A Life Worth Ending

The era of medical miracles has created a new phase of aging, as far from living as it is from dying. A son’s plea to let his mother go.

By Michael Wolff Published May 20, 2012

From left, Nancy, Van, and Michael Wolff in 1958.
On the way to visit my mother one recent rainy afternoon, I stopped in, after quite some constant prodding, to see my insurance salesman. He was pressing his efforts to sell me a long-term-care policy with a pitch about how much I’d save if I bought it now, before the rates were set to precipitously rise. For $5,000 per year, I’d receive, when I needed it, a daily sum to cover my future nursing costs. With an annual inflation adjustment of 5 percent, I could get in my dotage (or the people caring for me would get) as much as $900 a day. My mother carries such a policy, and it pays, in 2012 dollars, $180 a day—a fair idea of where heath-care costs are going.

I am, as my insurance man pointed out, a “sweet spot” candidate. Not only do I have the cash (though not enough to self-finance my decline) but a realistic view: Like so many people in our fifties—in my experience almost everybody—I have a parent in an advanced stage of terminal breakdown.

It’s what my peers talk about: our parents’ horror show. From the outside—at the office, restaurants, cocktail parties—we all seem perfectly secure and substantial. But in a room somewhere, hidden from view, we occupy this other, unimaginable life.

I didn’t need to be schooled in the realities of long-term care: The costs for my mother, who is 86 and who, for the past eighteen months, has not been able to walk, talk, or to address her most minimal needs and, to boot, is absent a short-term memory, come in at about $17,000 a month. And while her LTC insurance hardly covers all of that, I’m certainly grateful she had the foresight to carry such a policy. (Although John Hancock, the carrier, has never paid on time, and all payments involve hours of being on hold with its invariably unhelpful help-line operators—and please fax them, don’t e-mail.) My three children deserve as much.

And yet, on the verge of writing the check (that is, the first LTC check), I backed up.

We make certain assumptions about the necessity of care. It’s an individual and, depending on where you stand in the great health-care debate, a national responsibility. It is what’s demanded of us, this extraordinary effort. For my mother, my siblings and I do what we are supposed to do. My children, I don’t doubt, will do the same.
And yet, I will tell you, what I feel most intensely when I sit by my mother’s bed is a crushing sense of guilt for keeping her alive. Who can accept such suffering—who can so conscientiously facilitate it?

“Why do we want to cure cancer? Why do we want everybody to stop smoking? For this?” wailed a friend of mine with two long-ailing and yet tenacious in-laws.

In 1990, there were slightly more than 3 million Americans over the age of 85. Now there are almost 6 million. By 2050 there will be 19 million—approaching 5 percent of the population. There are various ways to look at this. If you are responsible for governmental budgets, it’s a knotty policy issue. If you are in marketing, it suggests new opportunities (and not just Depends). If you are my age, it seems amazingly optimistic. Age is one of the great modern adventures, a technological marvel—we’re given several more youthful-ish decades if we take care of ourselves. Almost nobody, at least openly, sees this for its ultimate, dismaying, unintended consequence: By promoting longevity and technologically inhibiting death, we have created a new biological status held by an ever-growing part of the nation, a no-exit state that persists longer and longer, one that is nearly as remote from life as death, but which, unlike death, requires vast service, indentured servitude really, and resources.

This is not anomalous; this is the norm.

The traditional exits, of a sudden heart attack, of dying in one’s sleep, of unreasonably dropping dead in the street, of even a terminal illness, are now exotic ways of going. The longer you live the longer it will take to die. The better you have lived the worse you may die. The healthier you are—through careful diet, diligent exercise, and attentive medical scrutiny—the harder it is to die. Part of the advance in life expectancy is that we have technologically inhibited the ultimate event. We have fought natural causes to almost a draw. If you eliminate smokers, drinkers, other substance abusers, the obese, and the fatally ill, you are left with a rapidly growing demographic segment peculiarly resistant to death’s appointment—though far, far, far from healthy.

Sometimes we comb my mother’s hair in silly dos, or photograph her in
funny hats—a gallows but helpful humor: Contrary to the comedian’s maxim, comedy is easy, dying hard. Better plan on two years minimum, my insurance agent says, of this stub period of life—and possibly much more.

Next: Why this is not just a drawn-out, stoic, and heroic long goodbye.

A Life Worth Ending

The era of medical miracles has created a new phase of aging, as far from living as it is from dying. A son’s plea to let his mother go.

By Michael Wolff Published May 20, 2012
On the way to visit my mother one recent rainy afternoon, I stopped in, after quite some constant prodding, to see my insurance salesman. He was pressing his efforts to sell me a long-term-care policy with a pitch about how much I’d save if I bought it now, before the rates were set to precipitously rise. For $5,000 per year, I’d receive, when I needed it, a daily sum to cover my future nursing costs. With an annual inflation adjustment of 5 percent, I could get in my dotage (or the people caring for me would get) as much as $900 a day. My mother carries such a
policy, and it pays, in 2012 dollars, $180 a day—a fair idea of where heath-care costs are going.

I am, as my insurance man pointed out, a “sweet spot” candidate. Not only do I have the cash (though not enough to self-finance my decline) but a realistic view: Like so many people in our fifties—in my experience almost everybody—I have a parent in an advanced stage of terminal breakdown.

It’s what my peers talk about: our parents’ horror show. From the outside—at the office, restaurants, cocktail parties—we all seem perfectly secure and substantial. But in a room somewhere, hidden from view, we occupy this other, unimaginable life.

I didn’t need to be schooled in the realities of long-term care: The costs for my mother, who is 86 and who, for the past eighteen months, has not been able to walk, talk, or to address her most minimal needs and, to boot, is absent a short-term memory, come in at about $17,000 a month. And while her LTC insurance hardly covers all of that, I’m certainly grateful she had the foresight to carry such a policy. (Although John Hancock, the carrier, has never paid on time, and all payments involve hours of being on hold with its invariably unhelpful help-line operators—and please fax them, don’t e-mail.) My three children deserve as much.

And yet, on the verge of writing the check (that is, the first LTC check), I backed up.

We make certain assumptions about the necessity of care. It’s an individual and, depending on where you stand in the great health-care debate, a national responsibility. It is what’s demanded of us, this extraordinary effort. For my mother, my
siblings and I do what we are supposed to do. My children, I don’t doubt, will do the same.

And yet, I will tell you, what I feel most intensely when I sit by my mother’s bed is a crushing sense of guilt for keeping her alive. Who can accept such suffering—who can so conscientiously facilitate it?

“Why do we want to cure cancer? Why do we want everybody to stop smoking? For this?” wailed a friend of mine with two long-ailing and yet tenacious in-laws.

In 1990, there were slightly more than 3 million Americans over the age of 85. Now there are almost 6 million. By 2050 there will be 19 million—approaching 5 percent of the population. There are various ways to look at this. If you are responsible for governmental budgets, it’s a knotty policy issue. If you are in marketing, it suggests new opportunities (and not just Depends). If you are my age, it seems amazingly optimistic. Age is one of the great modern adventures, a technological marvel—we’re given several more youthful-ish decades if we take care of ourselves. Almost nobody, at least openly, sees this for its ultimate, dismaying, unintended consequence: By promoting longevity and technologically inhibiting death, we have created a new biological status held by an ever-growing part of the nation, a no-exit state that persists longer and longer, one that is nearly as remote from life as death, but which, unlike death, requires vast service, indentured servitude really, and resources.

This is not anomalous; this is the norm.
The traditional exits, of a sudden heart attack, of dying in one’s sleep, of unreasonably dropping dead in the street, of even a terminal illness, are now exotic ways of going. The longer you live the longer it will take to die. The better you have lived the worse you may die. The healthier you are—through careful diet, diligent exercise, and attentive medical scrutiny—the harder it is to die. Part of the advance in life expectancy is that we have technologically inhibited the ultimate event. We have fought natural causes to almost a draw. If you eliminate smokers, drinkers, other substance abusers, the obese, and the fatally ill, you are left with a rapidly growing demographic segment peculiarly resistant to death’s appointment—though far, far, far from healthy.

Sometimes we comb my mother’s hair in silly dos, or photograph her in funny hats—a gallows but helpful humor: Contrary to the comedian’s maxim, comedy is easy, dying hard. Better plan on two years minimum, my insurance agent says, of this stub period of life—and possibly much more.

Mike Wallace, that indefatigable network newsman, died last month in a burst of stories about his accomplishments and character. I focused, though, on a lesser element in the Times’ obituary, that traditional wave-away line: “He had been ill for several years.”

“What does that mean?” I tweeted the young reporter whose byline was on the obit. Someone else responded that it meant Wallace was old. Duh! But then I was pointed to a Washington Post story mentioning dementia. The Times shortly provided an update: Wallace had had bypass surgery four years ago and had been at a facility in Connecticut ever since.

This is not just a drawn-out, stoic, and heroic long good-bye. This is human carnage. Seventy percent of those older than 80
have a chronic disability, according to one study; 53 percent in this group have at least one severe disability; and 36 percent have moderate to severe cognitive impairments; you definitely don’t want to know what’s considered to be a moderate impairment.

From a young and healthy perspective, we tend to look at dementia as merely Alzheimer’s—a cancerlike bullet, an unfortunate genetic fate, which, with luck, we’ll avoid. In fact, Alzheimer’s is just one form—not, as it happens, my mother’s—of the ever-more-encompassing conditions of cognitive collapse that are the partners and the price of longevity.

There are now more than 5 million demented Americans. By 2050, upward of 15 million of us will have lost our minds.

Speaking of price: This year, the costs of dementia care will be $200 billion. By 2050, $1 trillion.

Make no mistake, the purpose of long-term-care insurance is to help finance some of the greatest misery and suffering human beings have yet devised.

I hesitate to give my mother a personality here. It is the argument I have with myself everyday—she is not who she was; do not force her to endure because of what she once was. Do not sentimentalize. And yet ... that’s the bind: She remains my mother.

She graduated from high school in 1942 and went to work for the Paterson Evening News, a daily newspaper in New Jersey. In a newsroom with many of its men off to war, Marguerite Vander Werf—nicknamed “Van” in the newsroom and forevermore—
shortly became the paper’s military reporter. Her job was to keep track of the local casualties. At 18, a lanky 95 pounds in bobby socks, my mother would often show up at a soldier’s parent’s front door before the War Department’s telegraph and have to tell these souls their son was dead. Many decades later, she would still go pensive at this memory. She married my father, Lew Wolff, an adman, and left the paper after eleven years to have me—then my sister, Nancy, and brother, David. She did freelance journalism and part-time PR work (publicity, it was called then). She was a restless and compelling personality who became a civic power in our town, elected to the board of education and taking charge of the public library, organizing and raising the money for its new building and expansion. She was the Pied Piper, the charismatic mom, a talker of great wit and passion—holding the attention of children and dinner-party drunks alike.

My father, whose ad agency had wide swings of fortune, died, suddenly, in that old-fashioned way, of a heart attack at 63, during one of the downswings. My mother was 58—the age I am now—and left with small resources. She applied her charm and guile to a breathtaking reinvention and personal economic revival, becoming a marketing executive at first one and then another pharmaceutical company. At 72, headed to retirement but still restless, she capped off her career as the marketing head of an online-game company.

For 25 years, she lived in an apartment building in Ridgewood, New Jersey, in a sitcom mode of sociability and gossip. Once a week, every week, she drove into Manhattan to cook dinner for my family and help my three children with their homework—I am not sure how I would have managed my life and raised children without her.

This is the woman, or what is left of this woman, who now resides in a studio apartment in one of those new boxy buildings that dot the Upper West Side—a kind of pre-coffin, if you will. It is even, thanks to my sister’s diligence, my mother’s LTC
insurance and savings, and the contributions of my two siblings and me, what we might think of as an ideal place to be in her condition. It is a spacious room with a large picture window that, from the ninth floor and my mother’s bed, has an uninterrupted view across town. The light pours in. The weather performs. The seasons change. A painting from 1960 by March Avery, from the collection she and my father assembled—an Adirondack chair facing a blue sea—hangs in front of her. Below the painting is the flat-screen TV where she watches cooking shows with a strange intensity. She is attended 24/7 by two daily shifts of devoted caregivers.

It is peaceful and serene.

Except for my mother’s disquiet. She stares in mute reprimand. Her bewilderment and resignation somehow don’t mitigate her anger. She often tries to talk—desperate guttural pleas. She strains for cognition and, shockingly, sometimes bursts forward, reaching it—“Nice suit,” she said to me, out of the blue, a few months ago—before falling back.

That is the thing that you begin to terrifyingly appreciate: Dementia is not absence; it is not a nonstate; it actually could be a condition of more rather than less feeling, one that, with its lack of clarity and logic, must be a kind of constant nightmare.

“Old age,” says one of Philip Roth’s protagonists, “isn’t a battle, it’s a massacre.” I’d add, it’s a holocaust. Circumstances have conspired to rob the human person—a mass of humanity—of all hope and dignity and comfort.

When my mother’s diaper is changed she makes noises of harrowing despair—for a time, before she lost all language, you could if you concentrated make out what she was saying, repeated over and over and over again: “It’s a violation. It’s a violation. It’s a violation.”
The numbing thing is that you see this all coming—you see it, but purposely and stubbornly don’t see it.

As it started with my mother, it was already advanced for a college friend and close colleague. As an only child, he had less room to hide. I looked on with mild concern at his helplessness. I kept thinking my situation could never get as bad as his—he spoke actually, not comically, of murder. But we all catch up with each other. All train wrecks occur on a time line.

For my mother, it began with her feet. Her complaint, which no doctor could put a useful name to or offer much respite from, was that she felt the skin on her feet was too tight. One evening, almost three years ago, getting into the shower, she caught her lagging foot on the rail of the shower door and went down into the tub. She lay there, shivering in the tepid water until morning, when her neighbor became alarmed. There is a precept here, which no doctor quite spells out: Once it has begun, it has begun; decline follows decline; incident precedes incident. Here’s the medical language: “A decrement in capacity occurs.”

But we’ll cope, of course. My mother’s shower was equipped with special chairs (the furniture of aging is its own horrid story), grab-bars and easy-reach phones installed and I-can’t-get-up beepers subscribed to. She actually learned how to fall (not falling not being an option). At the least sign of a tumble, she would sink almost elegantly to the ground, and then, not being able to get up, she’d beep the police, the affable police, who would come and hoist her to her feet, whereupon she’d fix them coffee and all would be sort of well.

And then a holiday—those unfailing barometers of family health. Thanksgiving 2009 was already a weird one. My wife and I had
split earlier in the year. The woman I was seeing—and had moved in with—was coming. My children were boycotting. It was my mother who was trying to be the strong and constant pillar. She insisted she could do the job. Her neighbor—a man who had been squiring her around for many years—would load the turkey, too heavy for my mother to lift, into the oven. My sister and I would arrive before the handful of other guests to do the finishes. All was in order when we got there—the potatoes boiled and ready to be mashed in one pot, the carrots roasted, the onion custard baked—all in order except that my mother had done these preparations a week before. Every pot yielded an alarming odor. What was worse was her lack of comprehension—and lack of alarm.

Plans, obviously, had to begin in earnest. Her three children—my sister and I in New York, my brother, a software consultant, in Maui—conferred. An independent life goes into receivership—and you think, How did we miss all the failing indicators? My mother, like a rogue accountant, had been hiding much of the evidence: She could no longer tell time, nor count, nor keep track of dates.

Anyway, this is what assisted living is for, no?

We would move her to Manhattan, and, we managed to convince her and ourselves, she’d begin a great new adventure.

She was game—and relieved. The place, the Atria on West 86th Street, was just a few blocks from where my sister, an artist, lives and works. A national chain of residences for the elderly, the Atria is more a real-estate business than a health-care enterprise, providing, at hefty cost—the apartments are in the $8,000-a-month range—quite a pleasant one-bedroom apartment in a prewar building, full of amenities (terraces and hairdressers) and gradations of assistance. But it is important to understand—and there is no reason why one would—that assistance in an assisted-living facility, even as you increase it and pay more for it, is really
not much more than kind words and attendance, opened doors, a bit of laundry, and your medications delivered to you. If there is a need for real assistance of almost any kind that involves any sort of calibration of concern, of dealing with the real complications and existential issues of aging people, then 911 is invariably called. This is quite a brilliant business model: All responsibility and liability is posthaste shifted to public emergency services and the health-care system.

The rate of hospitalization for all other age groups is declining or holding steady, but for people over 65 it’s skyrocketed. The elderly use 50 percent of all hospital days, according to one study. Emergency rooms, the last stop for gangbangers and the rootless, at least in the television version, are really the land of the elderly, and their first step into the hospital system—where, as Medscape matter-of-factly explains, the “inability to recognize normal aging changes ... raises the chances of iatrogenic illness.” Iatrogenic illnesses being the ones caused by hospitals or doctors.

My mother went to the Atria’s after--dinner movie—*The African Queen*, as I -recall—one evening in May and then told someone she was short of breath. My sister got to the emergency room first—St. Luke’s Roosevelt—and called me to say I ought to come.

Everybody would manage his or her parent’s decline differently. Nobody is proud of himself. We all mess it up. This is partly because there is no good outcome. And it is partly because modern medicine is a random process without a real point of view and without anyone ultimately being in charge. The buck is relentlessly passed. Down this rabbit hole, we all become ineffective and pitiful.
My mother’s cardiologist, Dr. Barbara Lipton, a peppy younger woman who, annoyingly, called my mom “Mom,” had been for many years monitoring her for a condition called aortic stenosis—a narrowing of the aortic valve. The advice was do nothing until something had to be done. If it ever had to be done.

This was good advice insofar as she had lived with this condition uneventfully for fifteen years. But now that she was showing symptoms that might suddenly kill her, why not operate and reach for another few good years? What’s to lose? That was the sudden reasoning and scenario.

My siblings and I must take the blame here. It did not once occur to us to say: “You want to do major heart surgery on an 84-year-old woman showing progressive signs of dementia? What are you, nuts?”

This is not quite true: My brother expressed doubts, but since he was off in Maui, and therefore unable to appreciate the reality of, well, the reality of being near, we discounted his view. And my mother protested. Her wishes have always been properly expressed, volubly and in writing: She urgently did not want to end up where she ultimately has ended up. She had enough sense left to resist—sitting in the hospital writing panicky, beseeching, -Herzog-like notes, to anyone who might listen—but of course who listens to a woman who scribbles such notes?

The truth is you’re so relieved that someone else has a plan, and that the professionals with the plan seem matter-of-fact and unconcerned, that you disregard even obvious fallacies of logic: that the choice is between life as it was before the operation and death, instead of between life after the operation and death.

Here’s what the surgeon said, defending himself, in perfect Catch-22-ese, against the recriminations that followed the stark and dramatic postoperative decline in my mother’s “quality-of-life baseline”: “I visited your mom before the procedure and fully informed her of the risks of such a surgery to someone showing
signs of dementia.”

You fully informed my demented mom?

The operation absolutely repaired my mother’s heart—“She can live for years,” -according to the surgeon (who we were never to see again)—but left us longing for her level of muddle before the valve job. Where before she had been gently sinking, now we were in free fall.

She was reduced to a terrified creature—losing language skills by the minute. “She certainly appears agitated,” the psychiatrist sent to administer anti--psychotic drugs told me, “and so do you.”

Six weeks and something like $250,000 in hospital bills later (paid by Medicare—or, that is, by you), she was returned, a shadow being, to 86th Street and her assisted-living apartment.

Unmoored in time, she began to wander the halls and was returned on regular occasions to the emergency room: Each return, each ambulance, each set of restraints, each catheter, dealt her another psychic blow.

And then we were evicted. I had been pleasantly surprised when my mother moved in that only a month-to-month lease was required. Now I learned why. Dying is a series of stops, of way stations, of signposts. Home. Assisted living. Nursing care. Hospice. You are always moving on.

But before we were evicted, there was another Thanksgiving—this one at my house, my mother collected and transported, my children reassembled—and then the next day, the “event.” The big one.

We had reached, I gratefully believed, her end.
MS arrived, and once more, we were back in the St. Luke’s emergency cubicles. My mother’s “presentation” could not have seemed bleaker. The young resident was clearly appalled that we might have strayed outside the time frame for administering the drug that could slow the effects of what surely seemed to be a stroke. Of course, they were yet game to try. But we held our ground: We elected to do nothing here (prompting much renewed scrutiny of the health-care proxy). And please note the DNR. Hours passed. I left and came back. My sister left and came back. One of my mother’s aides left and came back.

And then those words, which turn out, in some instances, not to be a relief at all: “She seems to be out of the woods.”

What? How?

She had not had a stroke. She’d had a massive seizure. The differences between which being not exactly clear. And, if she had more seizures, which she likely would, this would kill her, an explanation and urgency that somehow resulted—“Did you agree to this?” I said to my sister. “I don’t think I did, did you?” “I don’t think so”—in my mother getting vast amounts of anti-seizure drugs, as well as being moved, once again, into more or less long-term hospital residence.

Coherence was completely gone. All that was left was a jumble of words and incredible anger.

Oh, yes, and here was the thing: The anti-seizure drugs were preventing further devastating and probably lethal seizures but, in themselves, were frying her brain even more.

And too, within a few weeks of lying in bed and resisting this final cataclysm, what abilities she had to walk, what slow and
shambling remnant of walking, were gone.

This is where we were: immobile and incoherent. And filled with rage.

And so the first effort to directly talk about the elephant.

It happened in an interior room at the hospital, too small for much, and filled with cast-off furniture, into which fit her doctor, her neurologist, her social worker, and my sister and me. It seemed like the adult thing for us to do, to face up to where we were, and to not make these people have to tiptoe around the obvious.

I thanked everybody for what they had done, and then said reasonably: “How do we get from here ... to there?”

An awkward number of beats.

NEUROLOGIST (shifting in his chair): “I think we want to define here and there”—and tossing to the doctor.
DOCTOR: “Your mom is quite agitated. So we don’t really know what her less-agitated state will be.”

MY SISTER: “What are the chances that she will come back to anything like where she was before the seizure?”
SOCIAL WORKER: “We always have to deal with a variety of possible outcomes.”
ME: “Maybe you could outline the steps you think we might take.”
DOCTOR: “Wait and see.”
NEUROLOGIST: “Monitor.”
DOCTOR: “Change the drugs we’re using.”
MY SISTER: “Can we at least try to get a physical therapist, someone who can work her legs, at least. I mean ... if she does improve, she’s left without being able to walk.”
NEUROLOGIST: “They’ll have to see if she’s a candidate.”
ME: “So ... okay ... where can you reasonably see this ending up?”
NEUROLOGIST: “We can help you look at the options.”
ME: “The options?”
SOCIAL WORKER (to my sister): “Where she might live. We can go over several possibilities.”
ME: “Live?”

It was my Maui brother who, with marked impatience, suggested that I obviously had no idea how the real world works. Such a conversation, treading on legal fine lines and professional practices, must be conducted in a strict code—keep saying, he advised, “quality of life.”

A week later, same uncomfortable room:

ME: “Obviously we are concerned on a quality-of-life basis.”
my sister: “She is completely transformed. Nothing is as it was. She’s suffering so much.”
DOCTOR: “The baseline has clearly dropped.”
NEUROLOGIST: “The risk is that the levels of medication that the agitation might respond to could depress her breathing.”
ME: “Again, this is a quality-of-life issue, right?”
DOCTOR: “Of course.”

ME: “The agitation seems extreme enough to warrant I would think going some distance, considering the quality-of-life issues. Even if that—”
NEUROLOGIST: “I’m not sure I’d be comfortable ...”
ME (with a sudden brainstorm): “Or what happens if you just discontinue the drugs? Just cut them out.”
NEUROLOGIST: “Cold turkey could precipitate a massive seizure.”
ME: “And death?”
ME: “Is this an option?”
NEUROLOGIST: “You have to make that decision. We can’t force her to take medication.”
ME: “Hum.”
Discontinuing the medication felt like both a solemn and giddy occasion. A week passed, and then the doctors began to report in a chipper way that she was doing well, all things considered. She had withstood the shock to the system. She was stable.
And then the social worker came around to say we were coming threateningly close to the maximum number of hospital days for which Medicare would pay. (We’d heaped another few hundred thousand in cost on the American taxpayer.)

“Now,” said my sister taking the straight-man role, “what do we do?”
My mother—infuriating us with her primal stubbornness—was transferred to the locked-floor dementia ward at the Atria facility in Riverdale, where the only caveat to patient behavior seemed to be a strict rule against hitting. Nine days later, after my mother socked a locked-floor aide, we were back in our room at St. Luke’s, where—because of her brief discharge, she could begin her Medicaid hospital-stay allotment from day one—she was happily received (for another couple of hundred grand).

What do you do with your mom when she can’t do anything—anything at all—for herself? This is not, first and foremost, about how you address her needs but about where you put her. No, it is first about who or what facility will take her. No, it is first about what member of the family will actually sort through the incredibly byzantine and deadening options—or lack of options.
It is at this point that I became unreasonably mad at my Maui brother. In a way I understood the basis of his excuse: It was not a coincidence that he was living in Maui—his twenty years in paradise were in part an exercise of the modern right to distance himself from his family, a point which he was militantly maintaining now. He lived in Maui precisely to be far from all
this. It was notable that among the people with whom I shared my tales-of-mother crisis, many, with far-flung ailing parents, identified themselves as the Maui brother. Of all things to escape, this might be the big one. And, too, in my Maui brother’s defense, all responsibility is relative: If he was doing less than I was doing, I was doing by a significant leap less than my sister was doing.

It is among the most reductive facts in this story: Women take care of the old. They can’t shake it because they are left with it. In the end, it is a game of musical chairs. The girl is the one almost invariably caught out.

My sister assembled the list of potential nursing homes, special elder-need facilities, and palliative-care centers in commutable distance. I grudgingly went along to the best after she’d eliminated the worst. Medicare grades each of these institutions on a five-star scale. Four stars were already charnel houses. One star therefore unimaginable. Just about the only five-star facilities in Manhattan are for HIV-positive patients.

Finely tuned into my mother’s profound fear of virtually all strange presences, touches, and noises, and yet her need for constant attention and reassurance, my sister found fault with every place. This might have finally annoyed me, except for the fact that each of these places wanted you to pay prodigiously for its depressing indifference, and, what’s more, many either excluded my mother’s condition or had waiting lists that would, it seemed reasonable to assume, outlast my mother.

Hospice was the best alternative. But while my mother was surely dying—with her doctors gladly willing to certify her in this regard—hospice, we so learned, was not for the certainly dying but the promptly dying.

Curiously, and unhelpfully, it was at this time that one of the neurologists making occasional visits took it upon himself to reevaluate my mother, declaring that her diagnosis was wrong. She did not have Alzheimer’s, as everyone seemed to assume. She had dementia, surely, but it was not going, and would not follow, the pattern of Alzheimer’s. She would not disappear; she
would maintain some awareness and consciousness of her surroundings, he said, as though this were good news. It was Marion, my mother’s aide, a woman of remarkable humor and constancy, who had shown up one day, sent by a random agency—and who has now been with my mother every day for almost eighteen months, not a day missed—who suggested just “bringing her home.” The best Manhattan approximation of “home” when there is no family homestead seemed to be the studio apartment where she is now, a short walk from my sister’s house.

My brother could only see this as a quagmire of cost and responsibility. My sister assured him, as the doctors were assuring us, that six months was a realistic outside framework. My brother did his own Google search. “Yes, yes, they’re right, six months at this stage is what you can expect. But you know what they die from? They die from neglect! **Neglect!** There’s no neglect here! It’s unnatural!” I signed the lease.

“Who can believe it’s been a year?” said Marion when I signed the lease for another year a few weeks ago.

My sister comes over every morning. She brings the groceries, plans the menu, and has a daily routine for stretching my mother’s limbs (this in addition to the administration and paying of caregivers, and the collecting of monies from the always recalcitrant John Hancock). I’m here a few times a week (for exactly 30 minutes—no more, no less). Her grandchildren, with an unalloyed combination of devotion and horror, come on a diligent basis. And we have our family events: holiday meals eaten around her bed. Her 84-year-old brother and his wife visit regularly, and so does her 89-year-old cousin and her daughter. She even has one friend left who still calls her every day (all the other friends fell away a long time ago), conducting an extremely one-sided conversation over the speaker phone.

An occasional letter arrives from retired friends in sunny climes who have somehow missed or have been unwilling to register my mother’s condition. They take up in mid-conversation, proposing lunch the next time they are in the area, and recounting details of lives still going on. They continue to regard my mother as a
woman who chats, cooks, reads, gossips, and commands attention. Always, suddenly, shatteringly, reading these letters, I see her this way too. The absurdity of where we are, here on death row, measured not just in our heartache but nationally in hundreds of billions of dollars, can only be missed by the people who have no experience with the true nature and far-flung extremes of quality of life. A few weeks ago, my sister and I called a meeting with my mother’s doctor. As others had fallen to the wayside, the head of gerontology at St. Luke’s, Dr. Brenda Matti--Orozco, a patient, long--suffering woman had stepped up to this job.

The doctor eased into our meeting with tales of health-care-administration woes, of cuts in Medicaid, of fewer beds in fewer facilities around town—did we know, she asked, that Cabrini had closed? Some people, she said, just upped and left their old relatives in the hospital. So much for the small talk.

“It’s been a year,” I began, groping for what needed to be said: Let’s do this, close it down, end it, wanting to murder the euphemisms as much as my mom. “We’ve seen a series of incremental but marked declines.” My sister chimed in with some vivid details. The doctor seemed at first alarmed that we might be trying to foist my mother back on her and the hospital and relieved when we said, frankly, we planned never to return to a hospital. We just wanted to help her go where she’s going. (Was that too much? Was that too specific?) She does seem, the doctor allowed, to have entered another stage. (These half-life stages of death, such that you never reach it.)

“Perhaps more palliative care. This can ease her suffering, but the side effect can be to depress her functions. But maybe it is time to err on the side of ease.” Another advance of sorts in our grim descent: Over uncertain weeks or months, her functions will depress even further in this ultimate, excruciating winding down.

“Your mom, like a lot of people, is what we call a dwindler,” said
I do not know how death panels ever got such a bad name. Perhaps they should have been called deliverance panels. What I would not do for a fair-minded body to whom I might plead for my mother’s end.

The alternative is nuts: to look forward to paying trillions and to bankrupting the nation as well as our souls as we endure the suffering of our parents and our inability to help them get where they’re going. The single greatest pressure on health care is the disproportionate resources devoted to the elderly, to not just the old, but to the old old, and yet no one says what all old children of old parents know: This is not just wrongheaded but steals the life from everyone involved.

And it seems all the more savage because there is such a simple fix: Give us the right to make provisions for when we want to go. Give families the ability to make a fair case of enough being enough, of the end’s, de facto, having come.

Not long after visiting my insurance man those few weeks ago, I sent an “eyes wide open” e-mail to my children, all in their twenties, saying this was a decision, to buy long-term-care insurance or not, they should be in on: When push came to shove, my care would be their logistical and financial problem; they needed to think about what they wanted me to do and, too, what I wanted them to do. But none of them responded—I suppose it was that kind of e-mail.

Anyway, after due consideration, I decided on my own that I plainly would never want what LTC insurance buys, and, too, that this would be a bad deal. My bet is that, even in America, even as screwed up as our health care is, we baby-boomers watching our parents’ long and agonizing deaths won’t do this to ourselves. We will surely, we must surely, find a better, cheaper, quicker, kinder way out.
Meanwhile, since, like my mother, I can’t count on someone putting a pillow over my head, I’ll be trying to work out the timing and details of a do-it-yourself exit strategy. As should we all.