



A Bittersweet Season: Caring for Our Aging Parents--and Ourselves

By Jane Gross

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When Jane Gross found herself suddenly thrust into a caretaker role for her eighty-five year-old mother, she was forced to face challenges that she had never imagined. As she and her younger brother struggled to move her mother into an assisted living facility, deal with seemingly never-ending costs, and adapt to the demands on her time and psyche, she learned valuable and important lessons. Here, the longtime *New York Times* expert on the subject of elderly care and the founder of the *New Old Age* blog shares her frustrating, heartbreaking, enlightening, and ultimately redemptive journey, providing us along the way with valuable information that she wishes she had known earlier. We learn why finding a general practitioner with a specialty in geriatrics should be your first move when relocating a parent; how to deal with Medicaid and Medicare; how to understand and provide for your own needs as a caretaker; and much more. Wise, smart, and ever-helpful, *A Bittersweet Season* is an essential guide to caring for aging parents.

Includes chapters on the following subjects:

Finding Our Better Selves

The Myth of Assisted Living

The Vestiges of Family Medicine

The Best Doctors Money Can Buy

The Biology, Sociology, and Psychology of Aging

Therapeutic Fibs

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Editorial Review

Review

“Unique and lovely. . . . How wonderful to have [Gross’s] mix of sage advice, pithy insights and practical discoveries at hand.” —Abraham Verghese, author of *Cutting for Stone*

“Nothing can fully prepare you for the overwhelming experience of caring for your elderly parents, but Jane Gross’s new book, *A Bittersweet Season*, comes awfully close Gross is an incisive critic of our systems and institutions.” —*The Seattle Times*

“A forthright story and trenchant advice. . . . Intimate and affecting.” —*The New York Times Book Review*

“A smart and highly detailed book about navigating the complex eldercare system as it related to healthcare, insurance and end of life. . . . The kind of book social workers might suggest to the family who craves more perspective about the logistical issues mentioned above. . . . Readers will find they are engaged by how much they learn in reading Gross’s account.” —*Psychology Today*

“Hugely informative, and a gripping read.” —Betty Rollin, author of *Last Wish*

“*A Bittersweet Season* is sure to become required reading for anyone with an elderly parent who depends on long-term care. It’s also a worthwhile read for anyone who is interested in America’s health care system as it braces for the demands posed by demographic changes that include a sharp rise in the group now termed the “old old.” —*The Huffington Post*

“An invaluable guide. . . . Excellent. . . . Jane Gross has taken her own painful experiences and worked hard to give needed help to us all.” —*Commonweal Magazine*

“With great insight and empathy, Jane Gross guides us through one of the most difficult of all life transitions—the decline and death of our parents. Not only does she provide a wonderfully helpful guide for how and what to do, and when. She also enables us to understand what our parents need, and what we ourselves need, during this passage.” —Robert B. Reich, author of *Aftershock*

“This is tough stuff, and Gross writes movingly about the toll it takes on her and other caregivers. . . . She’s serious about documenting the often hidden workload borne by middle-aged daughters and sons.” —*The Boston Globe*

“*A Bittersweet Season* deals with a sobering topic. But the narrative is so lively and informative that readers will come away feeling more prepared than pessimistic An intelligent guide to handling the onset of old age with sagacity and sensitivity.” —*BookPage*

“This book is an invaluable and comprehensive primer on what most Americans will face soon. Its honest and loving message is to prepare yourself now.” —Jeff Madrick, author of *Age of Greed*

“Readers may pick up this very well-written book to learn about taking care of their own ailing parents, but will soon realize that it’s also a wake-up call to become educated in order to make informed decisions about

their own inevitable aging.” —*The New York Jewish Week*

“*A Bittersweet Season* is a brave and compelling book by a masterful storyteller.” —Carol Levine, director, Families and Health Care Project, United Hospital Fund

About the Author

Jane Gross was a reporter for *Sports Illustrated* and *Newsday* before joining *The New York Times* in 1978. Her twenty-nine-year tenure there included national assignments as well as coverage of aging. In 2008, she launched a blog for the Times called *The New Old Age*, to which she still contributes. She has taught journalism at the University of California, Berkeley, and at Columbia University, and was the recipient of a John S. Knight Fellowship. She lives in Westchester County, New York.

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Prologue

Finding Our Better Selves

The day I started writing this book, I spent hours commiserating by telephone with three friends who were being turned upside down by the needs of their aging parents.

One lived a short distance from her mother, who was in precarious health, bouncing back and forth between home and hospital, unwilling to consider a retirement community or nursing home. For months, without time to rest and regroup, my friend, herself nearing the end of a fatal illness and keeping it from her mother, had managed a series of medical and home care emergencies. She was running on empty.

The second friend, rocked by the financial strains and childrearing conflicts that often follow divorce, had largely abdicated to his siblings the demands of long-distance supervision of two increasingly disabled parents, one lost in the fog of Alzheimer’s disease and the other plagued by stress pain and the broken bones of osteoporosis. When my friend tried to do his fair share of the work, he was overwhelmed. When he didn’t try, he was conscience-stricken.

The third friend was considering making a cross-country move to be closer to his mother, who was then past ninety and losing her customary verve. Driving had become risky, and her once-daily walks to the store or the library were just too much sometimes, now that simply dressing or preparing meals took so much energy. My friend knew his mother needed more from him than three-times-a-day phone calls. And he wanted more from her as their time together dwindled.

Before that day was over, I had also spoken to each friend’s mother, as I do regularly, since all of them are dear to me. What they had to say, unbidden, was the flip side of my earlier conversations with their children. These three strong-willed old women were grateful for their children’s devotion but resistant to giving up the reins. They were embarrassed by their own diminished capacity and frightened of what lay ahead, but nothing was worse, they said, than being a burden. Like my mother, who died in 2003, they fought dependence, even as it became inevitable.

All of my conversations served as a fitting reminder that we stand at an unprecedented demographic

crossroads. Never before have there been so many Americans over the age of eighty-five. Never before have there been so many Americans in late middle age, the huge baby boom cohort, responsible for their parents' health and well-being. Most often, neither the aged parents nor the adult children are prepared for this long, often tortured, time in life, or for these role reversals, which are unanticipated, unwelcome, and unfamiliar. How do we become our parents' parents without robbing them of their dignity? How do they let us? How do we collaborate with our siblings, leaving behind any baggage we may have with them, or manage on our own if we are only children?

The task is to get through it with grace, mindfulness, and good sense: to do the very best we can for our parents without sacrificing the lives we've built for ourselves—our families, our jobs, and our own financial future, which is the last thing they'd want us to do. But how do we know when it's still appropriate to aggressively pursue medical care, try to fix everything that's broken, and restore our parents to a measure of health, vitality, and dignity? How do we know when, logistically and financially, we must break a solemn promise not to "put them away" (and how do we forgive ourselves for doing it, if we must)? How do we know when the time for heroics has passed? Our parents may have escaped earlier threats to their health—strokes, cardiac events, cancer—and lived longer than any generation before them, but eventually some things are just going to wear out. Their death certificates will say they died of heart failure or diabetic complications or respiratory failure, because the government has decreed that "old age" is not an acceptable cause of death. I beg to differ. At a certain point, the wheels simply fall off the bicycle.

So here we are, not just with a herculean job but with a front-row seat for this long, slow dying. We want to do all we realistically can to ease the suffering, smooth the passing, of our loved ones. But we also have the opportunity to watch what happens to our parents, listen to what they have to say to us, and use that information to look squarely at our own mortality and prepare as best we can for the end of our own lives. In fact, we have the opportunity to become better people, wiser and stronger, not simply older and grayer. We can make something of this crisis, or we can endure the experience until it's over and then escape back into the daily buzz of our lives until suddenly it's our turn.

That is what this book is about: how we get through this time, no matter how long it lasts. It is written from the far shore of caregiving, an all-consuming and life-altering experience that wrings you out, uses you up, and then sends you back into the world with your heart full and your eyes open, if you let it. First and foremost it is my own story—mine, my mother's, and my brother's—the one I know best. But it will be amplified and enriched, at every turn, by the people I've interviewed on this subject over the years as part of my job for *The New York Times*—the elderly, their adult children, professionals in the field—and more recently by the hundreds of thousands of monthly readers of the blog I launched for the Times, called *The New Old Age*, the first such forum for two intersecting generations finding their way through a timeless challenge but never before experienced in these daunting new ways or in these numbers.

Although my caregiving days are behind me, they are vivid still. In the space of three years, between 2000 and 2003, my mother's ferocious independence gave way to utter reliance on her two adult children. Garden-variety aches and pains became major health problems; halfhearted attention no longer sufficed, and managing her needs from afar became impossible. The time had come for my mother's reverse migration, from a retirement community in Florida to another in New York, and in short order to a nursing home. By the end of her life, at eighty-eight, she was paralyzed, incontinent, could not speak, was losing the ability to swallow, and wanted nothing so much as a dignified way to die.

Those are the bare-bones facts. Missing is the panic of being in charge; and the shock to my brother, Michael, and me when our competence and resources proved all but useless in the face of America's

incoherent and inadequate safety net for the frail elderly. We were flattened by the enormous demands on our time, energy, and bank accounts; the disruption to our professional and personal lives; the fear that our time in this parallel universe would never end and the guilt for wishing that it would. I can tell you now that it was worth every dreadful minute, a transformative experience. But at the time, living in the eternal present tense, all we could manage was muddling from one day to the next.

My brother and I were late children, so we reached this juncture before our friends and colleagues, who, innocent of experience, telegraphed the belief, painful to us, that we were exaggerating how awful it was. Only occasionally did they say it out loud, but in the silence between sentences I could hear judgment: *This can't be as hard as you're making it sound. Old people get sick and die all the time. This isn't your child, or your spouse, or yourself. It's inevitable.*

It was a lonely time. I was too tired and too sad for socially appropriate chitchat; I emptied the room at cocktail parties with gloom-and-doom stories nobody wanted to hear and quickly found it easier to just stay home. My brother, luckily, seemed to cross more easily between these disparate worlds in which we found ourselves.

At work, I tried to keep pace with my job while fielding my mother's incessant phone calls, chasing down doctors, phoning in prescriptions, hiring geriatric care managers and aides, arguing with my brother, fighting back tears, and dashing out of the newsroom for emergencies. Had I been a parent, I might have been just as stressed, but part of my energies would have been invested in a child's bright future. Old people may have good days, and it was my job to maximize those for my mother, but they don't have bright futures.

Among my somewhat younger friends and colleagues, the fear and confusion I remember has now become commonplace. I hear it from behind the partitioned cubicles at work, in weary discussions on the train platform or in the supermarket checkout line, at business meetings with people I barely know. A total stranger confides his feelings of guilt at letting his sister do all the heavy lifting. Another, ashamed, says he recoiled when shaving his father for the first time. A third is at her wit's end because her parents, usually frugal coupon clippers, have for months been paying rent at an assisted living facility but still refuse to leave their home. A fourth cannot afford home care for his mother and wants her to end her days in his house but wonders at the effect on his children.

The same day that I tried to console my three friends, and their mothers, I had an appointment with my internist, who spent half the visit telling me about her mother's ups and downs since her move to a continuing care retirement community. When I spoke to my literary agent, whose father was in failing health and would die within months, she was passing the caregiver's baton to her brother on the eve of an overseas vacation. Colleagues wanted to know the cost of a home health aide, an explanation as to why adult diapers fit women better than men, and product reviews for medical alert pendants and staircase chair-lifts. I also bumped into a neighbor whose mother-in-law, recently widowed, was no longer talking to her. With the best of intentions and a clear head, my neighbor had invited a geriatric social worker to help open a difficult family dialogue. Her mother-in-law was enraged. The list goes on.

So what did I have to offer the dozen-plus people who had shared their heartache with me in the space of a single day (and not an atypical one in that regard)? And, more pertinent, what do I have to offer you? Alas, not a comprehensive rule book for being your parent's parent; I don't believe there is such a thing, not one that tells the truth. If there had been, I assure you I would have found it and read it when I needed it most.

But I can share with you my hard-earned list of tips that you won't find in the growing collection of how-to books and websites. I can describe my mistakes and triumphs—I hope in a constructive way—as well as

make other suggestions, things for you to do or at least think very hard about, regardless of the fact that no two families face the same issues.

I can tell you, from experience, that if you take charge too soon, you will patronize and humiliate your parents, but if you step in too late, their manageable problems will have turned unmanageable. I will try to give you advice for determining when the right time has arrived. I can tell you how to initiate family discussions if your parents or siblings prefer to avoid them and how to participate in such conversations even if you'd rather not. I can tell you that most bad decisions are made in the heat of a crisis, when alarm and ignorance collide. I can tell you that it is usually possible to slow things down—refuse to be rushed by doctors, discharge planners, and others who have different agendas than yours—and demand the time to consider alternatives calmly and deliberately.

I can tell you how to work out a fair division of labor with siblings whose hearts are in the right place but who are not hardwired to help in certain ways. I can tell you how to appreciate assistance when you get it, how to conserve energy by avoiding unproductive resentment when you don't, and how to relax exacting standards that guarantee nothing anyone else does will be good enough. I can make suggestions about looking after yourself so you don't fall apart when someone else needs you, having learned the hard way. And I can ask uncomfortable questions about whether your insistence on doing everything, your way and with less help than is available, is about solving real problems, satisfying your ego, or settling old scores.

I can tell you what various entitlement programs pay for, and what they don't; which situations are covered by long-term care insurance, and which aren't; and why workplace accommodations designed for child care don't help much when you're caring for an elderly parent. I can tell you when it might be wise to avoid specialists, who are trained to cure and consider anything less a failure, and instead search for a primary care doctor with an interest in geriatrics—the biology, physiology, sociology, and psychology of the elderly. Among other things, geriatricians know the difference between quality of life and quantity of life, and can explore with an elderly parent, and with you, where to draw that line.

I can tell you to stay out of emergency rooms and hospitals to the extent possible and never to leave your parents there to fend for themselves. I can tell you that taking an elderly person for a single test—say, an MRI—is generally an all-day affair, so it's a bad idea to tell your boss you'll be back after lunch. I can tell you to leave a spare pair of glasses in the car; to keep the gas tank full and the driveway shoveled; to always carry your cell phone charger; and to maintain an updated list of your parents' medications. All of this will prepare you best for dealing with inevitable emergencies.

I can tell you not to be impressed by grand marble staircases in assisted living communities, which are too slippery and steep for the elderly ever to use; these decorative flourishes are there to reassure you that you've moved Mom or Dad to a nice place and needn't feel bad about it. Better you should ask if there's anyone with medical training around after six at night. And I can tell you that the rude sounds and smells of a nursing home, which assault you the first time you cross the threshold, will likely become less depressing over time, and that they count for less than the number of registered nurses or the turnover among aides; more important, they will be less disturbing to your parents than to you because old people are at a different, more accepting place, or will be soon.

I can tell you all of these things and more. But the most important thing I can tell you is that being clueless—utterly clueless—is the central and unavoidable part of this experience, perhaps the greatest challenge to those of us who pride ourselves on knowing what we're doing, who like being in control. That's because every decision—medical, residential, financial, personal—is contingent on the particular trajectory of your parent's decline. I can't tell you how your mother or father will die, how long it will take,

how much suffering it will involve, what it will cost, how you will pay for it, what will happen to your career or your marriage in the meantime, or whether the experience will bring your family together or pull it apart. All of that depends on imponderables, things you can't know or prepare for no matter how smart you are, how organized, or how loving and attentive.

So even more important than seeking and dutifully following prescriptive advice, in my experience, is learning to roll with the punches, to play without a net. To some, improvisation comes naturally. To me, it didn't. I hated it when my elaborate plans went awry. And I beat myself up over "bad" decisions when there really was no such thing, given the situation. Forgive the New Age-speak, but this is all about the journey, not the destination, because we all know the final outcome.

My brother, who flies by the seat of his pants better than anyone I know, found my obsessive strategizing exasperating and a waste of energy, my own and his, when I tried to force his participation. I found what I considered his la-di-da approach infuriating and irresponsible. With the benefit of hindsight, we've come full circle. He says he's grateful for the plans I made that actually worked, and I'm grateful for his nimbleness when they didn't. So consider, if you must, possible if/then scenarios. But try to avoid woulda-coulda-shouldas, except as a guide for the next crisis or as hardwon wisdom to pass along—gently, very gently—to friends.

My mother's lament, that we live too long and die too slowly, has become more common, with impact on two generations, as medical science has made it possible to keep very sick and very old people alive longer. The typical eighty-five-year-old, geriatric researchers say, can expect more than two years at the end of his life when he is totally dependent on others for the most basic daily activities: getting out of bed, getting dressed, going to the bathroom, eating. And the eighty-five-and-over group, by far the fastest growing in America, is expected to more than double by 2035, according to census projections, to 11.5 million, from about 5 million as I write. By then the youngest of the baby boomers, 77 million strong, will be celebrating their seventieth birthdays. This is a demographic Category 5 hurricane bearing down on weak levees.

These alarming numbers were not at my fingertips until my mother was face-to-face with the serial humiliations of advanced age; nor, for the most part, were they at my friends' or colleagues'. So what I took for judgment I now see as ignorance or denial. That denial—the widespread notion that our parents, and by extension ourselves, will beat the odds, play tennis at eighty or ninety, and then drop dead with no fuss and bother—has been fed by the mainstream media, which until very recently offered little or no information to help two generations through this unprecedented and arduous passage. Why is the coverage of old age mostly happy talk—wizened mountain climbers or marathoners; nursing homes that permit, even celebrate, consensual sex; weddings on the far side of one hundred? Uplifting?

Sure. Possible? Of course. Typical? Hardly.

No wonder we're so ill prepared.

When my mother, Estelle Gross, became my brother's and my responsibility, we knew nothing about entitlement programs. (*What do you mean Medicare doesn't cover the cost of home care or assisted living or a nursing home?*) We knew nothing about the advantages and disadvantages of hiring aides through agencies or word of mouth. (*What do you mean the agency aide needs permission from a supervisor before picking up my mother from the floor if she falls?*)

We knew nothing about hospital discharge planning. (*What do you mean she has to leave tomorrow when we*

have no satisfactory place to take her?') We knew nothing about geriatric medicine. (What do you mean emergency rooms and intensive care units can cause a form of psychosis in the elderly or that a catheter can lead to an undiagnosed urinary tract infection and even death?)

We knew nothing about Medicaid spend-downs, in-hospital versus out-of-hospital “do not resuscitate” orders, Hoyer lifts, motorized wheelchairs, or assistive devices for people who can neither speak nor type. We knew nothing about “pre-need consultants,” who handle advance payment for the funerals of people who aren’t dead yet, or “feeders,” whose job it is to spoon pureed food into the mouths of men and women who can no longer hold a utensil.

Obituaries and paid death notices tell stories of the dead and those who loved them, generally chronicle lives of accomplishment, cite cause of death, and list survivors. But they rarely include any mention of suffering other than the occasional reference to a long illness. What was that long illness like? Who did the messy work that often surrounds dying? Did some family members go missing when the going got tough? Did the dying man or woman know or care? Did he or she hear the bedside squabbles about end-of-life decisions? And what happened next, after the donations-in-lieu-of-flowers, the wake or the shiva, the graveside service? Did the grown children fight over their inheritance or, by then, was there nothing left?

My aim here is to give more precise and vivid meaning to the platitude that old age isn’t for sissies. I want to try to make sure that adult children, our ranks growing, are not as isolated and ignorant as my brother and I were, lurching from crisis to crisis without enough reflection, information, or support. Maybe I can help other sons and daughters empathize with the growing mountain of loss in their parents’ lives, make peace with an unwelcome role reversal, and adjust to the changed architecture of their families. Maybe I can set an example for how to finish unfinished business with parents, find a more peaceful place in relationships with siblings, and lay a foundation for a mature relationship with brothers and sisters once all the “grown-ups” are gone.

Even before I understood how desperate people were for this kind of information, my editors at the *Times*—many of them entering the time of life when responsibility for their own parents was a daily concern—embraced the line of reporting I’d initiated. The demographics trumped the old notion that nobody would want to read such depressing fare over breakfast. Most of my stories wound up on the front page, the precious real estate usually reserved for war, politics, and natural disasters. The reader response was overwhelming, and the stories invariably rode the top of the “most e-mailed” list.

Between 2004 and 2008, *Times* readers learned, along with me, about the astronomical cost of advanced old age for all but the wealthy and the destitute, an unintended consequence of government programs that date to the mid-1960s, when life expectancy was seventy. They learned, along with me, the difference between Medicare and Medicaid, between assisted living and continuing care retirement communities, between home health aides hired from agencies and those recommended over the back fence, between slow medicine and comfort care.

In the summer of 2008, I launched a blog, *The New Old Age*. The introductory post, “Our Parents, Ourselves,” drew 710 comments; the first month there were 907,000 page views. Readers were hungry for information and grateful for a place to vent. Mostly they were overwhelmed adult children, but their parents chimed in, too, usually saying that they yearned for a legal and graceful exit when frailty or dementia trapped them in lives that no longer had meaning for them. The generously shared comments, like the findings of my earlier reporting, sometimes confirmed and sometimes contradicted my personal experience, and filled in many of the gaps.

I am not an only child or a member of a large extended family, so I've called on the experience of others who have walked that path, amateurs and professionals alike. I am childless, as is my brother, so I've turned to those who are themselves parents for stories of the daily choices they made between cheering at a child's Little League game and bringing dinner to an ailing parent. I've compared my own good fortune to the experience of adult children who, unlike my brother and me, have no savings to dip into.

I've distilled advice I've heard and read on taking away a parent's car keys or on begging them to leave a beloved home. I've done the same for guidance on caring for two failing parents in tandem or one right after the other, or moving a frail parent into your home or relocating to theirs. I'll discuss, in a very limited way, the special rigors of Alzheimer's disease and the unenviable task of taking care of someone who no longer knows who you are. And I'll review disputed end-of-life decisions—say, when one sibling wants a feeding tube and the other doesn't—as well as squabbles over inheritances.

My family's story began at a moment of crisis, when my mother's routine medical problems ceased to be routine, her relatively independent life was threatened, and all three of us were reeling at the time when a clear head mattered the most. This is the way it often happens, a before-and-after event, the day when everything changes.

Like so many in her generation, and legions more to come in ours, my mother had lived into her eighties without succumbing to cancer, a sudden heart attack, a disabling stroke, pulmonary disease, severe diabetic complications, or other diseases that once killed people, often swiftly, and generally before the long, slow ravages of dementia or frailty. That is not to say there wasn't plenty wrong with her: arthritis, obesity, high blood pressure, an inner ear disturbance that caused extreme vertigo, mild diabetes, hearing loss, cataracts, and lifelong depression. All of it was unpleasant but not life-threatening.

Widowed at fifty-eight and justifiably proud of her self-sufficiency, she asked little of her two adult children and mostly took matters into her own hands. *She* told *us* when it was time for her to stop driving, sell the house on Long Island, and move to a more supported environment. She figured out which of many Florida retirement communities suited her best, what size apartment she wanted, and which furniture to take and which to leave behind. The proceeds from the sale of her house would cover the rent in Florida for years to come. Taking no chances, she hired a financial planner once she got there to guide the process. She had a living will, a health care proxy, a durable power of attorney—all without any prodding. My mother was a realist. She neither expected to live forever nor wanted to.

During the seven years in Florida, when she declined but not dramatically, my mother was glad for the emergency call button in her apartment, the meals she didn't have to prepare, the grass that somebody else cut. My brother and I were glad we could call the front desk if she didn't answer the telephone and someone would check on her. Her cane gave way to a walker, but she continued to ride a van to the grocery store and shop for herself, bringing home a few small bags after each trip. She enjoyed a regular bridge game, occasional dinners out with her sister-in-law who lived nearby, and several visits a year from her two children and daughter-in-law. Michael and I were not terribly attentive, except for weekly phone calls. That was fine with her. Our lives were still mostly our own, as was hers. Then came the bombshell from her Florida internist. Our mother, we were told, had a benign tumor sitting on the outer surface of her spine. Without surgery she would wind up paralyzed from the waist down and incontinent.

Was this the “after” moment?

Now, nearly a decade later, I see all the mistakes we made. I had never even met her Florida doctor or talked

to him on the phone until this diagnosis. What had prompted him to give my mother an MRI? Had she complained to him of some new symptom she had kept from us? I would have known all this if I'd bothered to develop a relationship with the doctor, joined my mother at appointments when I was there, and talked to him on the phone when I wasn't. My mother wouldn't have welcomed my intrusion, but I should have been pushier. I should have paid more attention. But I liked our family's rules of (dis)engagement because they made my life easier.

Thus the diagnosis left me totally unprepared. My heart raced. My stomach was an elevator falling down the shaft. My head was noisy with static. I made fast decisions rather than good decisions, partly because the sooner we could take care of everything, the sooner we'd be done and back to normal. This was just another to-do list, and I'd work my way from top to bottom, as would my brother.

Maybe this was the moment for my mother's inevitable reverse migration, back to the embrace of her children. Perhaps this was the time to shut down her Florida apartment and move all her worldly goods to another residence near us, I said to myself, time to close bank accounts at one end and open new ones at the other. Go-visit-Mom weekends would be replaced with quick visits on the way to work. And Michael and I had the skill and metabolism to make it all happen quickly, which was better for us. I didn't stop to think that the pace would be dizzying, exhausting, and ultimately traumatic for her.

I sprinted when I should have cautiously watched my step, rushed when I should have ruminated, barked orders when I should have discussed things with my mother. I heard what I wanted to hear, not what doctors or admissions directors of long-term care facilities were actually telling me. Does any of this sound familiar to you? If it does, slow down. Get your bearings. You can't bulldoze your way through this like a work project. Still, you can take comfort in knowing that this precipitating crisis, for many of us, is the hardest part, because you probably still think you can make it right, that you can stop the clock.

It takes a while to learn that some decisions are far more important than others; some things are actually in your hands and some not. What is vital, and well within your control, is being present in a consoling way and respectful enough to bear witness to the inevitable. This, too, is about slowing down. At first it's hard to walk at a snail's pace beside your mother or father when they can no longer keep up, at least without impatiently rolling your eyes. Or to kneel at their level if they're in a wheelchair. But the pace and the vantage become more natural and annoyance softens into tenderness, if you let it.

I keep saying that this experience can become something other than desperate and bleak, if you let it. It really is a choice. We all know grown children who have bolted when the moment arrived. You aren't one of those, or you wouldn't be reading this book. But imagining running away doesn't make you a bad person. I fantasized, usually in the hypnagogic space between sleeping and waking, facing another day of ignorance and exhaustion, about pointing the car west and driving, driving, driving. I'm glad that I didn't, because instead I learned what I was made of; I found my better self. I found my mother. I found my brother. But all of that came later.

From the Hardcover edition.

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