At Peace: choosing a good death after a long life

is simply a practical look at declining health, old age, progressive debility, and practical choices that people can make to minimize the likelihood of the unconsidered death and to maximize the likelihood of a “better” death

Therefore, the restated goal of this book is to use the knowledge of disease trajectories to choose a point in the disease process at which one considers stopping aggressive treatment and recognizes that palliative treatment is likely to offer a better outcome.

Combining the understanding of disease trajectories, an appreciation for the process of natural death, and skepticism of a system designed to treat excessively with practical end-of-life decisions will help patients have a better chance at a better death.

Do you want to die in an ICU, on a ventilator, unconscious, unrecognizably bloated, oozing from sores and pores, every orifice violated with a tube, and unable to communicate with family and friends? Cardiopulmonary resuscitation (CPR) is much more brutal and much less effective than people are led to believe. 0-8% hospital discharge, less cognitive intact.

Alternatively, do you want to die warehoused in a nursing home, surrounded by elders who are infirm and incontinent; fighting bedsores and begging for a diaper change; being spoon fed or tube fed; and being aided by well-intentioned, but understaffed and underpaid, nursing services?

The effect is that those of us who do not die suddenly or unexpectedly will die older, later in life, with progressive disability and diminished faculties. “Old age” will be our terminal diagnosis, and living longer than desired is likely to be our punishment for lack of planning.

If, while still cogent, you put in place the decision-making paperwork that would allow for early hospice registration and restrictions on nutritional support, hospitalization, and aggressive medical treatment, then a long, uncomfortable, lonely decline in a nursing home can be avoided.

I want to promote planning that will maximize the possibility that one can pass away surrounded by friends and family, with minimal suffering, uninterrupted by ineffective medical interventions, at home (if desired or possible) and at peace.

But when it has been studied, a good death includes control, comfort, closure, affirmation, trust, understanding, and communication. Very rare in hospitals.

Consider your concept of a good death. • Think about the level of medical intervention you want. Outline your goals and expectations. • Communicate your goals and wishes to your friends and family while you are still able. • Remember, aggressive treatment to the very end results in futile and painful therapies. • Look for opportunities to review less aggressive options.

These same companies have convinced consumers to expect excessive medical care, leading American patients to believe that a cure for whatever ails them is just around the corner while generally overlooking the compassionate, supportive, and thoughtful care the elderly patient really needs.

First, just as safer highway engineering inspires drivers to increase their speed, better outcomes tempt physicians to treat older and weaker patients. Second, by supplying more hospitalist care to deal with the medical complications, the medical or surgical specialist is less invested in deselecting patients who are likely to have limited benefit or who have a higher risk of complications. And third, it takes less time to plug an overeager patient into a system of care than to advise them that system was not built with their individual needs in mind.

The momentum to treat in America is unmatched around the globe or throughout history.

as life expectancy, infant mortality, or quality of life after sixty-five—the United States ranks in the lower third of developed countries, sometimes dead last.

At the intersection of American exceptionalism and media manipulation lies a uniquely American persona filled with hopefulness, optimism, anticipation, and expectation. Courtesy of our society's emphasis on youth, celebrity, and consumerism coupled with the successful marketing of medical advances, health care products, and political promises, much of this optimism is based on overstatements.

s. In a provocative essay published in The Atlantic in October 2014, Ezekiel J. Emanuel coined the phrase and named this character "the American immortal."1 He describes this individual as obsessed with exercise, mental puzzles, diets (juices, nuts, berries, protein), and vitamins (antioxidants, etc.). Their practices are the result of the fusion of American exceptionalism and a belief in the concept that by living a longer healthy life, one is likely to die more suddenly, with less disability and dependence. In his essay entitled "Why I Hope to Die at 75"

Healthy at 65, 19 year average lifespan. Of those nineteen years, ten and a half are likely to be healthy years and eight and a half are likely to be disabled years.

Equally important to note is that one year before their death, 80 percent of Americans are living lives complicated by disability.

If your strategy is to die late in life, then you should acknowledge that you will be old and will need a strategy to die better.

A strategy to die better is an important concept in our personal efforts to take control of the last phase of our life.

combination of disease, weakness, and functional status beyond which you will allow only palliative care.

But many disabilities acquired with old age are less obvious—though equally limiting—and include deafness, visual deterioration, loss of muscle mass, loss of dexterity, nerve damage, diminished exercise tolerance because of poor circulation, and loss of dental soundness. Debility, specifically, is the weakness of illness or aging that ultimately saps our independence and renders us wheelchair dependent or bed-bound. It is not subject to improvement with treatment or rehabilitation

Things to Remember/Things to Consider • Remember you are mortal, not immortal. • Keep in mind that, on average, if you are lucky enough to live past the age of seventy-five, you are likely to have to cope with eight years of variable disability. • Consider the occasional inventory of your age, diagnoses, disability milestones, and performance status. • Understand that with age the risk of treatment increases and the benefit decreases. • Consider a combination of disease, debility, and functional status beyond which you will not seek aggressive care. • Do not look for potential problems with screening tests; address active illnesses purposefully.

The patients selected are chosen because they have less confounding illness and are expected to live long enough to measure the benefit of the treatment. Therefore, when the median survival is determined for a research paper, it is not what one should expect for the frail and elderly patient discussing said treatment with a clinician.

somewhere between 100,000 and 400,000 Americans die annually from the treatment they receive.7 The larger number includes adverse outcomes that are considered unavoidable, but are still included as errors.

You can intuitively grasp that the complexity of care increases with the number of diseases a patient has, the severity of their illnesses, the number of medications they take, the aggressiveness of the treatments they choose, and their age.

In the intensive care unit setting, where the most complicated patients are treated, unavoidable adverse incidents occur with regularity. Studies show that something goes seriously wrong every four or five days, more than half of those negative occurrences are unavoidable, 13 percent of them are fatal, and the majority of those who suffer fatal medical errors are elderly.

If you think that you have lived “past the expiration date,” then you are enjoying the first inkling of a reality check. Embrace it. Promoting aggressive medical treatment at that point increases the likelihood of prolonging a life of decreasing ability and diminishing returns. Transitioning to a more passive and accepting posture while actively refusing all but palliative care will give you as much control as possible.

Seeking less treatment is not “giving up.” It is choosing a path that appears passive but is more natural and nurturing. Recognizing misguided hopefulness need not result in paralyzing hopelessness but can lead to peaceful purposefulness.

Things to Remember/Things to Consider • Create a vision of your death. Any vision, even one of dying from tobacco or alcohol abuse, becomes a point from which further understanding can develop.

• Internal organs age too, resulting in medical complexity and randomness of outcomes. • You can will yourself to tolerate treatment; you cannot will the outcome of that treatment. • Avoid magical thinking. The median is the message. • Do not be afraid to discuss median survival for a serious diagnosis with your physician. Make them discuss it. If they dodge the subject, ask for a referral to a consultant who will discuss it.

In general, the fatigue of old age is hard to recognize and hard to acknowledge. Gradual appetite loss, decreased strength, and fatigue are more likely to be attributed to depression or, worse yet, a lack of will than to an actual physical illness known to the layperson only as old age.

A small part of the American medical establishment does recognize fatigue for what it is. Geriatricians define frailty as a clinical syndrome of three or more of the following symptoms: self-reported exhaustion (Dad's "fatigue"), unintentional weight loss, weakness (decreased grip strength, for example), slow walking speed, and low physical activity.

To underscore the importance of this concept, this definition of frailty is independently predictive of falls, progressive disability, hospitalization, and death at two to four times the rate of the non-frail population.

Eighty percent of elderly people suffer a fall, with or without injury, sometime, some way. According to the CDC, more than 3 percent of elderly people die as a direct result of traumatic injury, most of which is precipitated by these falls. Those who do not die, but are injured, suffer variable degrees of long-term damage.

Six chronic diseases (congestive heart failure, cancer, chronic obstructive pulmonary disease, stroke, dementia, and diabetes) are responsible for, or credited with, causing 90 percent of the deaths among Americans over the age of sixty-five.

Congestive Heart Failure (Responsible for about 34 Percent of Deaths over Sixty-Five)

Cancer (Responsible for about 28 Percent of Deaths over Sixty-Five)

Another cruel truth about cancer is that the treatment is frequently difficult to bear and fraught with complications. Surgery hurts. Radiation therapy and chemotherapy inflame tissues, induce fatigue, and nauseate patients.

Chronic Obstructive Pulmonary Disease (Responsible for about 9 Percent of Deaths over Sixty-Five)

Cerebrovascular Disease—AKA Stroke (Responsible for about 8 Percent of Deaths over Sixty-Five)

Tiny strokes (micro-infarcts) that occur below the cortex (the surface of the brain) are called lacunar strokes. They may not cause an immediately definable event but have a cumulative effect leading to neuromuscular deterioration and multi-infarct dementia.

Again, recurrent hospitalizations for aspiration pneumonia, blood clots, or catheter-induced urinary infections define the glide path to death.

Dementia (Responsible for about 6 Percent of Deaths over Sixty-Five)

Therefore, death from Alzheimer's can result from trauma incurred from wandering abroad or falling down familiar stairs; poison consumed; mistaken dosages of medicine; or myriad other insults visited upon those who cannot think clearly, remember accurately, or protect themselves. Most commonly, those patients who live into the late stages of the disease die of pneumonia or other infections after multiple episodes of choking and aspiration.

Diabetes Mellitus (Responsible for about 4 Percent of Deaths over Sixty-Five)

Type 2 diabetes is a systemic disease that causes the deterioration of multiple organs and systems. In isolation, it is less likely to be the sole cause of death, but it contributes to multiple other fatal pathways.

In summary, type 2 diabetes causes accelerated damage to all the organs subject to the ravages of atherosclerosis (brain, heart, kidneys, and blood vessels) as well as liver dysfunction and peripheral nerve damage.

Of course, we grieve when we lose something dear, including some aspect of our health. We despair when we recognize that each treatment cycle results in less benefit and more deterioration. But we are empowered when we can see that when treatment is increasingly ineffective, then treatment is no longer the only option and comfort care might be a better choice.

CHOOSING COMFORT OVER CYCLICAL TREATMENT: HAVING A VISION

Things to Remember/Things to Consider • Disease can be characterized; the course of disease can be observed; an understanding can be developed. • Consider "old age" to be a diagnosis. • Discuss the course of your particular chronic illness with your physician. • Recognize the pattern of recurrent symptoms, treatment, deterioration, and stabilization. • If you recognize a cycle of unproductive treatment and progressive decline,

Discuss in advance such a complication and plan to establish a line in the sand: not Emanuel's arbitrary seventy-fifth birthday, but a combination of disease, weakness, and functional status beyond which you will allow only palliative care.

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somewhere between 100,000 and 400,000 Americans die annually from the treatment they receive.7 The larger number includes adverse outcomes that are considered unavoidable, but are still included as errors.

However, medical complexity is the driving force behind the unpredictability of unavoidable errors.

This use of multiple medications has created the concept of polypharmacy.10 In simple terms, polypharmacy means the more medications we use, the harder it is to predict the benefits or complications of their interactions.

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In general, the fatigue of old age is hard to recognize and hard to acknowledge. Gradual appetite loss, decreased strength, and fatigue are more likely to be attributed to depression or, worse yet, a lack of will than to an actual physical illness known to the layperson only as old age. "I am too tired" sounds like a weakness of purpose rather than a hard-to-quantify symptom of disease.

A small part of the American medical establishment does recognize fatigue for what it is. Geriatricians define frailty as a clinical syndrome of three or more of the following symptoms: self-reported exhaustion (Dad's "fatigue"), unintentional weight loss, weakness (decreased grip strength, for example), slow walking speed, and low physical activity.2 To underscore the importance of this concept, this definition of frailty is independently predictive of falls, progressive disability, hospitalization, and death at two to four times the rate of the non-frail population.

Things to Remember/Things to Consider • Discuss with your doctor what they foresee as likely causes of death given your diagnosis: pneumonia, respiratory failure, or hemorrhage, for example. • Create a vision of where that death might best occur. • Share your vision with friends, family, and physicians. • Consider an exit strategy—an illness for which you will decline treatment. • When aggressive treatment results in complications and limited benefit, consider passive care, then hospice care, and then an exit opportunity

"Geriatric failure to thrive" is one medical expression used for "dying of old age."

When does one know that the terminal phase of old age is at hand? One certain guide is to study the Medicare requirements for admission to hospice care for the latter diagnosis. That information is available at the Center for Medicare and Medicaid Services (CMS) website.

"Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short, not often painful illness, the old man escapes those 'cold gradations of decay 'so distressing to himself and his friends."—

"Get educated; be aware; question aggressive therapeutic recommendations; question overly optimistic promises; exercise judgment." When the time is right for you, exercise aggressive passivity.

choosing treatment over palliation increases the risk of painful and ineffective treatment, loss of control, and even an earlier death. If you know your days are numbered, you know the "why" of your death. Ask yourself how you want to spend those days and visualize the "where" of your death. Do you want to spend them in a doctor's office, treatment center, nursing home, or hospital? Or would you prefer to spend those days with friends and family? Acknowledging a terminal diagnosis prepares a patient and their family to recognize a terminal condition.

When an oncologist offers a treatment to "buy some time," consider ignoring that advice. Early hospice care buys more quality time, at home, with family and friends.

Recognizing the reality of a disease is empowering. • Communicating your vision unburdens your family. • The recognition of a terminal diagnosis does not immediately consign you to a terminal condition. • Know the "why" of your disease so that you can visualize the "where" and consider the "when" of its terminal evolution. • Remember your option to limit or decline treatment.

Your physicians are the most important resource that you have for understanding your prognosis. But it is the rare physician that will push this information at you. Only a minority will discuss it willingly. Part of that hesitation is because long discussions are not well compensated. Another part is the patronizing perspective that patients cannot really absorb the information. If pushed, most physicians will acquiesce. If they don't, consider another physician. It is your right to be informed. Don't take no for an answer.

Things to Remember/Things to Consider • You have a prognosis whether you choose to recognize it or not. • Ignoring your prognosis encourages denial, promotes the momentum to treat, and often

results in futile and painful therapies. • Discuss your prognosis with your physician. • If your physician declines to discuss it, ask for a referral to a geriatrician or palliative care physician who will talk with you.

There are many ways to open The Conversation. The easiest and most common is to segue from a practical discussion of a health-related matter to a deeper discussion of end-of-life goals, but other starting points include a legal perspective, a medical perspective, and finally a moral perspective. Some form of denial is always a factor in postponing the process, but it should never be delayed to "protect" the patient. Usually, the discussion gets delayed because it is easier to ignore problems than to engage them. When in doubt, one must blunder ahead, taking care to be respectful and trying to avoid a brow-beatingly specific agenda.

Though the difficulties associated with The Hard Conversation increase with the proximity to death, the more frequently the discussions occur throughout life, the easier they are, in general. The later the discussions occur in the trajectory of an illness, the harder they are to initiate because they are now intertwined with the actuality of death and the end of hope. But the closer to death these discussions occur, and the more frequently they are reviewed and revised, the more power and influence they have to assert your control over the process of moving toward a more peaceful death.

In the absence of pathological denial, resistance to the most difficult conversations, especially when facing serious illness late in life, is fundamentally about losing hope for an extended future.

In the health care setting, the automatic assumption is that hope exists solely for a positive outcome, at least long-term survival and at best a cure. The universal tendency among family members to admonish elderly patients to "not give up hope" must be tempered with reality. The seduction of "medical progress" and the fear of death delay The Hardest Conversation and blind us to the consequences of the false hope born of excessive treatment. Those consequences are the pain and suffering of ineffective care.

When the attributes of "a good death" are analyzed, researchers conclude that the most important characteristic is some degree of "control."6 The dying patient wants to assert some influence on this process. To do so, they need a vision and a plan. Although the moment of death is irreversible and, at that instant, uncontrollable, the days, weeks, months, and even years leading up to that moment can be managed for the aging patient to include more self-assertion and less overtreatment. Planning is essential for control, and The Conversation is essential for a plan.

Overtreatment at the end of life will, at a minimum, waste some of your precious time and, in the worst case, cause a complication that will shorten your life. Hospice care breaks that momentum by offering an alternative perspective that focuses on maximizing the quality of life while the disease takes its natural course.

Hospice Care

There is no limit to treatment options as long as they are palliative, not life-prolonging, in intent. However, pain control and anxiety control are the central focus of most treatment plans. Physical pain is treated with a variety of medications, including opiates. Emotional pain is treated with spiritual or psychological support, tranquilizers, and psychiatric medications as indicated. Spiritual pain is addressed by pastoral care. As performance status declines, the complications of prolonged bed rest become almost universal. Skin care and the prevention of skin breakdown are emphasized. An air mattress will be supplied. Bowel habits will be closely monitored to prevent the complications of constipation (a fecal impaction). Steroids are given to suppress inflammation. Antibiotics can be added to control the discomfort of certain infections or can be declined to hasten death (e.g., in the case of pneumonia or sepsis). Hospice providers supply mechanical devices intended to improve the quality of life. Wheelchairs, commode chairs, lift devices, bedside tables, urinals, bedpans, catheters, diapers, and other things improve quality of life and prevent complications. Hospital beds help patients and caregivers. Variable flow air mattresses prevent bedsores. Mechanical lifts help patients from bed to chair and delay the bed-bound status. Condom catheters and diapers limit transfers, and limiting transfers limits opportunities to fall.

The benefits of hospice should be described as the emotional and physical comfort of dying at home, surrounded by the familiar, and with control over as many factors as possible. Admission before the distractions of a final medical crisis allows families the opportunity to value one another and the possibility of repairing frayed relationships. That may not sound like much, but it should be contrasted with the unpleasantness of death in a hospital without personal effects or memories and subject to the whims, misunderstandings, isolation, and regulations of a team of doctors, nurses, technicians, and orderlies.

One way of introducing the concept of hospice care is to introduce its first cousin, palliative care, as soon as a serious illness is identified.7 The old model of health care consisted of life-prolonging care with the intent to cure until overtreatment becomes futile and imminent death undeniable. Then the unpleasant conversation about death and hospice care tends to be weighty and late. Now, palliative care specialists are available well before end-of-life care is needed. They can help with the control of symptoms associated with serious illness such as diarrhea, constipation, shortness of breath, anxiety, itching, and, of course, pain. Not only do patients do better with months or years of palliative care but they tend to enter hospice earlier in the course of their illness with improved quality of life throughout.

Caregivers and family members will resonate with this temporary optimism and they will amplify it. “Oh, he’s not ready for hospice, he’s not ready to give up.” This practice simply delays the inevitable to the detriment of all. Rather than enjoying the fresh optimism in the sense of a good day, or the best possible day, in a series of difficult days, a good day is assumed to be a sign to continue hoping for better.

Another benefit of hospice care, unclear to the uninitiated, is the elimination of unnecessary doctor visits. These usually result in diagnostic tests and a tendency for follow-up tests or visits.

way. I do presume to advise you that every hospitalization and every medical treatment has some degree of unintended consequence, and the degree of damage from those interventions accelerates with age while the degree of benefit is simultaneously reduced. Most important, if you put control of your end-of-life care in the hands of the average physician, you are likely to receive more treatment than is truly beneficial.

The paradigm shift we need is not a technical one; it is a spiritual, emotional, or intellectual one. We need to stop believing that advances that are likely to help young people will equally benefit old people.

Good Death

Karen Kehl concludes that the attributes of a good death are (in order of decreasing importance) being in control, being comfortable, having a sense of closure, being valued as a person, trusting one's care providers, recognizing the impending death, honoring beliefs, minimizing the burden, optimizing relationships, utilizing the appropriate amount of technology, leaving a legacy, and being cared for by family. Of these twelve attributes, most require advance planning.

Given that nine of the twelve attributes of a good death require enough advance planning to achieve control, comfort, closure, self-worth, trust, honored beliefs, the setting of choice, and family care, I maintain that understanding and acknowledging illness, in concert with a vision of the end, is central to achieving a better death.

If we accept the preceding as the attributes of a good death, then the attributes of a bad death are losing control (not in accord with wishes, not in location of choice, prolonged, dependent, traumatic), suffering (in pain or distress, cognitively impaired, fearful, or angry), being unprepared, being subjected to disorganized care, lacking knowledge of impending death, being a burden to the family, being alone, and being young. Except for the final condition, the remaining attributes of a bad death define a medicalized death in the ICU or a warehoused death in an institution.