which includes the Eucharist, confession of sins, and anointing in one pre-mortem bundling of sacraments.

Funeral

A funeral is a rite passage for survivors, intended to help loved ones adjust to separation from the deceased and begin life post-mortem. As writer Mitch Albom remarked: “You always wonder about your funeral. How big? Who’ll show up? In the end, it’s meaningless. You realize, once you die, that a funeral is for everyone else, not
This ritual occurs when the guest of honor is absent, silent, and unable to appreciate the tribute. The logistics of funerals are as complicated as weddings but with less time to prepare for gathering family and friends, obtaining flowers, selecting readings, and planning a ceremony. Senator John McCain was exceptionally far-sighted as he orchestrated his passing, relieving his family of the complexities of planning a state funeral. Often during the dying process, the focus is on treatment, leaving families scrambling to accomplish tasks related to body disposition and honoring the deceased with an obituary, wake, funeral, memorials, and internment. Even when death is expected, many resist facing this transition until urgency forces. Some people believe death is the end; however, lack of preparation can create a form of hell, an afterlife replete with the legal and financial turmoil that death occasions. Some nationalities, such as the Irish, celebrate after the funeral with a wake, a post-mortem party that honors and celebrates the deceased.

**Spiritual, not necessarily religious**

While not everyone embraces formal religion, the existential aspect of life is universal and spiritual. A holistic approach that integrates body, mind, and spirit can bring peace of mind and hope, even in the face of imminent mortality. First, it takes acknowledgment that human existence is more than physical and that dying is not just a medical event, but that people’s essence, for which there is no diagnostic exam, survives the perishable body. While viewing an autopsy during clinical pastoral education (CPE), it was clear: the body was dead, not asleep. Based on examination, a pathologist can

---

154 Albom, 137.
determine cause of death, whether heart or brain failure, which caused disruption of biological life. If critical organs fail and can’t be fixed, a person dies. However, a scalpel does not reveal intangibles like spirit. Even to an untrained onlooker, the cadaver’s animating force was gone. Humans are mammals, but imbued with a vital essence that extends beyond flesh. In the autopsy suite, the dissected heart registered no residual love; the brain revealed no thoughts, hopes or dreams; and no organ corresponded to soul. Dissection identifies physiology and pathology, but the knife does not reveal love, memories, or insights.

Philosopher priest Teilhard de Chardin suggests, “We are not human beings having a spiritual experience. We are spiritual beings having a human experience.”

Spiritual derives from the Latin root spiritus, meaning breath, a root that is also shared with the words inspiration and respiration. If we have breath, we have a spiritual core, whether or not we follow a particular religious tradition. Palliative care specialists from the United Kingdom offer a definition:

Spirituality is multidimensional and relational, encompassing meaning and purpose, self-reflection, hope, faith, beliefs, and a sense of sacredness and separateness. Common to all expressions of spiritual need among those facing end-of-life issues is a search for meaning. Spiritual needs are about the need to be valued, to repent and be forgiven, to achieve self-integrity, and to face and accept death. Spiritual resolution is frequently about the ability to affirm and value relationships with one’s self, with family, with community, and with the ‘other’—whether that is a deity, unseen spirits, nature, humanity, or the unknown. Spiritual needs can be seen as different from psychological needs in that they are embedded in a sense of the sacredness of life.

Acknowledging that human beings have mental, emotional, and spiritual facets in addition to physicality allows us to face and transcend humanity’s primal existential


\[156\] Grant, 2.
crisis, which is the finality of death. The magnum opus of life is not the physical body which fails and dies, but the body of work, service, and love that prevail. Will we be remembered? Is there a way to reach out to future generations? Is it possible to acknowledge death’s role as a reminder to wake up because life doesn’t last? There is no single route for dying well, but unless planning takes place before needed, the cultural default of focusing on the body will triumph and death becomes conclusion without redemption. In the *Human Side of Cancer*, psychiatrist Jimmie Holland states, “Healing is an inner process through which a person becomes whole…. The healing process has a tendency not only to bring people closer to appreciating their individuality and their unique purpose in this world, it also brings them closer to God, spirit, inner peace, connectedness or whatever we choose to call that which is great and mysterious.”  

![Image: Life’s through-line or Soul](image)

*Figure 5: Life’s through-line or Soul*

Nature teaches that energy is conserved even when it changes form, which also applies to humans. While not believed universally, a soul may be the element that makes someone human. Scientific research affirms the importance of soul to well-being.  

---

157 Holland, 265.

element that survives bodily death (Figure 5). Did we exist before birth? Does anyone remember pre-birth consciousness? Will we exist after death? Some believers would point to the soul as an immortal entity that continues even after the body expires. How much does matter matter? Some religions disagree with organ donation, transplantation, amputation, and even transfusions and surgery. Jehovah's Witnesses believe that blood represents life and is sacred to God. They refer to passages from the Bible (Genesis 9:4, Leviticus 17:10, and Acts 15:28-29) to justify their way of thinking. Rastafarian musician Bob Marley159 (1945–1981) was diagnosed with melanoma on his toe, refused to have it amputated, and died. He based his decision on Leviticus 21:5, which prohibits cutting bodies. Are we human because of matter or spirit? While scientifically unprovable, the temporal body might contain a divine core or perpetual light, especially when you consider deceased luminaries such as Jesus, Shakespeare, Einstein, or Mozart, have legacies that survived mortal death.

159 https://www.thoughtco.com/why-did-bob-marley-die-3552830
Memento Mori

While you live, consider the end. Memento Mori\textsuperscript{160} means Remember you will die, which embraces a practice of reverse engineering. By pretending that life continues indefinitely and acting like we will be the exception to existential certainty, we forego planning for morbidity and mortality. We cannot count on health or time. While calamity sometimes jolts us out of complacency, somatic senescence also changes everything. Throughout life, we try to block the knowing whisper: Remember you will die. In the sixth century, Christian monk Benedict of Nursia founded monasteries in Italy and wrote The Rule, a manuscript codifying instruction for monastics. Chapter 4 “The Instruments of Good Works” contains the admonition, “Keep death daily before your eyes.”\textsuperscript{161} Various religions have embedded death awareness practices. Reflecting on death helps illuminate life because “We are prophets of a future not our own.”\textsuperscript{162} Knowing and yet denying we will die is a unique aspect of human cognition; we can block awareness that life will end, even as we know not how or when. Without planning and preparation, medicine and treatments will engulf the end-of-life, frustrating the possibility for a spiritual experience. At the heart of spirituality is integration: the prospect of wholeness instead of fragmentation. Under the care of specialists focused on body parts, life will conclude as a patient, not a person. While crisis can catalyze transformation, sometimes there is no time to respond. Humans cannot solve death, but we can control the dying

\textsuperscript{160} Translation: Remember you will die

\textsuperscript{161} St. Benedict, 4.47. \url{http://www.gutenberg.org/files/50040/50040-h/50040-h.html#chapter-4-nl-what-are-the-instruments-of-good-works}

\textsuperscript{162} Concluding line of the prayer dedicated to assassinated Archbishop Oscar Romero
process. Psychologist Brené Brown claims, “If you own the story, you get to write the ending.”  

In *When Breath Becomes Air*, Paul Kalanithi shared the intangible insight that lies beneath skin and skull: “What patients seek is not scientific knowledge that doctors hide but existential authenticity each person must find on her own… The angst of facing mortality has no remedy in probability.” He questioned the human condition, “What makes human life meaningful, even in the face of death and decay”? Psychiatrist and Holocaust survivor Viktor Frankl wrote concerning his World War II concentration camp experiences, “Man must decide, for better or for worse, what will be the monument of his existence.” He explained the loss of meaning as “people have enough to live by, but nothing to live for.” What makes life worth living is more than simply surviving—it requires discernment of and living out a life mission. Frankl recounts Nietzsche’s wisdom, “He who has a *why* to live, can bear with almost any *how*.” Under the grueling prison conditions, Frankl’s insights evolved:

> It did not really matter what we expected from life, but rather what life expected from us. We needed to stop asking about the meaning of life, and instead to think of ourselves as those who were being questioned by life—daily and hourly. Our answer must consist, not in talk and meditation, but in right action and in right conduct. Life ultimately means taking the responsibility to find the right answer to its problems and to fulfill the tasks which it constantly sets for each individual.

---


164 Kalanithi, 135.

165 Kalanithi, 42.

166 Frankl, 143.

167 Frankl, 164-65.

168 Frankl, 126.

169 Frankl, 77.
Each of us needs to ask and answer these essential questions throughout our lives, before becoming patients, before encountering the reality of ultimate outcome, and being forced to deal with unrelenting symptoms of illness and treatment. Failing to confront reality has its own side-effects. “Patients often struggle to explain their spiritual needs… [which] can result in increased angst about unresolved issues, uncertainty, lack of self-confidence, and vulnerability, which in turn can further heighten spiritual distress. This distress can affect patients’ ability to sleep and their capacity to cope with pain.”\textsuperscript{170} Every day brings us closer to death, as Dr. Kalanithi learns:

There are…two responses to that realization. The most obvious might be an impulse to frantic activity: to “live life to its fullest,” to travel, to dine, to achieve a host of neglected ambitions. Part of the cruelty of cancer, though, is not only that it limits your time; it also limits your energy, vastly reducing the amount you can squeeze into a day.\textsuperscript{171}

Life’s singular, fundamental question is: what is my reason for living? Contemplation needs to be balanced with action as Kalanithi reflected, “If the unexamined life was not worth living, was the unlived life worth examining?”\textsuperscript{172} We must live with the end in mind, a dictum that guides not only writing papers and planning projects, but anticipates how aging might unfold with the prospect for loss of meaning and agency. Confronting the end is no easy task: “Severe illness wasn’t life-altering, it was life-shattering. It felt less like an epiphany—a piercing burst of light, illuminating What Really Matters—and more like someone had just firebombed the path forward.”\textsuperscript{173} To live a “no regrets” life means imagining ourselves at life’s penultimate terminus reflecting back. Gawande

\textsuperscript{170} Sulmasy, 25.
\textsuperscript{171} Kalanithi, 196.
\textsuperscript{172} Kalanithi, 31.
\textsuperscript{173} Kalanithi, 120.
reveals, “People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete.”

Professor Stark suggests:

Only by remaining continually aware that we could die at any moment, not simply that we are going to die at some point, will we create a life that is both singular—authentic to our own values because we have no time to waste on anyone else’s—and vivid, one that uses each second to the hilt because time is scarce.

The key to dying well is living fully, which includes recognizing human ephemerality but also entails broadening identity beyond the body. Superstitions about death, as if talking about this taboo will jinx us, cause delays dealing with the topic of mortality. By the time people are at death’s threshold, side-effects from illness or debility often dominate: pain, nausea, dementia, and/or sleepiness. Before this point, spiritual interventions can encourage examination of life’s purpose. Mindfulness about death adds meaning to how we live. Keeping the end in mind may ensure focusing on things that matter most or changing direction while we can. Life will pass whether we live consciously or on autopilot. We can’t wait until we’ve received a terminal diagnosis or an admission to hospice to explore what has brought meaning to life.

Legacy

“When it's over, I don't want to wonder if I have made of my life something particular, and real”

174 Gawande, 155.
175 Sharp, 71.
176 Mary Oliver, “When Death Comes”
Will I be remembered? If so, how? Is there a way to reach out to future generations? Is it possible to acknowledge death’s benevolence, which reminds us to wake up because life doesn’t last? We live our legacy every day. Meaning and purpose add up to an inheritance paid forward to the future. More significant than the dates of birth and death is the gap between life’s beginning and end. Immanuel Kant suggested a simple formula for a joyful life: “Rules for happiness: something to do, someone to love, something to hope for.” Some people maintain bucket lists of things to do before dying. If a list includes places to visit or things to do, act while energy and health endure. While those who have raised children consider them a living legacy, they might heed Kahlil Gibran’s caution from *The Prophet:*177

Your children are not your children.
They are the sons and daughters of Life’s longing for itself.
They come through you but not from you,
And though they are with you yet they belong not to you.

Those who never birthed children need to recognize and appreciate their parentage of creations and initiatives. Erikson’s psycho-social stage for adulthood suggests that reviewing and reflecting on our journey can bring a sense of satisfaction and completeness, knowing that our lives have made a difference. One way of capturing and communicating experiences is with a document called an ethical will “that you create in order to communicate your values, experiences, and life lessons to your family.”178

Stories link generations. St John of the Cross proposed, “In the twilight of life, God will not judge us on our earthly possessions and human success but rather on how much we

---

177 [http://www.katsandogz.com/onchildren.html](http://www.katsandogz.com/onchildren.html)
178 [https://www.everplans.com/articles/ethical-will-worksheet](https://www.everplans.com/articles/ethical-will-worksheet)
have loved.”\textsuperscript{179} While living, remember \textit{Ars Essentia}, the art of the essential. In the end what matters will be the lives touched and connections made. Until dates are carved in stone, we have opportunities to revise our legacy and know that what remains is more than a perishable body.

\begin{center}
\textbf{Practicalities: Preparation before expiration}
\end{center}

Crystal ball foresight is unnecessary, since ready or not, death will come. Just like some people postpone preparing for a hurricane and hope the storm won’t hit, many also avoid planning for life’s final phase. While the outcome is predictable, it is also capricious. It will happen; we just don’t know timing or cause. Being oriented to the present and biased against the future causes us to procrastinate. We fail to anticipate and take practical steps before the inevitable occurs, so crisis complicates the process. Initiating uncomfortable conversations while healthy can ease the emotional vortex created by illness, debility, and diagnosis. Consider whether you want your life to end as a person or a patient, as someone with agency over what happens or as an object where others decide. Personhood requires proactivity as well as remembering that death is not just about the person who is facing life’s end. Loved ones are left to cope, not only with the loss, but also with decision-making, details, and disruptions. Forewarned is forearmed.

\textsuperscript{179} \url{https://www.azquotes.com/quote/528804}
Advance Directives (AD)

What would you want done or not done, and who would you want making decisions on your behalf in the event of a medical emergency? Advance planning is the process of considering the types of treatment and care that you desire. Advance Directive (AD) documents create a record of wishes, values, and choices to ensure a patient receives appropriate care based on needs and preferences. Advance planning anticipates and assesses potential clinical benefits, burdens, and risks, but also considers factors such as the patient’s personal circumstances, beliefs, and values. Given the inevitability of needing healthcare, patients can optimize encounters by planning ahead. Medical care is usually the gateway to end-of-life, sometimes leading to a temporary reprieve and recovery, but at other times foreshadowing death. Given the likelihood of needing medical care, an AD goes into effect sooner than any other estate planning document, but only if a patient cannot make healthcare decisions or speak for him/her-self, due to unconsciousness or mental incompetency. The best time to prepare these documents is before needing them. Advance Directives extend patients’ autonomy by outlining desires for interventions, or the lack thereof. Before reaching the stage of functional decline that activates a document, the AD can be used to initiate discussions and explain wishes. In the process of clarifying values, consider desires for quality versus length of life. If you are uncertain about what you deem important, consider visiting a nursing home. Often in long-term care facilities, patients are immobile, restrained, or unresponsive. Determine if that is a future you would desire for yourself. Use this visit as a wake-up call because deciding what you don’t want may be easier than figuring out what you want. A lack of forethought, fantasies perpetuated by media, or doctors’ communication failures leave
many with misconceptions about what medical interventions can accomplish. Doctors are complicit when they hide behind jargon or obscure the gravity of prognosis. If a goal is to “do no harm” and minimize suffering, it will require blunt discussions about heroic versus futile care. Discerning what constitutes living can establish acceptable levels of impairment, pain, and dependence. Although better than no document, Advance Directives have problems. Even if the person has completed an AD, is it retrievable? Some documents are vaguely worded, or a patient’s situation doesn’t match specifics indicated on the form. A proxy may not even realize that s/he was identified as the surrogate decision-maker. Or a family member may choose to ignore the patient’s stated wishes.180 When disagreement arises, physicians may defer to the wishes of a potential litigant, not the dying patient. Telling someone your desires doesn’t take the place of a document. Verbal rather than written expression does not meet clear and compelling evidence guidelines, and such situations led to the prolonged dying of Schiavo, Cruzan, and Quinlan, among others who exist in vegetative states for years while courts deliberate their fates. Doctors use a Karnofsky status index to assess functional impairment. The Personal Self-Assessment Scale (PSAS)181 form in Appendix 4 mirrors the Karnofsky scale and outlines varying levels of mobility, activity, and cognition ranging from fully functioning to needing total care. Patients can complete this form to supplement their AD, providing detail on your wishes by matching medical interventions with functionality. Patients’ values, desires, and goals of care may vary depending on

180 For proxy, it may be better to choose bond (someone whose philosophy agrees with yours) over blood relatives
circumstances. Communication and documents are essential. In extremis, an advance directive can extend your autonomy. If a patient doesn’t choose, someone else will.

CPR

Some incidents as a chaplain are unforgettable. One was watching an older woman receive cardiopulmonary resuscitation (CPR) three times over the course of eight hours. Twice she was resuscitated. Death won the last episode, but not without a fight from the code team. Before the attending doctor instructed the team to stop, the woman’s abdominal area looked like a trampoline. With each compression, her stomach heaved and sloshed, probably because of broken ribs. CPR is not like what you see on TV.

![Figure 1: Pooled estimates of cardiopulmonary resuscitation (CPR) success rates among the elderly declined from 15 percent for patients younger than 70 years to 0 percent for those patients older than 89 years.](image)

**Figure 6: Estimated success rates for CPR**

If 911 is called, paramedics who respond to a person with a heart stoppage will begin CPR. First responders and doctors are required by law to perform chest compressions, unless the patient has a written and available doctor order, either Do-Not-Resuscitate (DNR) or Physician Order for Life-Sustaining Treatment (POLST). As

---

182 Schneider, 94.
Figure 6 shows, the in-hospital success rate for CPR varies, ranging from 15% for those under age 70 to 0% at ages over 89. One conundrum—the most successful CPR occurs when someone is hospitalized, which indicates there must be some illness or injury already. Risks from CPR include potential for rib fractures, internal organ trauma, and permanent neurological damage.183

How is success defined? Obviously, it would be restoration of a heart rhythm, but what does that mean for the patient: survival for 24 hours, discharge from the hospital to a custodial care facility, or regaining of functionality? Criteria vary from facility to facility. Although 72.9 percent of the post-CPR deaths occur within 72 hours, sometimes successfully resuscitated patients have permanent neurological impairments.184 The Wall Street Journal reported on a 2010 study of more than 95,000 cases of CPR found that only 8% of patients survived for more than one month.185 Of these, only about 3% could lead a mostly normal life. Despite these statistics, the standard of care requires CPR, without regard for age or underlying disease.

Notwithstanding technological advances that extend body functioning, death ultimately comes. Unless someone concedes that death is part of the human condition, there is no reason to change how we approach end-of-life. Awareness of reality allows the ability to frame dying in alignment with values. Many people have misconceptions about the effectiveness of procedures. Examples of interventions shown in the media deceive by looking routine, easy, and reliable. On the contrary, someone who undergoes

---

183 Schneider, 98.
184 Schneider, 94.
185 https://www.wsj.com/articles/SB10001424052970203918304577243321242833962
chest compressions heads to an ICU, not sauntering out of the hospital, seemingly little worse for the wear after getting pummeled.

Like CPR, intubation with a ventilator is a relatively recent phenomenon. While routinely used, if a vent does not provide a bridge back to health, patients should assess its value for their particular illness. As a reality check, patients should keep in mind that doctors don’t want for themselves the interventions that they routinely prescribe for their patients: “Almost 90 percent of doctors would forgo resuscitation and aggressive treatment if facing a terminal illness.”186 Given that doctors know more about medical interventions and side-effects, patients should choose treatments cautiously. Especially with elderly patients, those who survive may be worse off physically and mentally than before the ordeal.

Having conversations ahead of time, writing down preferences, and having the documents available help ease tough choices. Since 2016, Medicare pays doctors for end-of-life planning consultations with patients.187 Currently state motor vehicle agencies (DMV) ask applicants to declare organ donation preferences, including soliciting contributions for its support, although circumstances where solid organs can be harvested are relatively rare. Existing driver’s license databases could be modified to allow for making ADs easily retrievable. Each state has different rules for ADs, but having preferences documented establishes intent if a situation ever arose requiring adjudication.

187 Discussions about EOL was a political hot potato when in 2009, Sarah Palin described the consultation as a death panel. https://www.npr.org/2017/01/10/509164679/from-the-start-obama-struggled-with-fallout-from-a-kind-of-fake-news
While some changes would require systemic overhaul, any adult can immediately complete advance directives and discuss desires with families.

Given the choice, most people would choose divine intervention over advance planning. During interactions with patients and families, I became aware of the propensity for embracing magical thinking, from the expectation of a miracle (which by definition doesn’t require a hospital or health care) to a misconception about what heroic procedures entail and can accomplish. My CPE supervisor suggested a noncommittal but positive response for families who awaited their ICU phenomenon, “Wouldn’t that be wonderful!” In our modern era, we look to science rather than religion for our miracles.

ICE-teas: a forum for action

People need a headfirst orientation for end-of-life planning. After receiving a diagnosis or experiencing cognitive or physical declines, emotional involvement complicates decision-making. Individuals should take responsibility for anticipating and preparing for their needs. The government could assist by using certain inflection points, activities such as obtaining/renewing a driver’s license, enrolling in Medicare, or applying for Social Security, as triggers to initiate or update advance directives, although such actions would require regulatory changes and systemic reform. Consider the requirement to file tax returns in April: few people would voluntarily complete forms and submit payment without government insistence. Designing systems using behavioral economics techniques would require people to opt-out from preparing ADs rather than deciding to opt-in. Entitlement access should carry responsibilities for beneficiaries, with benefits contingent on planning for end-of-life eventualities. Many people know that they should prepare themselves for the future, yet the awareness does not always translate into
action. Tweaking current systems can ensure that more people clarify and document health care desires with advance directives.

Anyone who has dealt with the aftermath of a loved one’s death or been appointed as an executor knows how complicated the process is. The post-mortem phase of life is like a puzzle, with participants not knowing where to start, let alone what the various pieces are. Experiences of others can guide our journey by providing a framework or outline. Like the process of writing a thesis, identifying a path eases the overwhelm factor of having too much to do without a clue of where to start. Others have already blazed the trail. With a map and series of next steps spelled out, the focus can be on remembrance of the deceased rather than administrative and regulatory details.

After thesis completion, I intend to distill and share my research findings\textsuperscript{188} through workshop presentations to guide the end-of-life planning process and encourage accountability for accomplishing the responsibilities required. Considering “preparation before expiration” tasks can be distressing, both emotionally and practically. Instead of waiting for a doctor’s suggestion to “get your affairs in order,” a series of “ICE-teas: facing tomorrow today” workshops can nudge work on nagging unfinished tasks (NUTs). Like de-sensitization exercises to ease fear of flying, discussion and actions can inoculate by lowering fear and lessening stigma about dying. As envisioned, these workshops will include short expert presentations followed by discussions and assignments, aided by accountability focused on collecting information and compiling documents. ICE-teas can help with anticipating and preparing for a good death, however an individual defines it. At some point in the future, loved ones will thank you for lessening their burden.

\textsuperscript{188} A physician who read a draft of my thesis suggested incorporating the information into a book rather than seminars. He indicated workshops take a lot of effort for limited payback.
Just one thing…

After reading this thesis, one practical step can potentially help you, loved ones, and your health care team: prepare an In-Case-of-Emergency ICE card. If you have never been in the situation, you probably haven’t considered the ramifications of an emergent trauma admission for patients who arrive unconscious, intubated, unable to speak, or dying. If a wallet or purse happens to accompany the person (and in the case of a car crash, it may go with the responding police), cards often do not identify who to contact or provide health information essential for immediate treatment. An ICE card should list medications, medical devices, an abstract of medical history (such as heart ailments or diabetes), allergies, primary physician, and next of kin (NOK) contacts. Also, if you have a pet, where is it located and who can feed or walk it? Even if someone has an AD, most people don’t routinely carry them. Similar to the fragmented system of medical specialties, access to vital ICE information is disjointed. If you take only one step, place a card in your wallet with this information. You cannot expect your phone to survive a crash, submersion, or code breaking skills to have device-embedded information accessible in an acute situation.

Conclusion

Time inexorably counts down. We will never be younger or have more time than right now. If you have a goal you want to accomplish, seize this moment. Nothing comes without risk. Proverbs indicates “Where there is no vision, the people perish.”\(^{189}\) Even with vision, life eventually ends. We can’t change that outcome, but acknowledging and

\(^{189}\) Proverbs 29:18.
developing a plan can awaken us to the things that matter most while we have time and health to accomplish them, as well as limiting collateral damage for those left behind. Similar to residents who fail to plan for an approaching storm and choose to stay in place despite warnings, death is an existential threat. Abstraction and innate optimism about reprieve-potential trick us into inertia. When a meteorological or medical tempest hits, it’s too late. In the moment of crisis, the only option is dealing with the consequences of the chosen strategy. This Treatment chapter of *Awakening to Mortality* suggests facing death in order to revise the paradigm. Although other areas of life might permit multiple chances, life presents only one opportunity to get dying right. If tomorrow comes, there are no guarantees about cognitive or physical functionality. We need a series of baby steps that help us accept and be ready for reality. The Scout motto proclaims “Be prepared.”  

190 Enjoy the present moment but plan for the future. Knowing how life’s journey ends keeps us grounded in the present, while our spiritual core intimates dwelling in the mystery forever.  

191 As we marshal the courage and resources to rise above the inherent dilemma of impermanence, let us consider the big picture and make changes while we can. If you’re reading this, you have time to face your fears and change your game plan to avoid painful consequences.

---

190 [https://blog.scoutingmagazine.org/2017/05/08/be-prepared-scout-motto-origin/](https://blog.scoutingmagazine.org/2017/05/08/be-prepared-scout-motto-origin/)

191 23rd Psalm
Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. Susan Sontag

*We thought we had more time. No one told us. We weren’t ready.*

Reflecting on his father’s death, Kevin Toolis, author of *My Father’s Wake*, wrote: “Death is most often seen as tragic happenstance, a usurping by a surprise enemy, a conspiracy against our limitless possibility, a singular meteor falling from the heavens, not a common rain shower.” Medical inventions and technology have given a false sense of security and hope. Dying should not happen; it is an aberration, a mistake. But there comes a point where we are “living dyingly” as *Mortality* author Christopher Hitchens put it. We often lose our way to a peaceful, dignified death, sure that there will be a reprieve—another treatment or medicine—a mortality deferment. And, because we do not expect to die, we have let the path get overgrown and lost the map that might guide dying well.

Katy Butler recollects in *Knocking on Heaven’s Door*, “Once upon a time we knew how to die. We knew how to sit at a deathbed. We knew how to die and how to sit because we saw people we loved die all through infancy, childhood, youth, middle age,
and old age: deaths we could not make painless, deaths no machine could postpone.”

Intense fear of death leads to a covert process, with reality denied and hidden. Fear means that unlike expectant parents and their birthing plans, we do not develop a dying plan. We ignore making advance preparations that would help anticipate and rehearse challenges beforehand. An end-of-life counterpart would formulate the way to transition through the dying process. Asking a doctor about the right way to die would more likely result in a referral to a psychiatrist as a suicide risk than a substantive answer. The health care system and professional staff primarily manage physical symptoms of illness and pain without consideration for the emotional component, practical tasks, and spiritual readiness as death approaches. Theologians, artists, and poets are better suited to addressing existential components by trying to make sense, rather than fix. Patients and families may be complicit with a quick-fix orientation, preferring pills, surgery, and false optimism over diet, exercise, and realism. Doctors conform by focusing on longer living through chemistry and procedures. Physicians and patients alike are compliant consumers of immortality Kool-Aid, having forgotten that everyone at some time passes the point of no return, no matter how many pills popped, minutes sweated on an elliptical machine, or bad fats avoided. Even when we use it, we are ultimately going to lose it. No one advises on how to die. Even Shakespeare wrote about our propensity to stick with the cards in our hand, referring to death as “The undiscovered country from whose bourn no traveler returns, puzzles the will / And makes us rather bear those ills we have than fly to

---

194 Butler, 211.
195 When I was hit and thrown by a bus, not once did medical staff ask how I was doing. The primary focus was assessing physically then fixing broken bones.
others that we know not of."¹⁹⁷ Most would choose present hell than deal with the uncertainties of death and afterlife. No matter that lifespans have lengthened, extinction is still our fate, although sometimes postponed by employing the best science future generation’s money can buy. We have lost awareness of death as a natural life phase, with potential for transformation. We know a lot of stuff but consciously turn from big Stuff. Because of fear and failure to plan, our resistance and uncertainty leave us deferring to medical personnel in the face of death, assuming that the system and practitioners will shepherd dying appropriately and humanely.

Once upon a time — the Art of Dying (Ars Moriendi)

Figure 7: Frontispiece from Wyer’s Ars Moriendi.

In the post-plague years (~15ᵗʰ century CE), one of the most popular documents (besides the Bible) produced in Europe with the newly invented moveable-type printing press was death literature: “Ars Moriendi. Here Begynneth a Lytell Treatyse Shortlye Compyled, and Called Ars moziendi/that is to Saye, for the craftie to dye, for the helth of

¹⁹⁷ Shakespeare — Hamlet, Act 3, Scene 1, Lines: 79-83.
Manes Soule.198 Because ability to read was rare, one version of the book consisted of block-cut pictures. Intended to prepare Christians for death, this manual addressed elements that constitute a good death and how one should prepare for it.199 Because there were few clergy and limited healers, accompanying the dying was a matter of availability. Family or friends respected the deathbed as a privileged time and assisted with necessary tasks. Cleric Jeremy Taylor’s mid-seventeenth century devotional book *Holy Dying* was an early form of self-help literature covering rules and exercises for dying: “In which are described The Means and Instruments of preparing ourselves, and others respectively, for a blessed Death: and the remedies against the evils and temptations proper to the state of Sicknesse.”200 Taylor’s book reflects on life’s brevity, cautions about temptations, addresses spiritual preparation and personal qualities to cultivate, and provides deathbed etiquette for family and friends. The purpose of this consolatory tradition of literature was to raise awareness about death and to provide guidance, under the premise that the more we know, the less we fear. Reverend Taylor wanted his congregation prepared, because no one knows when time is up.

**The Modern way of dying**

In contemporary times, we have mostly forgotten the spiritual aspects of dying and chosen to put faith in science. We suffer from a failure to anticipate and prepare for this universal experience. Fearing personal apocalypse, we demonstrate collective thantophobia (Greek origin: thanato (death), phobia (fear)), a dread triggered by the

198 Wyer, cover.
199 Blake, 547.
200 Taylor, 4.
existential realization that having been born, we will die. The disorder’s pervasiveness causes delusions, thinking that everything can be fixed and failing to recognize the point of diminishing returns for rescue and resuscitation medical care. The death sentences we live with will get carried out—with no stays, commutations, or reprieves—usually under the province of the health care system, no matter how plaintive the appeals or convincing the arguments. In our culture, dying is a health crisis, with the expectation that physicians will not only repair bodies but an assumption that they will also engage in essential Ars Moriendi responsibilities, such as hearing confessions, forgiving sins, reconciling families, performing absolution, and easing the path for dying well. When a need for these tasks arises, health care professionals will often request a chaplain visit, since most hospitals have pastoral care departments. However, thin staffing of chaplains (chaplain to patient ratios might be 800 to one), may limit the availability, time, and depth for spiritual care visits.

Without planning, an ICU often becomes the default, which will provide attentive care at a premium price of around $4000 per day, the most expensive holiday many people will ever experience. An ICU stay is all-inclusive, including room service bedside meals, clothing, and even personal hygiene. Itemized charges may apply for necessities like tubes for nutrition, hydration, elimination, and sometimes breathing. A patient will be maintained, probably sedated, and possibly restrained. Monetary costs may pale in the face of intangibles such as pain and suffering. An ICU represents a high tech / low touch episode or finale. Suffering can amplify the physical dimension of pain:

Spending one’s final days in an ICU because of terminal illness is for most people a kind of failure. You lie on a ventilator, your every organ shutting down, your

---

mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said good-bye or “It’s okay” or “I’m sorry” or “I love you.”

Family members may not realize what intubation means—a respirator blocking the mouth with sedative and paralytic drugs administered to counteract discomfort and tube-pulling—resulting in patients who can no longer speak. If we’re going to play God, we better get good at it.

Norms, idolatry, and cults

What do you worship? The Merriam-Webster Dictionary defines idolatry as “the worship of a physical object as a god” or “immoderate attachment or devotion to something.” Whether religious believers or not, people are invested in body devotion and care, endowing human physicality with a significance that extends beyond perishable flesh. A cult is a system of social control with specific beliefs, rites, and acolytes. One definition of cult pertains to medicine: “a system for the cure of disease based on dogma set forth by its promulgator.” Body worship has spawned a health care system with bodies deconstructed into constituent elements, defined hierarchies, and identified authority figures. We have bought into the medical system with blind faith committed to indiscriminate life extension, trusting in the system’s power to redeem from aging and dying. Cultural norms of ignorance, passivity, and complacency have bred dependency.

---

202 Gawande, 155.
203 Paraphrase of Stewart Brand, 1968 Whole Earth Catalog
204 https://www.merriam-webster.com/dictionary/idolatry
205 https://www.merriam-webster.com/dictionary/cult
Desire for prolonged life overrides agency and reason. In medicine, we hope (World without end. Amen.\textsuperscript{206}).

Peak–end rule

The ending is what counts. In his book, \textit{Thinking Fast and Slow}, Nobel-laureate Daniel Kahneman writes about human cognition, judgment errors, and biases. He labeled one idea as the “peak-end rule… [a] rating was well predicted by the average of the level of pain reported at the worst moment of the experience and at its end.”\textsuperscript{207} Kahneman found that memories are inaccurate; with humans tending to recall the highlights and how an experience ended. Kahneman describes two selves:

The \textsl{experiencing self} is the one that answers the question: “Does it hurt now?” The \textsl{remembering self} is the one that answers the question: “How was it, on the whole?” Memories are all we get to keep from our experience of living, and the only perspective we can adopt as we think about our lives is therefore that of the remembering self.\textsuperscript{208}

To the best of our knowledge in the aftermath of death, the deceased does not have capacity to reflect back on his/her dying. However, in anticipation of the end, many express fears about pain that cannot be relieved and suffering related to fear, separation, and uncertainty. Even if a person is unconscious, pain is detectable by observing grimaces or blood pressure fluctuations. However, experiences of extreme pain and how an episode ends can either soothe or traumatize those who accompany their loved one. Ensuring a death that is peaceful, dignified, and comfortable can have ramifications beyond the direct experiences of the patient.

\textsuperscript{206} Concluding line of “Glory Be to the Father,” Catholic prayer
\textsuperscript{207} Kahneman, 380.
\textsuperscript{208} Kahneman, 381.
On our own terms: now and at the hour of death

How does one go about dying? How can we foster awakening?
Who on earth is going to teach me —
The world is filled with people who have never died. Franz Wright — “On Earth”

The decline and cessation of the physical body becomes likely the longer we live, which Roger Angell referred to as “my approaching visitor, death.” At its root, the body’s decay and weakening generates an existential imperative, affecting physical state but also an unacknowledged spiritual ache. How can we create meaning as the end approaches? How can we override the cultural deny-delay-defer death taboo default and anticipate and decide how we want to die? A key to dying well is living well, at the root of which is determining the definition of fullness of life and discerning life’s purpose: “I was driven less by achievement than by trying to understand, in earnest: What makes human life meaningful?”

Facing the end can evoke a profound spiritual awakening of meaning and recognition of connections. Frankl reminds: “Man is not destroyed by suffering; he is destroyed by suffering without meaning,” while St. Irenaeus of Lyon (202 AD) claimed “The glory of God is the human being fully alive.”

What matters most? When people think about what makes life worth living, the love shared with others is likely to top the list. After meeting physiological and safety needs, humans seek connection and love. The primal urge of forging and strengthening human relationships contributes to a meaningful life. Facing the inevitable intentionally and thinking purposefully about end-of-life can ease emotional and administrative burdens. From professional experiences as a hospital chaplain and personal experiences

---

209 Angell, 8.
210 Kalanithi, 31.
with the deaths of my parents, my husband’s parents, and a brother, I realize that failing to address death’s certainty creates immediate chaos and a sense of unfinished business, lingering post-traumatic upheaval, and awareness of stories and important details forever lost. According to ethicist Daniel Sulmasy: “Each person must live and die according to the answer each gives to the question of whether life or death has meaning that transcends both life and death… The facilitation of a dying person’s grappling with this question is an act of healing.”\textsuperscript{211} Author Stephen Jenkinson says that life’s end should be “an important event, like being born or getting married. [Otherwise], we end without any ending. We are gone without any leaving.”\textsuperscript{212} He also suggests: “Don’t ‘put away’ dying for some future date but treat it as a ‘prized possession,’ because it’s the awareness of death…that allows us to live fully in the time we have. If we think there will always be more time down the road, we put off both our dreams and our obligations.”\textsuperscript{213} We know it is coming and yet ignore or deny the fact. Dr. Gawande writes:

Two-thirds of terminal cancer patients reported having had no discussion about their goals for end-of-life care, despite being, on average, just four months from death. But the third who did have discussions were far less likely to undergo CPR or be put on a vent or end up in an ICU. Most of them enrolled in hospice. They suffered less, were physically more capable, and were better able for a long period to interact with others. In addition, six months after these patients died, their family members were markedly less likely to experience persistent major depression. …People who had substantive discussions with their doctor about the end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish.\textsuperscript{214}

\textsuperscript{211} Sulmasy, 26.
\textsuperscript{212} Hoffner, 5.
\textsuperscript{213} Hoffner, 6.
\textsuperscript{214} Gawande, 177.
Whether those who are dying reconnect with or renew prior religious beliefs or seek new religious experiences, they are likely to engage in some form of spiritual searching.

Harvard professor Arthur Kleinman suggests:

> Those who are concerned with religion have inspired physicians not to turn away from patients’ questions about ultimate meaning, but to listen and show respect for their quest. I am not convinced there is a single best strategy or discipline. Yet, I do believe that what doctors need to be helped to master is the art of acknowledging and affirming the patient as a suffering human being; imagining alternative contexts and practices for responding to calamity; and conversing with and supporting patients in desperate situations where the emphasis is on what really matters to the patient and his or her intimates.  

One British general practitioner explains that the core principle of health care is “valuing their soul qualities—it’s impossible to practice appropriately without caring for the spirit.” Illness can deprive us of spiritual closure when end-of-life belongs to medical protocols, intensive care, or pretense that one more procedure or drug regimen will save and restore length and quality to our lives.

Developing a coherent life narrative can generate a legacy that captures meaning and outlasts bodies. Viktor Frankl questioned: “Doesn’t the final meaning of life, too, reveal itself, if at all, only at its end, on the verge of death? And doesn’t this final meaning, too, depend on whether or not the potential meaning of each single situation has been actualized to the best of the respective individual’s knowledge and belief?” At some point, each of us will cease to be. If we ignore or deny death as reality, we do not get the opportunity to pass on our legacy or write our stories. It does not have to be

---

216 Grant, 3.
217 When I asked a friend whose brother-in-law had been in the ICU for several weeks whether the doctors suggested hospice, she said he had been told by his doctor that it was too soon and he wanted to try one more drug. The patient died hours later.
218 Frankl, 168
lengthy because as journalist Tim Russert observed, “Someday your entire life will be summed up in twenty minutes.” Dr. Gawande elaborates with this understanding:

In the end, people don't view their life as merely the average of all its moments—which, after all, is mostly nothing much plus some sleep. For human beings, life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens. Measurements of people's minute-by-minute levels of pleasure and pain miss this fundamental aspect of human existence. A seemingly happy life may be empty. A seemingly difficult life may be devoted to a great cause. We have purposes larger than ourselves.  

What matters most? Most people value and prefer recalling moments, rather than a life atomized, based on metrics, such as vital signs.

Contemplative practices can connect us to inner peace and help cope with overwhelming emotions. Practices including mindfulness, breath work (like pranayama in yoga or Lamaze techniques for birthing pain), prayer, exploring generativity (Erik Erikson’s work), and legacy writing/storytelling exercises (such as ethical wills) can aid in connecting to resilience, compassion, and hope in challenging situations. If we believe “We are spiritual beings having a human experience,” we must counter the cultural default with the health care system transforming people into patients. While discernment is appropriate on an ongoing basis, especially at inflection points such as retirement or qualifying for Medicare, a life audit can reveal whether people are living fully, whatever that means for each individual, or whether they need a course correction. Fullness of life means different things to different people. For some, a life worth living may be working on bucket list adventures; others may prioritize a life of service; and others may find no greater joy than a regular tee times with golfing buddies. It behooves us to be cognizant

Gawande, 238.
that physical and mental abilities may wane, so we are only temporarily able. While some age more gracefully than others, the older a person gets brings a greater likelihood of debility and chronic illnesses. Living a fuller, more abundant life needs to be planned (including contingency ideas) and arranged before receiving a terminal diagnosis. Facing the reality of mortality allows time to ensure that relationships are renewed or restored using words of healing and emotional closure: *I forgive you; forgive me; I love you; thank you.*  

People must consider their legacies while reasonably healthy, energetic, and alert. Knowing that we will die gives a sense of urgency to how we live.

The concluding line of the prayer dedicated to assassinated Archbishop Oscar Romero reminds: “We are prophets of a future not our own.” The prophet paradox applies to humans. We know our lives will end and yet we don’t know how or when. Acting like we will be the exception to biological certainty and pretending that life will continue indefinitely unaffected by morbidity ignores the truth of mortality. Professor Stark suggests:

> Only by remaining continually aware that we could die at any moment, not simply that we are going to die at some point, will we create a life that is both singular—authentic to our own values because we have no time to waste on anyone else’s—and vivid, one that uses each second to the hilt because time is scarce.”

The key to a good death is living fully, which includes acknowledging human ephemerality but also entails broadening identity beyond the body.

Is death beneficent or maleficent? Does its approach fill you with curiosity or dread? In “When Death Comes,” poet Mary Oliver (1935 – 2019) speculates, “What is it going to be like, that cottage of darkness?” She anticipates and prepares: “When it’s over,

---

220 Byock,  
221 Sharp, 71.
I don’t want to wonder if I have made of my life something particular, and real. I don’t want to find myself sighing and frightened, or full of argument.” Or, full of panic, turmoil, and disbelief, which are perhaps more typical reactions to death than a sense of acceptance, peace, and completion. Despite knowing, we delay acting, assuming there will always be more opportunities or a better time to get affairs in order or pass on information that makes it easier for loved ones to cope in the aftermath of death. Many subscribe to Mark Twain’s advice: “Never put off till tomorrow what you can do the day after tomorrow.” Death catches many people off guard, when they have not undertaken discussions that might have helped explore values, weigh options, and choose a different path.

People hope for a death without suffering, for a death with dignity that will not imperil or impoverish the family. Susan Spencer-Wendel (1966-2014) mused about her journey: “I do not think my death will ruin my family’s lives. But I realize the way I die may affect their ability to live with delight. To live with joy.” Just like we may not be able to benefit directly or immediately from planting a tree, we can imagine its value to those we love and for future generations. We can prepare survivors for life without us, so repercussions from death do not traumatize survivors.

Expecting the expected

Based on scans and test results, your doctor indicates that you are about to earn your finisher’s medal. You will complete the race no one wants to run, let alone win, because when we win, we lose. Along the way, you may stay in an expensive medical

---

222 Spencer-Wendel, 15.
bed and breakfast at a rack rate that you never would have considered paying, even on your honeymoon. There is no guarantee of a private room, but some amenities are included. The staff will be attentive to your every need, which may also include interruptions at all hours of the day or night for vital signs, blood draws, or excursions to radiology. They mean well; staff (and your insurance company) really want you to heal and leave. Unfortunately, you are probably unable to enjoy the experience. If you happen to be conscious, fear is as rational a response as any at this point.

Not everyone will give birth, but everyone who lives will die. If protocols around childbirth can change, then there is hope for life’s terminus, especially given the critical mass of Baby Boomers who are now facing that life transition. Let us act before emergency forces our hand. We need to plan before circumstances demand action, reacting to a crisis instead of responding based on values. Morrie Schwartz, immortalized in Tuesdays with Morrie reflected: “Now that I’m dying, I’ve become more interesting to people…. Here’s the thing. People see me as a bridge. I’m not as alive as I used to be, but I’m not dead yet. I’m sort of…in between. I’m on the last great journey here—and people want me to tell them what to pack.”223 That same curiosity, activism, and energy that led to revised childbirth protocols is poised to alter the “birth in reverse” phase of life. Changes will benefit not only individuals, but society. The default approach is unsustainable. Our country lacks resources to accommodate a medicalized model of aging for the large cohort facing end-of-life in coming decades. Professor Andrew Stark suggests that embracing mortality has certain advantages, including motivating us to act:

For existentialists, death and the self are joined at the hip. Because only if we remain constantly aware that our time is limited will we feel any urgency to get

---

223 Quoted in Holland, 257.
started in the world, make hard choices about what’s important to us, and carve out the narrative arc of our own singular self. If by contrast no final deadline loomed, then we would endlessly dally and dawdle, failing to make anything of ourselves—or even make ourselves in the first place. If we think about it deeply enough, we will see that mortality is thus a good thing. It’s necessary to our very existence. Only because death exists does our self exist too.224

At one time, we knew how to accompany others as death neared. Now, we leave this stage to chance. Prepared or not, the transition through death will happen, when the incarnation vacation ends and the body expires. By expecting the expected, we can anticipate the need and revitalize a rite that supports loved ones as they die, which in turn functions as a dress rehearsal for our eventual demise.

How we want to die

While “80% of Americans would prefer to die at home,” in reality, “60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.”225 Most would not consider this a good outcome. Additionally, an ICU death or one with aggressive interventions may predispose loved ones for post-mortem post-traumatic stress. A 2008 JAMA study found that “more aggressive medical care was associated with worse patient quality of life…and higher risk of major depressive disorder in bereaved caregivers”226 Patients on the med-tech conveyor may experience loss of identity, not unlike Dr. Mukherjee’s recounting of concentration camp imprisonment:

Among the most fatal qualities of the camp was its ability to erase the idea of a life outside and beyond itself. A person’s past and his present were annihilated as

224 Stark, 3.
225 Dying Well final lecture, slide 14 https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/ Probably close to 100% would prefer to skip dying all together...
a matter of course—to be in the camps was to abnegate history, identity, and personality—but it was the erasure of the future that was the most chilling. With that annihilation came a moral and spiritual death that perpetuated the status quo of imprisonment.\textsuperscript{227}

Is death the worst thing? Do physicians have a moral responsibility to weigh “saving” a life, but substituting suffering and dependency? After visiting a long-term care facility for brain injured patients, Dr. Kalanithi’s mentor concluded: “Sometimes, you know, I think it’s better if they die.”\textsuperscript{228} Pretending there is no outer limit to physical survival has ramifications beyond a patient’s well-being. Patients fear prognosis, treatment, and what’s next, but evasion or deceit from medical professionals and caregivers has a cascading effect on families, finances, and future.

Natural death

Generally, a natural birth involves no drugs or surgery, although expectant parents realize that an emergency may interfere with their hopes and plans. Access to technology has altered the determination of death and led to different religions weighing in on moral approaches to death.\textsuperscript{229} The Roman Catholic Church believes life has inherent dignity, and therefore maintains that human life be protected until natural death occurs, a “consistent life ethic” philosophy. There seems to be a mismatch between expectations and reality. Individual experiences may vary, but the dying process has certain consistencies. As the end-of-life nears, a person may withdraw emotionally, sleep more, and decrease eating and drinking. A friend explained how her mother who has dementia

\textsuperscript{228} Kalanithi, 38.
\textsuperscript{229} https://www.deathwithdignity.org/learn/religion-spirituality/
was refusing to eat with the family considering whether to initiate tube feeding. The body seems to know when the end is approaching, even if someone has minimal cognition. Natural death does not mean forsaking pain medicine and hospital admissions. Suffering can arise from psychological, emotional, or spiritual issues, such as anticipation of pain and clock-watching or begging for analgesic medication. Under-treatment of physical pain can threaten integrity of the self. It is the responsibility of care providers and families to ensure a balance between over-medicalized, prolonged dying and appropriate application of knowledge and inventions to repair sick and injured bodies.

Many people fail to understand or have forgotten what “natural death” entails:

The idea of letting nature take its course has fallen by the wayside from both the medical and technological perspectives. Most deaths now happen in institutions, and most are as the result of a decision—antibiotics refused, respirators turned off, feed tubes clamped.

A life in pursuit of noble purpose differs from an existence without cognition and awareness, but a person must choose the path they prefer while they still have capacity to act.

“Good” dying

The determination of “good” dying should arise from the perspective of the person whose life is ending. UCLA Professor Emeritus Edwin Shneidman explores elements of dying well: “A good death is one that is appropriate for that person…. The death fits the person.” His criteria for a good death speak more to completion and wholeness than the physical aspects of the dying experience; a stance which relates to the

---

230 Patients and prisoners are the only categories of individuals who can be involuntarily force-fed.
231 Fitzpatrick, Xii.
232 Shneidman, 246.
remembering self\textsuperscript{233} and the legacy left behind. Shneidman’s Golden Rule for dying anticipates how the death experience will affect those who bear witness and possibly suffer repercussions from the experience:

Do unto others as little as possible. By which I mean that the dying person consciously try to arrange that his or her death—given the inescapable sadness of the loss-to-be—be as little pain as humanly possible to the survivors. [Also] die in a manner so that the reviews of your death speak to your better self.\textsuperscript{234}

By taking time to prepare, each individual can set priorities based on the criteria for good death or add elements that are important to them. As life winds down, the patient establishes priorities, whether easing pain, reducing suffering, ensuring dignity, or establishing a serene setting. Possibilities listed in Shneidman’s chart in Figure 8 help distinguish what you anticipate will be important as end-of-life approaches, whether comfort, pain control, respect, and dignity.

\textit{Ten Criteria for a Good Death}

<table>
<thead>
<tr>
<th>NATURAL</th>
<th>Accepted</th>
</tr>
</thead>
<tbody>
<tr>
<td>A natural death, rather than accident, suicide, or homicide</td>
<td>Willing the obligatory; gracefully accepting the inevitable</td>
</tr>
<tr>
<td>MATURE</td>
<td>Civilized</td>
</tr>
<tr>
<td>After age 70; elderly yet lucid and experienced</td>
<td>Attended by loved ones; with flowers, pictures, and music for the dying scene</td>
</tr>
<tr>
<td>EXPECTED</td>
<td>Generative</td>
</tr>
<tr>
<td>Neither sudden nor unexpected; some decent warning</td>
<td>To have passed the wisdom of the tribe to younger generations</td>
</tr>
<tr>
<td>HONORABLE</td>
<td>Rueful</td>
</tr>
<tr>
<td>Emphasis on the honorifics; a positive obituary</td>
<td>To experience the contemplative emotions of sadness and regret without collapse</td>
</tr>
<tr>
<td>PREPARED</td>
<td>Peaceable</td>
</tr>
<tr>
<td>A living trust; prearranged funeral; some unfinished tasks to be done</td>
<td>With amicability and love; freedom from physical pain</td>
</tr>
</tbody>
</table>

Figure 8: Shneidman’s ten criteria for a good death\textsuperscript{235}

\textsuperscript{233} Kahneman
\textsuperscript{234} Shneidman, 246.
\textsuperscript{235} Shneidman, 246.
Dignity is a word often used in end-of-life discussions without being defined. A law dictionary describes dignity as a “sense of self-respect and self-worth, physical and psychological integrity and empowerment.”\(^{236}\) Dignity relates to the meaning of life consistent with values, choices, and relationships and is also wrapped up with ethical principles, such as respect for autonomy, including informed consent. A Canadian Court declared, “An individual’s response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy and maintained that denying physician-assisted death to seriously and irremediably ill people removed a choice ‘that may be very important to their sense of dignity and personal integrity [and that is] consistent with their lifelong values and that reflects their life’s experiences.’”\(^{237}\) Is dignity an inherent, integral aspect of personhood? Does cognition have a role in dignity? Individuals need to consider and make their own determination about if and whether dignity is important and what that means to them, while they can.

Euthanasia derives from Greek origin (eu ‘well’ + Thanatos ‘death’) and means good death. Given the alternative, most would prefer an easy death. Unfortunately, the word euthanasia has been hijacked; and like verbiage such as gay or bitch, it has assumed an altered meaning. The corrupted interpretation involves the practice of “permitting the death of hopelessly sick or injured individuals…in a relatively painless way for reasons of mercy,” \(^{238}\)\(^{239}\) which is illegal in most states. Physician-assisted death (PAD), which is sometimes called Death with Dignity or Aid-In-Dying (AID) allows a doctor to prescribe


\(^{238}\) [https://www.merriam-webster.com/dictionary/euthanasia](https://www.merriam-webster.com/dictionary/euthanasia)

\(^{239}\) Sound bite: “Killing Grandma.” Painless and merciful personally sound good to me.
medications at the request of a suffering patient. A patient, who qualifies based on strict criteria, acquires a lethal dose, which s/he can opt to consume in order to hasten the inevitable end. While palliative care and pain relief should be standards of care to treat end-of-life suffering, some patients gain comfort from having autonomy honored, even if they ultimately choose not to take the drugs. States that currently permit physician-assisted death include Oregon (first state to legalize in 1995), Washington, Vermont, California, Colorado, and Hawaii, as well as Washington, D.C.

Thirteenth century Roman Catholic priest and saint Thomas Aquinas formulated the principle of double effect (PDE), which allows for administration of narcotics to relieve pain, knowing that it may depress respiration with the unintended effect of hastening death. Physician-assisted dying differs from the principle of double effect (which may be more a matter of semantics). The Supreme Court clarified and affirmed the legality of PDE with a proviso “If the intention is the relief of suffering or to help breathing, even if it increases the possibility of hastening an inevitable death.”

Religions that forbid the practice of PAD allow PDE, understanding that pain relief outweighs shortened life. Intent is everything.

Hospice

Created in 1967 in London, hospice offers a holistic model for dying. Developed with the intention of providing a sacred space for end-of-life, it focuses primarily on caring, rather than curing. While lecturing at Yale, founder of the first modern hospice Dame Cicely Saunders introduced the idea of dedicated care for the dying in the United

240 https://www.thehastingscenter.org/briefingbook/physician-assisted-death/
241 Tisdale, 135.
States. Her talk inspired the launch of the first US Hospice in Connecticut in 1974. Hospice uses an interdisciplinary model that helps with physical pain and symptom management, as well as providing emotional and spiritual support tailored to the patient's needs and wishes. Hospice provides a contemporary update to the *Art of Dying*, offering guidance and protocols for a good death.

We are all terminal, but terminally ill is a phrase that conveys special legal and medical meaning. When considering the appropriateness of hospice, a doctor deliberates on whether it would be surprising if this patient might die within one year. If the conclusion is that death is a strong possibility, hospice is an appropriate option. Doctors and patients must concur that the illness is terminal and there are no more curative treatments. Many doctors seem reluctant to broach the idea of hospice, even when life expectancy is measured in days or weeks, leaving families to initiate a request for palliative care or referral to hospice. Because of hesitancy about broaching this fraught subject, enrollment may be delayed, limiting access to the gamut of resources. Some think that admission to hospice is an admission of failure—death wins. That mindset disregards death’s role as a universal outcome no matter how many life-“saving” interventions.

Currently, Medicare pays for hospice with the proviso that a physician certify that a patient is terminally ill with six months or less to live, a challenging calculation given uncertainties about prognosis, especially with non-cancer ailments. Unlike pregnancy tests, there is no definitive test for dying. As one doctor pointed out: “People are not like Butterball turkeys. There’s no indicator in their chests that pops out when they are
done.” Hospice can be extended as long as a patient is eligible, which means continued decline. For instance, Terri Schiavo resided at Woodside Hospice in Florida for a number of years, while loved ones and politicians battled over her potential for recovery. The paradox of hospice is that sometimes patients improve after curative treatments are discontinued. If they no longer meet the six-month prognosis criteria, certain patients disenroll. Although hospice offers a comprehensive approach to dying, it tends to be underutilized or employed late in the dying process. When a person is on the cusp of dying, the disease process interferes with patients taking full advantage of hospice services, including ministry to loved ones during the bereavement phase.

Conclusion: death as true north

Steve Jobs’ reported last words: “Oh wow. Oh wow. Oh wow.”

Despite the prevalence of medical care, death is a no-expert zone. The focus on treatment makes the do-it-yourself approach to dying harder than it needs to be. Understandably, a person facing death has no special proficiency, but surprisingly many medical practitioners often lack skills due to a singular focus on life extension / death prevention. No one returns from the dead to mark the path, provide lessons learned, and ease the way for the rest of us when it is our turn. Despite the paucity of self-help literature and a general distaste for the topic, death has value. When choices flow from understanding that time is finite, it helps to orient and clarify life’s path. When you imagine the moment of death approaching, do you picture being surrounded by strangers

242 Hardwig, 7.
243 Palliative care is an integrated approach to complex medical care that doesn’t require the six month terminal prognosis.
with a crash cart, performing chest compressions, and unsuccessfully shocking your heart back to rhythm; or are you hoping for serene space with loved ones comforting you and one another, holding hands, and expressing love? How much privacy, modesty, and dignity are you willing to forfeit for the possibility of life extension? What level of pain and suffering would you choose to endure, whether due to the nature of rescue medicine or as penance for sins committed in hopes of gaining entry to paradise?

Awareness of impermanence and the finitude of healthy days can be pearls of great price. As earthly time winds down, different people will have varying priorities, but we will only get one chance to write that ending. To fulfill destiny, one must plan and act. Living life to the fullest means being prepared for it to end. In a bedtime prayer, children recite: “If I should die before I wake, I pray to God my soul to take.” While attending to patients and families during the dying process, I’ve wondered if some of the anxiety and reluctance stemmed from a sense of incompleteness: relationships unhealed, things undone, loveliness unappreciated. Our prayer should be to wake before eternal sleep: *If I should live for other days, I pray that awe guides my way.* May we learn how to make a life, not just a living, and add life to years, not just years to life.  

---

244 Henry Johnstone prayer  
245 Paraphrase from Jeff Dickson’s ‘Paradox of Our Time’
Chapter 6.
Completion: Journey into mystery

“Teach us to number our days that we may gain a heart of wisdom.”

After prayers for the young man in the ICU, devastated family and friends shuffled out, having chosen not to witness the final steps. Trauma that brought him to the hospital was unfixable; medical science failed to restore functioning and prevent the inevitable. The nurse removed the ventilator, disconnecting the apparatus that had breathed into the physical vessel. Holding the patient’s hand as the nurse switched off the dials and withdrew the tube, I watched his face and prayed for the repose of his soul. With the machines off, his chest stilled. There was not even a residual gasp; the brain injury had completely interrupted the body’s impulses to pump and breathe. Color drained from his cheeks and temperature cooled with the stopping of mechanical “life” force. With monitor alarms silenced, the nurse charted the time of death for posterity. Spirit had returned to mystery, leaving behind a souvenir of incarnation.

We operate under a death sentence with a no money-back guarantee and no warranties on broken parts. At birth, everyone receives a one-way ticket, clueless about the length of the journey or adventures to be experienced along the way. Medical science can keep bodies alive longer than the people who inhabit them. Death comes, bringing conclusion, although not necessarily completion. We know how the story ends, and if we take advantage, we can draft the closing chapter, taking the opportunity to reflect on what

246 Psalm 90:12
matters most, summarize legacy, reconcile relationships, ask for forgiveness, say thanks, and express love. In our ignorance, we perceive mortal life as total reality without considering whether this might be a vacation from eternity, a corporeal time share. As temporary visitors, not owners, perhaps we are just passing through time and space to learn lessons, bring light to the world, and make a difference. Each of us arrives pregnant with death, with an unknown gestational period that unspools to a common terminus. The countdown started at birth and the Time Remaining (TR) number gets smaller each day. Our soul remembers that time is limited, an awareness we usually try to conceal given that “Our birth is but a sleep and a forgetting.” We manage to fool ourselves: death is a covert enemy, representing the foregone conclusion, demonic impermanence. Hope tempts, promising that with sufficient resources and scientific breakthroughs, we can eliminate our terminal outcome.

What if? Could we subscribe to the notion that humans are psycho-social-spiritual beings who happen to inhabit bodies? While bodies get the most attention, physical form is also the most vulnerable. A lack of consideration and preparation contributes to the prevailing medical model that dictates the path to death with a singular focus on keeping the body operating. Death serves as a reminder of our common humanity and fate. No matter how much wealth, power, or fame accumulated during mortal lives, those will all disappear, and bodies will disintegrate. Each person will cross the threshold into eternity, “going in search of a great perhaps,” as sixteenth-century physician Francois Rabelais purported. No GPS or app provides an optimal route or warns of potholes on the journey,

247 William Wordsworth, “Ode on Intimations of Immortality”
or even confirms that destination exists. Afterlife is a possibility, though the precipitating
event is certainty.

Whether death is a medical event or a spiritual experience depends on planning
and preparation. If someone desires serenity and dignity, with control over the setting and
treatments, those decisions must be made while conscious and competent. Otherwise, the
status quo health care system consumes patients, sweeping up the sick, frail, and injured,
and taking charge. To choose differently requires opting-out, with Advance Directives
completed and retrievable and with a health care agent who knows your wishes.

Eventually, everyone activates their “kingdom of the sick” visa, as Susan Sontag
described humanity’s dual citizenship.248 We don’t know how our world ends, only that it
will, with birth and death bookending the trip called life. Along the passage, people are
vulnerable to sickness and injury and grateful for medicine as a bridge back to health
with its ability to diagnose disease, treat illness, manage symptoms, and fix wounds.

Ultimately, there is no saving life; life will end although medicine may postpone that
eventuality. However much we try to repress, dismiss, or deny the specter of terminality,
our common fate finds us, distinguished only by cause and date. Living fully and dying
well require dropping the pretense and facing facts, exploring protocols, and preparing
before receiving a fatal diagnosis accompanied by debilitating symptoms.

Healthcare expenditures do not necessarily translate to increased well-being. Most
people want long and healthy lives with limited pain and suffering, but also acceptance
for their essential being rather than categorization as patient or pathology. To accomplish
this, we need to discern desires before calamity strikes. The technological siren song may

248 Sontag, 3.
lure dying patients to search for miracles that prolong without guaranteeing survival. Doctors worship at the same altar in an effort to maintain vital signs and preserve “life,” taking steps which unfortunately may result in prolonging dying. The healthcare system rewards heroic efforts, and not doing everything is viewed with suspicion. It’s time to shift the paradigm by accepting the reality of death—memento mori—and rooting out the intemperate, delusional optimism for immortality.

British writer GK Chesterton mused: “I don’t deny that there should be priests to remind men that they will one day die. I only say it is necessary to have another kind of priests, called poets, actually to remind men that they are not dead yet.” The current approach to life’s twilight fails to recognize that death is more than biological cessation. There is a need to anticipate end-of-life and transform the process to make dying more spiritual, less medical. Psychiatrist Elisabeth Kübler-Ross opened the door to discussions of death and dying with the development of a model that presents the emotional states experienced by patients after a terminal diagnosis. Based on her research and captured in a 1969 book On Death and Dying, Kubler-Ross postulated that dying patients encounter five stages including denial, anger, bargaining, depression and acceptance. Kubler-Ross helped popularize the subject of death and dying, which previously had rarely been part of medical school curriculum. Recent books on dying written by physicians recognize that the end-of-life system is broken, but embedded as they are in the crisis-oriented, life prolonging healthcare system, it is hard for them to jump off the speeding train. Even professional medical training seems insufficient for clarity on treatment choices and deciding when enough is enough. The time to consider dying and death is not during admission to an ER or ICU or after receiving a terminal diagnosis. When the reaper
knocks, no matter at what age, the clarion will startle and provoke fear, generating an immediate focus on cure and symptom management for side effects like pain, nausea, sleepiness, and confusion. That is how we are pre-disposed. But when cure options dwindle, hopefully someone will guide you to what matters most: meaningful interactions with loved ones and a life review that reminds of the wonders of a life lived fully. The thesis *Awakening to Mortality* urges us to consider dying as metamorphosis, not catastrophe. As writer and activist Barbara Ehrenreich surmised, “For those of us, which is probably most of us, who...have caught glimpses of this animate universe, death is not a terrifying leap into the abyss, but more like an embrace of ongoing life.”\(^ {249}\)

Diagnosis and prognosis are uncertain and dynamic: a matter of cause and effect. If we live, then we will die. After age 65, there are predictable, somewhat limited ways that people die. If people complete Advanced Directives and have them available, they can extend autonomy even in states of unconsciousness or incompetence. Someone who fails to declare treatment preferences will condemn loved ones to uncertainty, legal and administrative tangles, and potential bankruptcy. Even if someone believes death is the end, failing to plan creates an afterlife for survivors—hell compounded by bereavement. The course of diseases and the aging process have predictable elements, although individual realities vary and may diverge from expectations or statistics. The bottom line: “we can run but we can’t hide.” We must face the realities that humans have a *deadline* and all *saves* are temporary. Despite access to care and providers’ skills, ultimately, death manifests. While this outcome remains fixed, there are ways to ensure peace and dignity and minimize suffering. With grace, may we seek “serenity to accept the things we

\(^ {249}\) Ehrenreich, 208.
cannot change, the courage to change the things we can, and the wisdom to know the
difference.”  

Some expectations are deeply embedded in our cultural narrative. Enacting
changes requires making the physician/patient relationship a partnership with shared
decision-making and returning technology to its rightful role as servant instead of master.
Just because we can do something, doesn’t mean we should: “As people’s capacities
wane, whether through age or ill health, making their lives better often requires curbing
our purely medical imperatives—resisting the urge to fiddle and fix and control.”  
There is an “undiscovered country beyond death from which no one has ever
returned.” In anticipating this uncharted territory, a sense of perspective matters. We
can hope for healing even when a cure is impossible remembering that “At the end-of-
life, the only healing possible may be spiritual.” Death gets closer every day. We can
choose to face and accept, or ignore and “rage against the dying.” Ultimately, our
spark fades, but we have the “ability to generate a new cultural inheritance.”

Between those who believe that dying is a doorway to eternal life and others who
think death is the end lies common ground: agreement that death is “a subject on which
nothing final can be known.” We are members of a club few acknowledge and nobody
wants to be part of, a mortal race. So, let us live a life of purpose, prepare for the end, and
ensure that the things that matter most prevail over a system’s protocols or someone

250 Serenity Prayer
251 Gawande, 49.
252 Liu, 45.
253 Sulmasy, 31
254 Dylan Thomas. “Do not go gentle into that good night.” https://www.poets.org/poetsorg/poem/do-not-
go-gentle-good-night
255 Miller, 65.
256 John Stuart Mill, quoted Educated 259
else’s agenda. We can live fully, deeply, and humbly knowing: “Even if we lived forever, we could still do it wrong.”257 Life begets death. In the end, moments will have mattered more than metrics.

Epilogue: A prescription

Choice or chance? Can we take action or will we be forced to change? Are you willing to commit to taking steps to improve and advocate for intentional end-of-life experiences for yourself and loved ones?

- Awaken to the journey. Be grateful for the gift of time. Celebrate, if you happen to win the genetic and social lottery.258 “Don't cry because it's over. Smile because it happened.”259
- Face impermanence. Loss is the price we pay for living. Balance carpe diem with set it and forget it plans for eventualities.
- Examine your core values. What makes you feel alive?260 What does your religion actually teach about end-of-life?261
- Consider your legacy. Invest in growth: health, connections, and education.
- Fix the roof while the sun is shining. There may not be a cloud on the horizon, but life can change in a blink. Be prepared. Plan for contingencies. “Life is what happens to you while you're busy making other plans.”262
- Carry an ICE-card (in case of emergency) indicating your next of kin. If you live alone or with a companion animal, who would be alerted and have access to your home in an emergency?

257 Kagan, 304.
258 The bonus years after 65 herald a passage into elderhood with release from the tyranny of schedules and having time, health, and money. Post-65 lottery: eligible for a federal Social Security pension, and qualify for health care under Medicare. Longevity, health care, and income comprise a trifecta of opportunity. Few routinely celebrate winning this genetic and social lottery.
259 Dr. Seuss
260 Do you favor quality or quantity of life, vitality or vital signs Do you believe pain and suffering are penitential and necessary for attaining the afterlife?
261 http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/
https://www.deathwithdignity.org/learn/religion-spirituality/
262 John Lennon, “Beautiful Boy.”
• Consider who you trust with your life. Most Advance Directives are vaguely written. Your surrogate, whether identified by you or by law, will decide. Talk to that person about your values and desires.

• Make peace. You never know when a kiss will be the last. If you love someone and/or someone loves you, prepare for death realistically, practically, and emotionally. Imagine it as a love letter that shows you care.

• Advocate for social change. Applying for and accepting government benefits\textsuperscript{263} should incur personal responsibilities as a matter of justice and common good.

• Insist that the government designate a retrievable repository for AD forms. Forms should be available accessible at the moment of need.

• Let go. Go forth to love and to serve. “Be ignited, or be gone.”\textsuperscript{264} Remember that “Unless a kernel of wheat falls to the ground and dies, it remains only a single seed. But if it dies, it produces much fruit.”\textsuperscript{265}

\textsuperscript{263} When a person interacts with the government (initiating or renewing driver’s license, enlisting in the military, or signing up for Social Security / Medicare), have them identify a proxy and complete Advance Directives as part of the registration process (similar to indicating organ donation preferences).

\textsuperscript{264} Mary Oliver, “What I Have Learned So Far”

\textsuperscript{265} JOHN 12:24
**Blessing**

We are all great rivers flowing to their end.  
Swirling inside us is the silt of ages and creatures and lands  
and rain that has fallen for millions of years.  
All this makes us cloudy with mud,  
unable to see God.  
As we struggle for clarity and the open sky,  
the Lord keeps saying the same thing:  
Come to me now and be blessed,  
Come. Hafiz (1320 - 1389)
LEARNING FROM TREES

If we could,
like the trees,
practice dying,
do it every year
just as something we do—
like going on vacation
or celebrating birthdays,
it would become
as easy a part of us
as our hair or clothing.

Someone would show us how
to lie down and fade away
as if in deepest meditation,
and we would learn
about the fine dark emptiness,
both knowing it and not knowing it,
and coming back would be irrelevant.

Whatever it is the trees know
when they stand undone,
surprisingly intricate,
we need to know also
so we can allow
that last thing
to happen to us
as if it were only
any ordinary thing,

leaves and lives
falling away,
the spirit, complex,
waiting in the fine darkness
to learn which way
it will go.
Appendix 1.
Key terms: an end-of-life glossary

What would you want done or not done, and who would you want making decisions on your behalf in the event of a medical emergency? Advance planning is the process of considering types of treatment and care that a person might desire when facing a situation of limited decision-making capacity or inability to express preferences. These documents create a record of wishes, values, and choices to ensure a patient receives appropriate care based on needs and preferences. Advance planning anticipates and assesses potential clinical benefits, burdens, and risks, but also considers factors such as the patient’s personal circumstances, beliefs, and values. Without written proof of wishes, legal battles may erupt between family members as happened in the cases of Schiavo, Cruzan, and Quinlan.

**Advance Directives (AD):** legal documents regulated by each state. 1. A **living will** instructs about a person’s wishes for particular types of medical treatment. 2. A **health care power of attorney** identifies a person (also called surrogate, agent, or proxy) who can make decisions on behalf of another in the event of serious illness, incapacity, or inability to communicate. Using the principle of substituted judgment, doctors and family members try to make the decision that the patient would have made if he or she were able to speak and decide. If no document is prepared or can be found, the state will identify who is authorized to make decisions. Advanced directives augment other legal documents such as wills or power of attorneys, which deal with property and financial affairs. Completion of Advance Directives is voluntary, but ALL adults should prepare and update these forms. [An issue with AD is whether medical personnel will have access to them when needed.]

**Allow Natural Death (AND):** a patient or proxy directs a doctor to withhold or withdraw life sustaining treatment in cases of terminal illness or permanent unconsciousness. It

---

266 Key terms compilation based on chaplaincy experiences and consulting these sources:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2772257/
https://www.americanbar.org/content/dam/aba/publications/probate_property_magazine/v15/05/2001_abappte_pp_v15_5_article_williams_end_of_life_care_organ_donation_decisions.authcheckdam.pdf
https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf
https://organdonor.gov/about.html
http://polst.org/about/polst-and-advance-directives/
generally means no CPR or ventilator, but may also include refusing tube feeding and antibiotics in order to “Let nature run its course.” The underlying disease process is responsible for death; the interventions were prolonging dying. [The current US system defaults towards technological interventions. Natural death requires forethought, pre-planning, and documentation. Dignity and comfort have to be prearranged.]

**Artificial nutrition and hydration (tube feeding):** a clinical intervention for a patient who is unable to eat or drink through the mouth. Delivery methods to provide nutrients and fluids may include intravenous infusion of fluids (needle inserted in vein), a tube threaded into the nose for nasogastric feeding, or a surgically implanted PEG (percutaneous endoscopic gastrostomy). TPN (Total parenteral nutrition) is another term for a type of intravenous feeding.

**Brain death:** irreversible loss of all brain functions. When the brain dies, the person is considered dead. There is a specific methodology for clinical assessment and confirmation before a brain death diagnosis is made. Brain death differs from persistent vegetative state, in which some autonomic functions remain.

**Capacity:** the insight and ability to understand a medical problem, comprehend the benefits and risks of treatment options, and to make decisions. An adult is assumed to have capacity unless it becomes clear that he/she cannot understand or evaluate information needed to decide or communicate wishes. Capacity differs from competency, which is a court–rendered legal determination.

**Cardiopulmonary Resuscitation (CPR):** a medical procedure done on a person whose heart has stopped (cardiac arrest) or who has stopped breathing (respiratory arrest). It includes chest compressions and artificial ventilation. The patient may also receive electric shocks (defibrillation) and drugs

**Code:** cardiac or respiratory arrest, when an individual stops breathing or his/her heart stops beating.

**Competence:** mental ability of a patient to participate in decision-making and be responsible for actions

**Do-Not-Resuscitate/Do Not Intubate (DNR/DNI):** DNR and DNI are a doctor’s written medical orders instructing the healthcare team not to attempt cardiopulmonary resuscitation (CPR) when the heart or breathing stops or to insert a tube to support breathing. The DNR/DNI is requested by a patient or family and must be ordered by a doctor to be valid. DNR may also be called a Comfort Care Order (CCO).

**Double effect:** an ethical understanding that trying to relieve patient suffering through sedation may include the possible risk of depressing respiration and hastening death.
**End-of-life (EOL), Terminal:** patients approach the end-of-life when a doctor determines a person is likely to die within six months. This may include patients who have progressive incurable conditions like cancer or Alzheimer’s; those with general frailty and co-existing conditions that mean they are expected to die; or those at risk of dying from a sudden acute crisis because of a pre-existing, life-threatening condition.

**Healthcare agent, medical surrogate:** the person named in an advance directive or set by state law to make healthcare decisions for a person who is no longer able to make medical decisions for him/her self.

**Health Insurance Portability and Accountability Act of 1996 (HIPAA):** legislation that safeguards medical information data privacy.\(^{267}\)

**Hospice:** care for terminally ill patients whose doctors have diagnosed six months of life remaining. Goals of care change from cure to comfort. This holistic approach combines medical care with pain management and emotional and spiritual support. Depending on location, care is provided in the patient’s home (which may include a nursing home or assisted living facility) or a stand-alone inpatient hospice center. Medicare, Medicaid, and most private insurances cover hospice benefits.

**In Case of Emergency (ICE):** a document which provides emergency responders and hospital staff with the names and contact information for next-of-kin (NOK) contacts in case of medical emergency. It should also include a list of pre-existing conditions (like diabetes, hypertension, etc.) and a current list of medications. Some people setup an ICE contact in their phone, but if the device is password protected or breaks in an accident, the information is inaccessible.

**Intubation:** insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to help the patient breathe. See ventilator.

**Life support:** life-sustaining medical procedures that replace or support bodily functions. These may include CPR, breathing or feeding tubes, IVs, dialysis, or other treatments.

**Living will:** form of advance directive in which a person indicates preferences about medical treatment if he or she is unable to communicate. It may also be called a “directive to physicians,” “healthcare declaration,” or “medical directive.” This is usually paired with a Medical Power of Attorney.

**Medical Power of Attorney:** document that names someone for medical care decision-making in the event of incapacity. This form of advance directive also goes by the terms healthcare proxy, durable power of attorney for healthcare, or appointment of a

healthcare agent. The person named may be called a healthcare agent, surrogate, attorney-in-fact, or proxy. See Advance Directives.

**Natural death:** generally, an accidental occurrence in the US.

**Next-of-kin (NOK):** a person's closest living blood relative or relatives. If a person has no documentation, each state has a defined priority for determination of NOK. Medical surrogate decision making laws allow a person to make decisions about medical treatments for a patient who is unable to make their own decisions and did not prepare an advance directive.

**Organ donation:** providing an organ, eye, or tissue for the purpose of transplantation into another person. Donors can be living or dead. All major religions approve of organ and tissue donation. If a person or NOK agrees, doctors determine at the time of death who is eligible to donate what organs or tissues.

**Palliative care:** holistic care of patients focused on managing pain as well as providing psychological, social, and spiritual support to patients and their family. Palliative care does not require a terminal diagnosis or life-limiting prognosis. The goal of palliative care is to provide the best quality of life available to the patient by relieving suffering and controlling pain and symptoms such as nausea, shortness of breath, anorexia, and fatigue.

**Power of Attorney:** legal document allowing one person to act in a legal matter on another’s behalf about financial or real estate business.

**Persistent vegetative state (PVS):** diagnosis when a patient has suffered brain trauma deemed irreversible, which is characterized by lack of consciousness and thought, is unresponsive to psychological and physical stimuli, and displays no sign of higher brain function. The person is kept alive only by medical intervention. Some reflex activities, such as breathing, blinking, or movements, may continue.

**Physician Order for Life-Sustaining Treatment (POLST):** medical orders that detail specific medical treatments for individuals with a serious illness or advanced frailty near the end-of-life. POLST is a set of medical order whereas an Advance Directive provides general instructions from a person.

**Patient Self-Determination Act (PSDA), 1990:** most health care institutions (but not individual doctors) give patients a written summary of health care decision-making rights and the facility's policies regarding advance directives. It is the patient’s responsibility to ensure your care team has a copy of the advance directive.

**Ventilator, Respirator, Tracheotomy, AKA Vent or Trach:** mechanical ventilator that forces air into the lungs through a tube that is inserted into the nose, mouth, or throat. The machine keeps oxygen moving through the patient’s lungs. Because of discomfort, an
intubated person requires sedation. If prolonged airway access is needed, doctors may perform a tracheostomy by cutting a hole in the throat to insert the breathing tube.

**Voluntarily stopping eating and drinking (VSED):** a patient refuses food and liquids, including sustenance by feeding tube; with the understanding this will hasten death. Former NPR radio host Diane Rehm talks about her husband’s decision regarding VSED in her book *On my own.*
Appendix 2.
Resources for Contemplation and Discussion

• *The Bucket List*
• *Beaches*
• *Life As a House*
• *The Barbarian Invasions*: 2003 French-Canadian film examines assisted suicide, importance of restored relationships, and the meaning of a good ending. What is a good dignified death?
• *Dying Young*
• *I'll Be Me*: features singer/songwriter Glen Campbell’s farewell tour in the midst of his Alzheimer’s diagnosis. It gives insights into how the family copes with the early stages of his dementia. The movie includes the last song Campbell wrote: “I’m Not Gonna Miss You”
• *Stepmom*: shows a blended family dealing with the conflicts wrought by divorce and complicated by terminal diagnosis. The film portrays a broken family struggling for healing as death approaches.
• *My Life*
• *Ikiru*
• *Christmas in August*
• *Terms of Endearment*
• *50/50*
• *Get Low*: A hermit, feared and avoided by many of the local townspeople, decides to throw himself a party before he kicks the bucket.
• *Wit*: Portrays empathy and callousness of health care providers. Notable moment in the film: the CPR scene
• *Last Holiday*: how would you spend your last months if you had received a terminal diagnosis?
• *Other People*: a gay comedy writer returns home to take care of his dying mother, a family situation complicated by the staunch Catholic father’s objections to his son’s sexual orientation.
Appendix 3.
Workshop Outline for ICE-teas

Work in Progress: To be developed
Appendix 4.
Personal Self-Assessment Scale (PSAS)\textsuperscript{268}

![Personal Self-Assessment Scale (PSAS)](https://oktodie.com/pdf/PSAS.Form.Final.pdf)

### Personal Self-Assessment Scale (PSAS)

<table>
<thead>
<tr>
<th>PSAS Level</th>
<th>Morbidity</th>
<th>Activity Level &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSAS 100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 90%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 80%</td>
<td>Full</td>
<td>Normal activity with effort</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 70%</td>
<td>Reduced</td>
<td>Unable normal activity &amp; work</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>PSAS 60%</td>
<td>Reduced</td>
<td>Unable hobby/housework</td>
<td>Occasional assistance</td>
<td>Normal or reduced</td>
<td>Full or confusion</td>
</tr>
<tr>
<td>PSAS 50%</td>
<td>Mainly st/be</td>
<td>Unable to do any work</td>
<td>Considerable assistance</td>
<td>Normal or reduced</td>
<td>Full or drowsy or confusion</td>
</tr>
<tr>
<td>PSAS 40%</td>
<td>Mainly in bed</td>
<td>Unable to do most activity</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or drowsy + confusion</td>
</tr>
<tr>
<td>PSAS 30%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Reduced</td>
<td>Full or drowsy + confusion</td>
</tr>
<tr>
<td>PSAS 20%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Minimal sips</td>
<td>Full or drowsy + confusion</td>
</tr>
<tr>
<td>PSAS 10%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Mouth care only</td>
<td>Drowsy or coma</td>
</tr>
<tr>
<td>PSAS 0%</td>
<td>Dead</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### INSTRUCTIONS:

A) Each PSAS level is explained by reading across the rows from left to right.

B) After reviewing PSAS levels, move to the green columns under the title "Personal Preferences".

C) Each green "Personal Preference" column identifies medical decisions that you may choose in advance to have activated when you reach a certain PSAS level:
- **DNR** = Do Not Resuscitate order (no CPR, electrical shocks, breathing tubes)
- **No AN** = No artificial nutrition (example: feeding tubes)
- **No IVH** = No IVs for artificial hydration
- **Other** = Any medical treatment(s) that you may elect not to have (blood transfusions, dialysis, hospitalization for anything other than comfort care, etc.). Details of the "Other" category must be listed in the space provided beneath the columns.

D) For each medical decision that you wish to make in advance for yourself, place an "X" in each column (example, DNR) in the row matching the PSAS level of your choice (example, PSAS level 30%).

E) Sign and date this document. Place it in your living will. Give a copy to your health care provider, your surrogate medical decision maker and any family or friends whom you wish to have a copy. Take a copy with you whenever you go to see a doctor. You may write "VOID" on this document at any time, destroy it and create an updated version. Updated versions should be shared with your health care provider, your surrogate medical decision maker, and any family or friends who have a previous copy.

* You must be fully conscious in order to make decisions for yourself in advance.

---

**COPYRIGHT:** Personal Self-Assessment Scale (PSAS). M. Williams-Murphy and G. M. Downing, 2011. For exclusive use in preparing a living will or advance care plan within the context outlined. It is adapted from the Palliative Performance Scale (PPSv2) © copyright; used with permission from Victoria Hospice Society (see [www.victoriahospice.org](http://www.victoriahospice.org)). Also available for download at [www.oktodie.com](http://www.oktodie.com).

---

Sign your name: ___________________________ Date: ___________________________

Witness/Notary: ___________________________ Date: ___________________________

(It is strongly advised that this be reviewed at least every 6 months, or upon any major change in your medical condition in order to keep it current with your preferences. When renewing or if changes are needed, then use a new form with a new date of completion, and destroy the older one.)

\textsuperscript{268} [https://oktodie.com/pdf/PSAS.Form.Final.pdf](https://oktodie.com/pdf/PSAS.Form.Final.pdf)
Appendix 5.
Holistic Integrated Map (Model) to Health and Healing

https://www.alternative-doctor.com/love_and_sex/medical_model.pdf
Appendix 6.
Photos from the edge

Figure 10: Grave markers for two women, Cruzan and Schiavo, who spent years in PVS

Figure 11: PVS patient’s wrist contractures
Figure 12: NOV 2018: Screen shot from a news report video about a 10-year-old who attempted suicide. He was declared brain dead and became an organ donor.269

Figure 13: How does someone decide? This cartoon illustrates the confusing array of treatment choices 270

270 https://scholarblogs.emory.edu/philosophy316/2014/02/10/informed-consent-it-is-your-pick/
Appendix 7.

Framework for a good death

Framework for a good death, Emanuel, Ezekiel J. & Emanuel, Linda L.
Bibliography


Ars Moriendi. Here Begynneth a Lytell Treatyse Shortlye Compyleld, and Called Ars Moriendi/That Is to Saye the Crafte to Dye, for the Helth of Manes Soule. R. Wyer, 1532.

Balboni, Tracy Anne, et al. 2010 “Provision of Spiritual Care to Patients with Advanced Cancer: Associations with Medical Care and Quality of Life near Death.” *Journal of Clinical Oncology* 28(3) 2010, 445–452.


Endrizal Louras, Judith. *Dying in Place: Death Denial, Awareness, and Acceptance and the Changing Landscape of Terminal Care in Twenty-First Century America*. 134


Goozner, Merrill. "$I\text{ Think We're Finally past the Death Panels'"} *Modern Healthcare*, vol. 44, no. 45, 10 Nov. 2014, p. 30. EBSCOhost, ezp-


Hardwig, John. “Medicalization and Death.” *APA Newsletters on Philosophy and Medicine*. Vol. 6, Number 1. Fall 2006. 7


Silverstein, Jason. Dying Well, SSCI E-121 Lecture slides.


---, *Something More* (Cambridge, MA, 2016).


---. *Care of Souls*. (Cambridge, MA, 2018).


*USA Today*. “Biden on grief, and what might have been.” 16 Nov 21017. Print.


