Notes from Knocking on Heaven's Door.
by Katy Butler

From the dust jacket: "Like so many of us, the author always assumed her aging parents would experience healthy, active retirements before dying peacefully at home. Then her father suffered a stroke that left him incapable of most activities of daily living. Her mother was thrust into full-time caregiving, and Katy Butler became one of the 24 million Americans who help care for their aging and failing parents."

This is an honest, sobering look at what awaits so many elderly people and their caregivers, who are often family members. It is the story of a Medical-Industrial Complex gone wild: doing things to people for economic gain. Expensive procedures that have serious unintended consequences are, unfortunately, the rule. For a variety of reasons, many physicians perform lucrative tests and interventions that do little to improve patients' well-being. Death is seen as the ultimate enemy, yet we all will die. How one dies is important, yet this is not considered often enough.

Knocking on Heaven's Door is the story of a singular family. All families are unique. The narrative is memorable, but there is much more. Butler discusses American medicine and its domination of patients and families, and suggests ways we as patients and family members can try to protect ourselves. It is also a wake-up call to physicians to try to change our behaviors from running profit centers to being caregivers in the true sense of the word.

These notes may help some of you who are too busy to read the entire book, however, should you do so, you will find much more to interest you. I learned a lot by a fairly careful reading of Katy Butler's book, much that will help me as a son, a caregiver and a physician.

P. 3
Anton Chekhov wrote: "Whenever there is someone in a family who has long been ill, and hopelessly ill, there come painful moments when all, timidly, secretly, but at the bottom of their hearts long for his death."

In January 2007, I learned that my father's pacemaker could be turned off painlessly and without surgery thus opening a door to a relatively peaceful death.

P. 5
I did not know the road we would travel, only that I made a vow. In the six months that followed, I would learn much about the implications of that vow, about the workings of a pacemaker and of

the human heart, about law and medicine and guilt, about money and morality. I would take on roles I never imagined could be played by a loving daughter. I would watch my father die laboriously with his pacemaker still ticking.

I would discover something about the perverse economic incentives within medicine – and ignorance, fear, and hope within our own family – that promoted maximum treatment. I would contemplate the unintended consequences of medical technology's frighteningly successful war on natural death and it's banishment of the "good death" our ancestors so prized.

Death is wiley. Barred from bursting in like an armed man, it wages a war of attrition. Eyesight dims, joints stiffened, heartbeats slow, veins clog, Lungs and bowels give out, muscles withher, kidneys weaken, brains shrink.

When is it time to say "no" to a doctor? To say, "enough"? The questions surface uneasily in medical journals and in chat rooms, in waiting rooms, and in conversations between friends. There is no denying that the answers, given or avoided, will shape when and how someone we love meets death. This is a burden not often carried by earlier generations of spouses, sons, and daughters. We are in a labyrinth without a map.

P. 21
She described an orderly who did not need family photographs or a war history to treat my father with reverence. We were in an oasis of caring, everything the model modern hospital aspires to be and rarely is. And I was learning from a fat man with a tattoo whose name I didn't know, how to love my helpless, broken, and infinitely slowly dying father.

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It would take me more than a year to realize that my father had walked through the invisible gate that separates the autumn of healthy old age from the hidden winter of prolonged and attenuated dying. The time for fixing was over. The glass was already broken.

P. 31 ff
After his stroke, my mother can't care for my father the way she cared for my brothers and me when we were three or four.

There are 29 million unpaid, politically powerless and culturally invisible family caregivers – 9% of the United States population – who take care of someone over 74.

My mother's doctor gave her a prescription for Ambien, a sleeping pill. But she needed more than a pill and a so-called reliable daughter 3000 miles away. She needed a support team – a

social worker, a visiting nurse, and hired caregivers to give her respite.

The requirements for Medicare hospice benefits are so draconian – and doctors and some families are so over-optimistic about the patient's survival chances – that half of those who enter hospice care are enrolledfor no more than their last 18 days of life.

On the phone in California with my mother, I felt tied to her misery like a dog tied to a rattling can by a 3000 mile long string.

24 million sons and daughters – about 8% of the US population provide health care for aging parents.

One woman I know spent $20,000 on airfare to Florida in a single year of dual parental medical crises. Some European countries pay family caregivers modestly and contribute to their pension funds to make up for what they lose by reducing their hours in the workforce. Not in the United States.[this brings to mind the book, the American Healthcare Paradox. In the United States we spent far less on social programs than other first – world countries. We pay forward in the end with higher technical costs that don't accomplish all that much.]

Even though our parents are more likely than ever to live long in fragile health, we baby-boomer sons and daughters are often ill equipped to help.

P. 58
Slow medicine. This concept was first promoted by a cardiologist in Italy named Alberto Dolara. Slow medicine, like slow food, values restraint, calm and above all, time: time to weigh the emotional and physical costs of medical treatment; time to evaluate new methods and technologies; time as the end of life approaches to stop frenetic doing and to take care instead of the broader needs of patients and their families.

"To do more is not necessarily to do better," wrote one slow medicine colleague.

Some studies suggest that patients are more likely than their doctors to reject major elective surgery when fully informed of pros, cons, and alternatives – information that nearly half of patients say they don't get.

P. 60
Butler has a lengthy discussion about that life extending technologies. It starts on page 60.
At this crossroad, each miraculous life – extending technology pulls up from the depths a tangle of our most deeply held and unarticulated moral questions and puts them under a halogen light.

How grateful we are for the gift of life and what are we willing to undergo for more of it? Would we rather die too soon or too late? How do we make sense of the loss of human bonds that death brings even to those who believe in heaven? Does a caregiver's suffering have moral standing? Can a daughter express her love for a father by doing all she can to let him die, or is that an expression of her selfishness and buried hate?

Medicare and supplemental insurance covered almost every penny of my father's pacemaker even though they would not cover a cent of a temporary truss that might have bought us time for an informed decision about the pacemaker placement.
Medicare paid the surgeon $461 for the 45 minute pacemaker operation, and the hospital a lump sum of about $12,000 of which the lion's share, about $7500 went to the company that makes the pacemaker.

P. 78
ICUs
These units obliterated western death rituals, reshaped the architecture of the hospital, transformed the meaning of the body and brutally deformed the way families, doctors, nurses – and even the dying themselves behaved at the bedside.
In the metallic, machine filled ICU, where death was fought to a standstill and its arrival regarded as an emblem of medical failure, such sacred rites of passage all but disappeared. the dying person was no longer in charge of his or her own death; doctors were the new authorities, and they popped in and out on rounds. There were technical specialists to treat each discrete bodily organ but nobody to minister to the emotional or spiritual needs of the dying person with the family. Latin liturgy gave way to talk of blood gases. Family members who once kept the death vigil, wiped the brows of the dying, changed their bedclothes, and listened to their last words were restricted to the visiting hours.

P. 81
Wm. St.Clair Symmers at the Charing Cross hospital in London described a troubling case, a harbinger of thousands more to come. Life-saving machines were evolving so rapidly and scrambling moral and medical categories in such confusing ways that the soft technologies of clinical practice and common sense could not keep up. The unspoken maxim had become, "if we can, we must." See article in BMJ - 1968 - "Not Allowed to Die."

The new technologies seemed to have blunted medical staff to the suffering their procedures caused the dying and often postponed death without restoring health. They created unrealistic hopes of immortality in some doctors and patients and bred a toxic mistrust between them that still persists.

They helped produce doctors of great technical prowess but untrained in the art of emotional communications.

Now after the mid-1950s, the attitudes of many doctors and patients shifted from faith in God and acceptance of death to faith in medicine and resistance of death. There was always something, no matter how futile, that a doctor or nurse could do.

Patients weren't always grateful. In a small rural hospital in Virginia in the 1970s, the nurse came proudly to the bed of an elderly woman whose life she had saved by performing CPR that had cracked two of the old woman's ribs."I will hate you till the day I die," the old woman said. "You took away my chance to go to heaven, and on top of that you hurt me.

It has gotten to the point that the fundamental principles that have guided the practice of medicine – relieve suffering and do no harm – were up ended," Diane Meier wrote. "Almost without discussion, the primary moral principle underlying medical practice became the obligation to prolong life regardless of the toll and suffering, poor quality of life, or cost.

It had taken me more than a year to realize that my brothers weren't carrying much of a load.

Butler tells a nice story about Toni, one of her father's caregivers. She became one of 2.5 million street saints across the country who despite poor pay and the harshness of their own lives, draw on unseen wells of compassion and emotional skill for families like mine. These aids are not entitled to the minimum wage or overtime pay or any other basic protection from the government. This discussion on page 92 deserves to be read in its entirety. The home-health agencies want to keep the status quo and have lobbied Congress so that these arcane laws are not changed.

P. 104
Even though most of the skyrocketing increase in Medicare costs is due to advanced and expensive medical technologies, Congress in an attempt to cut costs, limited payments for hands on speech and physical therapy that year to about $1600 each. After an uproar from constituents, it's suspended the limit – but reiterated Medicare's long-standing practice of providing coverage only when well patients showed improvement, and not to keep them from slipping back.

Angela, the speech therapist, generously continued to come without pay on Saturday mornings, inspired by my father's desire she told me later, to continue to work to improve himself against all odds.

[Without the social supports patients decline, technology keeps them alive but provides no

quality-of-life.]

P. 113
Helping her mother, was like reaching through barbed wire to water a rose.

P. 123
I chanted every morning, "I am of the nature to grow old. There's nothing I can do to escape growing old. I am of the nature to die. There is nothing I can do to escape death." "My actions are my only true belongings, I cannot escape the consequences of my actions. My actions are the ground upon which I stand."

P. 133
The age – related degeneration the had earlier slowed my father's heart and shrunk his brain moved on to attack his eyes, lungs, bladder and bowels. He was collapsing slowly like an ancient shored up house. [So what happened? Specialists talked him into work on his eyes, lungs and other organ systems. He continued to age and deteriorate and become more dependent upon the medical – industrial system.]

He developed wet macular degeneration. He was treated a great cost by an ophthalmologist to no benefit.

Our optimistic, science–worshiping culture wants to medicalize aging and make it nothing more than a collection of specific diseases that medicine can prevent or fix, one at a time. But no matter what deal we make with the devil, nature wins out with us. Dying can be postponed, but aging cannot be cured.

When her father was treated with Lucentis, the total charge for a 45 minute office visit averaged $2100. It was not effective.

P. 139
Dementias can be avoided more easily than cured. A quick Internet search suggested that if I wanted to escape my father's fate, I should become a happy, hardy vegan who weighed less than average, had normal blood pressure, drank coffee or tea, was literate, well–off, and well-educated, kept up with friends and interesting hobbies, went to church, gave to others but not too much, took ibuprofen and estrogen, drank red wine but not too much, exercised hard, avoided salt, sugar, saturated fat and white flour, had a gene associated with longevity without dementia, and had been capable, in my 20s of writing a complex and coherent life narrative. Longevity is the biggest risk factor for cognitive decline and for most dementias including Alzheimer's. Each medical advance that fixes the body without helping the mind increases

widespread survival into extreme old age and fuels the dementia epidemic.
Wealth, traditionally transferred from one generation to the next, now flows instead into the treasury of assisted living chains, long-term insurance providers, homecare companies and nursing homes.

In the last five years of their lives, a quarter of the elderly now spend all of their savings, including the value of their home, on caregiving and other out-of-pocket medical expenses. (of course, this is really criminal but we all live with it.)

P. 142
A friend of the author's wrote, "When a fine old carpet is eaten by mice, the colors and what's left behind do not change." This was after she visited an old friend suffering from Alzheimer's disease in a nursing home.
Never would I wish upon my father the misery of his final years. But he was sacred in his ruins and I took from it the shards that still sustain me.

P. 145
Book, Elegy for Iris by John Bayley an obituary for his then – still – living wife the brilliant English novelist Iris Murdoch. In it, he tracked her descent into dementia. The books most famous phrase from an unnamed woman who told the author that her life with her demented husband was "like being chained to a corpse."

P. 146
There is no necessary relationship between the size and sophistication of the hospital and the quality of its nursing care, and when you are frail, the simplest touch from a good nurse can matter more than a high-tech specialist.
Many hospitals have become, in the words of one bereaved son–turned–investigative journalist, places that provide "bodily repair services under the direction of independent physician scientists," where overstretched nurses provide monitoring but very little old – fashioned nursing care.
Hospitals today usually lack three healing conditions that the Victorian era nursing reformer Florence Nightingale considered essential: quiet, rest, and fresh air.
My father had come to the tipping point. Death would have been a blessing and living was a curse. As he put it to my mother one day, in his classic understated style, "unfortunately, I come from a long–lived people."
If the pacemaker had never been implanted, I thought, my father might well have been out of his misery, and so would my mother and I be. I did not curse the mysterious ways of God, in whom I did not believe, for keeping my father alive. I cursed the machinery of man for disrupting the

natural order, which over millions of years of evolution has designed our hearts and brains to fail at pretty much the same time.

P. 159
The cardiac pacemaker and the defibrillator were creating ethical problems at the end of life, years after they were first put in. For many patients, the time will come when they need to be turned off.
She likens her problems to the Buddhist sutra of "second arrow." By throwing a complex machinery into the path of death, my father's doctors shot my parents with a second arrow.

P. 171
Medicare's payment structure punished doctors who practiced the slow medicine the elderly often needed and rewarded those on the high tech cutting edge.
Henry Greenberg, a cardiologist, delivered a contrary and an prescient paper called "in praise of sudden death." I will try to find this.

P. 175
The makers of pharmaceuticals and medical supplies constitute one of the capitals three biggest lobbies rivaling the defense industry and Wall Street.
Butler attended the Heart Rhythm Society meeting in San Francisco. All told, medical technology companies pay the Heart Rhythm Society $5.1 million, nearly a third of it 16.8 million annual budget, just to rent exhibit booths and otherwise promote themselves to the more than 3000 physicians attending the conference.
Salesman and -women with expensive haircuts circled clutches of slim, vital doctors in sharp dark suits. Suspended above our heads in the hanger like space what gigantic plastic signboards and whites and cool blues and greens advertising the technology industry.
She closed her hand around a sample pacemaker, a tiny little machine that had saved many a life, made many a fortune, and led my family, and many others, to so much unnecessary suffering.

P. 183
During a routine cardiology appointment, my mother asked Dr. Rogan to deactivate pacemaker. He said that she would need a court order declaring my father incompetent...
The poet Jane Hirschfield wrote, "some griefs augment the heart, enlarge. Some stunt."
A study of the DNA of family members who were looking after relatives with dementia showed that the ends of their chromosomes, called telomeres, had degraded enough to reflect a 4 to 8 year shortening of lifespan. By that reckoning, for every year pacemaker gave my damaged father, it took from my mother an equal year.

P. 192

Regarding the pacemaker. It's easy to say yes to a complex device and devilishly difficult to withdraw that yes. We were at the mercy of a strange new algorithm: those who knew my father best - his primary care Dr. Fales, my mother and I – wanted to let him die naturally but had no power. Those who knew my father least and least understood his suffering (especially the cardiologist) we're eager to prolong his life and had the know-how and the power to do so.
I wanted him to die because I loved him. I wanted to stop our familiy's suffering. And to do so, Judith Schwartz told me, I would have to speak in a foreign tongue and not as a daughter in grief.

We hadn't created this mess. My father's drawn out dying and my mother's suffering were the consequence of our culture's idolatrous, one-sided worship of maximum longevity. As far as I was concerned, this violated the way of the universe and was a moral crime. Why were we the ones being judged?

My mother copied out a haiku by the poet Issa on a 3 x 5 card and taped it to the bookshelf above her desk:
In this world,
We walk on the roof of hell,
Gazing at flowers.

P. 201
Even in the palliative care ward of the hospital no one would turn the pacemaker off. In desperation, Butler called a bioethicist at Harvard. He suggested I imagine that as if by magic, my once lucid and commanding father could appear at the kitchen table and talk with me for 15 minutes. I saw my dear father shaking his head In horror over what was no longer a "life" but a slow – motion dying.
I felt in the deepest wells of my being that doing whatever I could to hastened his death, short of manslaughter for which I had not the courage, was a moral act and a sorrowful necessity.

She writes about the palliative care program at the hospital. It is a growing, relatively new medical specialty that emphasizes relieving physical and emotional pain. It represents a ray of hope in a broken medical system. The emphasis here is on caring – for all of us – rather than trying to cure my incurable father.

P. 204
Jesus said that the stone the builders rejected would become the cornerstone. My father's caregivers, Alice and Toni, were our cornerstones. It didn't matter that they were paid for the mercy they showed us. I felt an almost religious gratitude to them, who gave their hearts, wisdom, and gentleness to us, near – strangers.

P. 211
Love can look heartless. We did not give my father oxygen or food or an IV of saline or a cup of water. If we had, we would have only slowed the shutting down his organs and the drawn out process of his death.
I was 59 and had never before sat at deathbed.
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 love die all through infancy, childhood, youth, middle age, and old-age: deaths we could not make painless, deaths no machine could postpone. The deaths of our ancestors were not pretty. Some died roaring in pain. But through the centuries we tutored ourselves in the art of dying by handing down stories about how those we loved met their deaths.

P. 215
My father was a guest in a hotel for the dying. The hospice nurses, practiced at filling the spiritual vacuums of contemporary life, would minister to us unobtrusively, the way priests and family members once did. To the hospice nurse, death was not an emergency. It was part of the plan.

P. 218
William Bodiford, an anthropologist, stated that, "One of the purposes of religion is to guide the living through the experience of death."

P. 224
Dying is hard on the dying. Death is hard on the living.

P. 227
My mother wanted no memorial service for my father. Phony eulogies made her skin crawl.
The dead don't care she said, quoting the undertaker and essayist Thomas Lynch.
But they held a memorial service anyway. We did not call it a "celebration of life." We were mourning a death and we knew it. We did not hire a minister to say vague things about a man he did not know. I downloaded a do it yourself memorial template and my brothers and I patched something postmodern together, the way people do now, out of the poetry and music we liked, and the tradition of public sharing borrowed from Quaker and 12 – step meetings.

P. 229
"How fleeting is a lifetime! Who in this world today can maintain a human form for even 100 years? There is no knowing whether I will die first or others, whether death will occur today or tomorrow" by the 15th C. Japanese priest, Rennyo.

P. 237
From her mother's diary, "the thought of going to live in a retirement "home" is simply a horrible idea to me. To be housed, even at a fine place, with a lot of old people waiting to die is not my idea of a way to go."

P. 239 ff
I found a New York Times article headlined, "saving the heart can sometimes mean losing the memory."Somewhere between a 10th and a half of heart bypass patients tested poorly on memory and other thinking skills six months after surgery. Doctors sometimes called the phenomenon "pump head." They rarely discuss this with patients preoperatively unless specifically asked.

My mother no longer saw physicians – perhaps with the exception of her internist, Dr. Fales - as healers or her fiduciaries. They were skilled technicians with their own agendas. I couldn't help feeling that something precious – our old faith in a doctor's calling or a healing that is more than a financial transaction or a reflexive fixing of broken parts – has been lost.

P. 247
More than a third of Medicare patients have surgery in their last year of life, nearly a 10th have surgery in the last month of life, and a fifth die in intensive care. Medical overtreatment costs the US healthcare system an estimated hundred and $158 to 226 billion a year.

Eihei Dogen the great Buddhist teacher in 12th-century Japan had these words to say about dying: "in birth there is nothing but birth and in death there is nothing but death. Accordingly when the birth comes become and manifest birth and when the death comes, become and manifest death. Do not avoid them or desire them."

My mother died like that.
She told the hospice nurses that she wanted to stop eating and drinking, and she wanted to die and never go home.
She died of old age, sickness and death. She died of a heart calcified and broken by six years of nonstop caregiving. She died of being 84. She was continent and lucid to the end. she took back her body from her doctors. She died the death she chose, not the death they had in mind. She reclaimed her moral authority from the broken medical system that had held her husband hostage. She died like a warrior. Her dying was painful, messy and imperfect, but that is the uncontrollable nature of dying. She faced it head-on. My brother Jonathan called it a triumph.

Regarding the death of her mother, she came to understand that things that look heartless to outsiders must sometimes be done out of love.

P. 259 ff
Ivan Illich, Medical Nemesis quote: “By working creatively, and in ways yet unthought of, the lobby of the dying and the gravely ill could become a healing force in society.
Chapter 18 beginning on page 259 recounts many of the people who wrote to Ms. Butler after her article appeared in the New York Times. She relates many moving. and interesting anecdotes.

P. 267
Reclaiming death from medicine, the way the natural childbirth movement recaptured birth in the 1970s, is already underway in the form of open rebellion by families like mine; the growth of hospice and palliative care programs; and the widening number of doctors who practice slow medicine contribute to this.

But the economic forces arrayed against reclaiming the deathbed are immense. Reimbursements for advanced medical technologies, which become forms of medical torture when inappropriately deployed, help cover the cost of a sales representative's mortgage payments, a hospital's money – losing emergency room, a surgeon's second or third home, or dividends to stockholders of technology companies. Nothing much will change until we pay doctors and hospitals when they appropriately do less as well as we do now when they inappropriately do too much.

Doctors are often insulted by the suggestion that such financial strictures help shape their medical treatment, but just as surely as the home mortgage deduction promotes home ownership, economic incentives and disincentives encourage specialists to refer patients to hospice care only days before death, essentially dumping them on the program for morphine drips after wringing out every last expensive procedure from their suffering bodies.

The antidote for overtreatment is not under treatment: it's appropriate care. When the body can no longer be healed, there can still be healing for the family and for the soul.
Between 1998 and 2011, pharmaceutical companies and makers of healthcare products spent $2.3 billion on lobbying, making them the single biggest influencer of members of Congress, who in turn pressure Medicare and federal agencies to create regulations that conform to lobbyists’ interests, sometimes to the detriment of patients.

Anyone who attempts to open a public conversation about rehumanizing modern death must be prepared to weather charges of medical rationing, promoting "death panels,", canonizing Dr. Kevorkian, and discriminating against the aged, demented, or disabled. The word "rationing" avoids the reality that our current way of dying maximizes both cost and suffering.

The ideal of Good Death, as our ancestors defined it, was a natural death free of medical flailing. It did not require experts. It took place at home and was neither sudden nor lingering. Just as we do know, our ancestors hoped to die in a familiar place among close friends and family; to be safe and gently cared for in the hour of need.

P.274 ff

In chapter 19, Butler describes "What I wish I'd known."
The natural death is no longer the default pathway. If you want it for yourself or someone you love, it is up to you to seek it out, and it is harder to find than you might think... Every mile on the way to a bad death, every "yes" to a doctor for a last ditch treatment, every dishonest hope, may look at the time like an expression of your love and caring.
The pathway to a natural death is not easily found. The gate maybe overgrown. You will have to use your own moral compass to find it, guided by your guts, your love, and whatever support group you can scrape together.
The Slow Medicine path to death is a path of acceptance. It does not promise freedom from suffering. Its sufferings are plainly visible.

P. 277
Shepherding a parent, spouse, or friend through the last phase of life encompasses six distinct, sometimes looping stages:
1. Fragility: shift your hopes from unrealistic "curing" to "caring." Maximize comfort, happiness, mobility and independence without extending life. Consider any medical treatment of an elderly person, no matter how seemingly minor, as a serious decision. Learn to tell a doctor, "no," or "let us wait."There is no need for your parent's final years to be consumed with pointless, tiring medical appointments.

2. Decline: Accepting that someone you love is beyond the reach of curative medicine is not the same as advocating medical neglect. Try to postpone disability, not death.

3. Disability: when possible, it's better to keep the person at home with various types of home health aides. The author discusses the memoir "Bittersweet Season" by Jane Gross.
Caring for the Caregiver: throughout this journey remember you are engaged in a marathon, not a sprint. Long-term caregivers struggle with exhaustion, the grief of ambiguous loss, anger, money problems, and guilt. They are vulnerable to insomnia, depression, anxiety, neck and back pain, illness and premature death. The typical pattern is to push to the point of collapse before gasping for help. Think in terms of two way compassion: for the afflicted person and for yourself.

4. Failing Health

Palliative care is not a death–oriented practice It is devoted to maximizing quality-of-life and comfort while living with chronic illness, including but not limited to conditions that are life-threatening and ultimately fatal.

A palliative care patient can segue smoothly into hospice care, because the philosophy – comfort first, shared decision-making, clarity about medical goals, coordinated support for the whole family, pragmatism, and limiting burdensome interventions – is similar. Palliative care can sometimes prolong life better than more aggressive medicine.

5. Active Dying

This section deals with avoiding ER visits for dying patients. A Do Not Resuscitate order may not be enough. POLST or MOLST can reduce the risk of unintended ER visits and hospitalizations for patients who are actively dying.

Dementia is a terminal illness and often a miserable death. One should be careful not to allow the medical complex to draw it out.

Dying is not an emergency. Emergency room visits, 911 systems, and intensive care units are all primed to prevent natural death. Engage them with caution. The most important sentences in this book may be, "I request a palliative care consult," "Can you refer me to hospice?," "I request comfort measures only," and "I am concerned about quality of life."

6. Bereavement

I can't help thinking that if we spoke of death more directly and honored its sacredness more – rather than honoring only "the sacredness of life" and pretending that death is part of nature or God's plan – we might respond more wisely in its face and more fully afterward.

There is less permission to grieve and mourn openly today, and it is especially hard for those who live far away from parents and birthplaces. And yet, at life’s great turning points we often hunger for ritual and community

Let the funeral or memorial service bless you with the healing power of shared grieving. Rituals – particularly holding my parents memorial services, responding to condolence letters, and lighting Yahrzeit candles each year in remembrance of them – helped me give form to the deep and complicated emotions that I felt after they died.

Do not be tyrannized by the notion of the Good Death. It is often painful, unpredictable and messy. You need to do the best you can for your loved ones and then forgive yourself. You've done the you could.