□ The Caregiver's Guide

Ready or NOT

You know it's coming; your parents aren't immortal. But when the storm hits, few of us are remotely prepared. The stress, the strain, the gravity of the task can level you. And yet, if you meet the challenge head-on—if you guide your parents to the end of their lives with compassion and grace—the experience can be moving and cathartic. Even beautiful. We'll help you find your way.

ILLUSTRATIONS
BY
Julien Pacaud

TAKE My Advice

Even though you don't want to. Even though you think you don't need to. (You do.) By *Jane Gross*

THE PHONE RANG. It was a friend calling for guidance—as friends often have since I've become what my brother calls the angel of death. Having started a blog and written a book about caring for aging parents, I'm now an expert, it seems, on what is broken about long-term care in America, which is pretty much everything.

My friend on the phone is one among many who profess to want help but who actually want to be told they don't need it. They'd rather hear that everything is fine and will likely remain that way for a long time, maybe forever.

If only I could reassure them that this were true—that their mother or father will still be playing tennis at 90, will return a stinging volley and then keel over, with no fuss or bother, maybe giddy at having won that last point.

My friend's parents live in a big house, once a gem but now gone to seed, as a home will do when its owners are too cash-strapped or infirm to maintain it. They don't want to move, he tells me. (Typical.) Readying the place for sale, even with the combined efforts of three grown children, will be onerous. (Indeed.) In its current condition, it isn't worth what they expected. (Sorry about that.)

My friend knows in broad strokes what I'm going to say. He's read everything I've written on the subject, and even agreed with it. But now he tries to silence my frank talk with uncharacteristic babbling. His father, he says, has begun asking annoying questions over and over, losing track of time, wandering aimlessly. His mother is his father's sole caretaker, and she has grown increasingly exasperated, isolated, overwhelmed. Healthwise, she is fine, my friend says—or at least, she's been fine since returning from the hospital after setting herself on fire at the stove.

"That's your definition of fine?" I ask.

So thick is the denial of death in our culture that people can ask for advice they desperately need and yet, once they receive it, manage not to hear a word. Vast numbers of us have our fingers in our ears. But trust me: Ignorance is not, in this case, bliss. What you don't know can hurt you. The longer you refuse to reckon with reality—that your parents will get older and pass away and will probably require significant assistance before they do—the more blindsided you will be when that reality lands like a ton of bricks. Or a searing stove. Or a broken hip. Or any number of events that can signal the caretaking journey has begun.

So just as you would for any other journey, you must prepare. If your parents are still well and if you haven't done so already, sit with them and begin the conversation, by turns practical and philosophical, that will help you help them in a manner that respects their wishes and eliminates as much confusion and exhaustion from your life as possible.

Start by telling them that, while it might be a long way off, there may come a time when you will need to see to their care. Tell them that in order to do so, you need to know both what they want and where things stand. Do they foresee themselves moving into a community for seniors? Where is their money, and how much do they have? What kind of insurance do they carry, and who are their doctors? Are all their important documents complete—healthcare proxy, power of attorney, standard will, and also living will—and in the right hands? Do they wish for extraordinary measures to be taken to prolong their lives? Because your parents' situation will change over time, this is a conversation you'll need to have more than once. I recommend every year.

If your parents have already begun to struggle to live independently, you must speak kindly but candidly about what you've observed, and what you believe to be the best course of action. It may be time for them to stop driving, to leave their home and move somewhere that offers assistance with daily life, or to turn over some of those routine tasks to you or another member of your family. Every set of circumstances is different, of course, but the principle is always the same: You cannot ignore the situation until it becomes a problem.

If I sound harsh, forgive me. It's just that I happen to know—to have seen—that some of the suffering people experience while caring for aging parents is preventable. Of course, however much you prepare, this will still be hard. You may find yourself burned out, emotionally and physically drained, angry, and hurt. You may think you cannot bear up to what is being asked of you. The end of this process—and I pray that for you it's many happy, healthy years in the future—will be unavoidably painful.

But in accompanying your parents through this final chapter, you will also find unexpected sweetness. You will, if you are lucky, experience occasional flashes of humor. And as you'll learn in the pages that follow, you will not be alone. Many have walked this path before you. Some have even made it their business, their life's work, to ease you down this path. (I'm one of them.) An abundance of invaluable resources—starting with the magazine you hold in your hands—is available to you.

This journey may be long, or it may be short. It may be arduous, or it may be less demanding than you fear. But when it is your turn to embark upon it, do yourself—and your parents—the kindness of going forth with open eyes. Godspeed.

LIGHTENING UP

"One of the benefits of older age is that we learn to 'travel light.' We become less invested in specific results. And we're less likely to fear death. As Shirley, 91, told us: 'I've made my will, and I am ready to die, but before I go, I sure would like to see the new slipcovers I ordered last week.' She wasn't always this relaxed. As she tells it, 'I came out of my shell at 70!'"

—Mindy Greenstein, PhD, coauthor of the new book *Lighter as We Go: Virtues, Character, Strength, and Aging*

Your Starter Kit

Three questions to ask your parents right now.

Do you have a living will?
Roughly 72 percent of seniors have advance directives specifying end-of-life medical wishes, according to a recent study funded by the National Institute on Aging. Make sure your parents are among them. While you're at it, confirm that the document has been revised in the last five years and that you know where to find it.

Where's the money?
Start with your parents' latest tax return to get an overview of their assets, says John Schall, CEO of the Caregiver Action Network. Then compile account numbers (savings, checking, credit card, 401(k), etc.) and phone numbers for the customer service line at each banking institution. If they bank online, find out their passwords (or, at the very least, make sure they add this info to a secure document you can access when necessary).

Who are your advisers?
Get names and numbers for the professionals your parents rely on—do they have an accountant? spiritual adviser? primary care physician? You'll want to reach out to them when you need input and support. And don't forget other medical specialists. "Most elderly people see multiple doctors, especially if they're managing several chronic conditions," Schall says. "You'd be surprised how fragmented the system is, so it's up to you to know all the players on their healthcare team."

—JIHAN THOMPSON

SPOT ILLUSTRATIONS: KATHRYN RATHKE

The Caregiver's Guide

The Way FORWARD

Blessed with a mom who's still as capable as ever, *Lise Funderburg* knows she's lucky—and also that nothing lasts forever.

A COUPLE OF YEARS AGO, my mother dropped a bombshell: She was moving out of her apartment, she announced, and into a continuing care facility.

This came as a surprise to my two sisters and me. At 88, my mother could walk circles around most 70-year-olds, drive well (if fast), and trounce all comers in Scrabble (the word for a Scottish sweetheart? *jo*). She took almost no medication, read without glasses, and alternated yoga with water aerobics. She Facebooked. And the only reason she'd cut back on the bike tours was a diminishing pool of able-bodied travel companions.

Mom was losing friends right and left—two funerals in one week was no rarity—and each loss cast a longer shadow. She told us she felt increasingly lonely, despite having daughters close by, and she couldn't always be bothered to eat a meal. Decisions were harder; she wanted to simplify.

She had put down a fully refundable deposit at a retirement place ten years earlier. When she activated her name on the waiting list, my sisters and I absorbed the shock and then counted ourselves lucky. We wouldn't have to police her home for trip hazards or sleep over in shifts or take on the second-job equivalents of managing bills and cleaning and meals. We'd never have to force a move. This decision was self-care on her part, but it was also a gift. She was watching out for us; she was still in charge.

For months Mom waited for an apartment to open up—which meant, we realized, waiting for an occupant to die or to be transferred into the euphemistically named Memory Care wing. In the interim, we occupied ourselves with the colossal minutiae of moving.

One afternoon Mom and I were discussing whether her beloved tea chest would fit in the one-bedroom unit she could afford. It was a thrift shop piece of no great value, but its clean lines and warm wood finish suited her completely. The question floored her, this woman who had managed to earn a master's degree at night while teaching full time and raising three children pretty much by herself. She stared at the chest blankly.

"It's just measurements, Ma," I said, hopping up to find her yardstick. Halfway to the hall closet, I got it. *Oh*, I thought. *Oh*. This move meant more than a daunting financial commitment. More than a new social life to build and dining hall to maneuver. This would be the last nest she feathered. She was choosing the place where she would die.

It was an irreversible awakening: Life is a series of beginnings and endings, and this was both. I was witnessing the start of my adventurous mother's last adventure. She's on a path that will only get rockier, and someday my sisters and I won't be able to keep her steady. At the edges of her still phenomenal physical health is a constant ebbing. She pushes the supermarket cart so she can lean on it; she sits back to watch us decorate her Christmas tree. "You need to look this over," she says to me after filling out a passport renewal application. "I'm old."

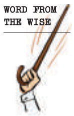
We're bracing ourselves for what's to come, comparing notes after visits, assessing everything from her driving (still good) to her appetite (so-so). "She's 90, after all," is our new refrain, our way of holding the truth in sight; of remaining alert to the constantly shifting ground; of staying mindful of the mother she is now. *Oh*, we say silently. *Oh*.

YOUR NEW MANTRA

"It's better to be kind than to be right. And pace yourself: This is a marathon, not a sprint.'"

—Veronica Leland, North Carolina

WORD FROM THE WISE



"Once they start calling you spry, you know you're on the down slope. Spry translates into 'It's amazing he's walking at all.'"

—Marvin, 83 Wynnewood, Pennsylvania

Man Plans, God Laughs

PETER APPLEBOME *on the lesson his family learned the hard way.*

MY FATHER believed his house in Connecticut, situated by a brook, was the most perfect place. He loved puttering around in it, trying to fix gadgets with duct tape or ward off marauding critters in a makeshift, invariably futile, way he called *potchkying*. But as he entered his 90s, the house became too much. It was time to go.

And thus began the scramble. My brother and sister and I made lists of retirement homes. We took countless tours, my mother in denial, my father heroically agreeable even as he brainstormed ways to avoid moving. But no option was perfect. We finally decided, out of exhaustion, on the least unpalatable place.

I took a picture of my father on the day he moved. He seems to be saying *I've got this*. It was the last photo we took of him. When the car pulled up to his new home, he tried to lift two bags from the trunk and fell, breaking his hip. He never got in the front door. He wound up in a rehab facility, where he went from confused to furious to resigned to lost in the mists of senility. Five months later, he died.

My father was always a skeptic about everything but family. He liked to repeat the old Yiddish saying: "Man plans, God laughs." All the agonizing we'd done, all the arrangements we'd made were as effective as trying to fix gadgets with duct tape. Not long ago, I looked up *potchky*. It's from the Yiddish *patshke*, meaning "to work in an amateur fashion for little gain." Our earnest planning was our familial *potchky*, a well-intentioned mission that veered horribly off course. I think my father would have understood.

Tech Support

These cutting-edge apps, websites, and services—not to mention one foolproof computer—can help lighten your load and keep Mom and Dad independent a little longer.

StandWith, a free iPhone app, coordinates help from friends and family, ensuring that you won't get yet another casserole when what you really need is a ride for your mom to physical therapy. Think of it as a registry for helping hands: Just list the tasks you'd love to outsource, and anyone who is available can sign up for them.

Doctor On Demand offers 15-minute video appointments with licensed physicians using your smartphone, tablet, or desktop. For $40 (the service is not yet covered by insurance), patients can get prescriptions or referrals for common ailments like colds and back pain, and you can avoid unnecessary hours spent in the waiting room.

Lively's tiny sensors can be attached to key chains, cabinets, or even a refrigerator door, where they provide updates (via a website, email, or text messages) on whether your mom took her medicine or your dad has eaten today. A safety watch with changeable bands offers a one-touch button for emergencies. (Starts at $40, then $25 monthly)

CareLinx, the Match.com of caregiving, helps you find home health aides without using an expensive agency. After undergoing a background check, aides post bios that include photos, qualifications, and the kinds of tasks they are willing to perform. You can then hire them for a one-time emergency or ongoing visits.

Telikin makes ready-to-go computers that require zero tech know-how. Your parents will appreciate the large display and touch-screen buttons (labeled with words like VIDEO CHAT and EMAIL), which will help them stay connected without making you their one-woman IT department. (Starts at $699)

—COURTNEY RUBIN

Don’t Go Broke

Yes, your parents’ finances are an issue. But *Suze Orman* wants to be sure you safeguard yours.

Adult children who become caregivers often pay a steep price. According to a 2011 MetLife study, women older than 50 who leave the workforce early to fulfill this role forfeit about $324,000 in wages, Social Security payments, and retirement benefits. However, with some smart strategies, you can avoid sabotaging your financial future.

Ask an accountant about potential tax breaks.
You may be able to claim an elderly parent as a dependent if they have an annual income of less than $3,900 and you provide more than half their financial support. If you cover medical expenses, those costs may also be deductible.

If you become a full-time caregiver, don’t support yourself by dipping into your 401(k) or IRA.
Generally, you’ll face a 10 percent penalty if you make an early withdrawal (before age 55 for a 401(k) and age 59½ for an IRA). And don’t take out a second mortgage, which can send you down a slippery slope of debt. I’d advise doing whatever you can to keep your day job, even on a modified schedule. If your employer isn’t flexible, you may be eligible for up to 12 weeks of unpaid time off through the Family and Medical Leave Act. With any luck, that grace period will buy you enough time to make other arrangements.

If you do quit work or go part time, talk to family members about being reimbursed for your services.
Considering how much you stand to give up in lost wages, negotiating a salary needs to be your first priority. You should have at least enough to cover basic expenses, including housing, food, insurance, and IRA contributions. (Go to irs.gov to learn about self-employment taxes for family caregivers.) If your parents are paying, consult an eldercare attorney to make sure you’re not jeopardizing Mom and Dad’s ability to collect Medicaid. (For more about the ins and outs of the system, see “Don’t Let Medicaid Break You” on page 138.) Ask for a salary that offers you financial stability and peace of mind—two must-haves for every caregiver.

“There’s a DAD in My Living Room!”

He came in peace, but he brought an awful lot of baggage. *Mimi Swartz* reports on life as she now knows it.

“WELL, MIN, HOW DID YOU SLEEP?” asks Martha, my father’s daytime caregiver. Min is short for Minnie Mouse, the nickname my dad gave me when I was 5. He and my mother were the only ones who ever called me that—until now. Meanwhile, the nighttime caregiver, Sandra, is snarling on her way out, “Why don’t you ever do what I *tell* you?” I flinch, but then I realize she’s talking to her teenager on her blinking Bluetooth. There’s always tension during the morning changing of the guard because Sandra does *not* like people in her business.

“How are ya?” calls out my 87-year-old father, with the smile that’s always charmed everyone.

Last Thanksgiving, Dad fell down our stairs and broke his hip. He then spent three months at a nursing facility, where he got pneumonia and started seeing things like teenagers skiing on roofs. My husband said, “We should bring him home—to live, not to die.” And that’s how my father came to occupy my living room.

He came with an entourage. His around-the-clock attendants have become part of the household, and so has his corgi, Trilby, who tussles with our two golden retrievers. Fortunately, my father, unlike his dog, is exceptionally sweet and easygoing. “Can I help?” he often asks, words I now find terrifying; his life-changing fall happened when he was—helpfully—carrying a pile of blankets upstairs.

Here’s my advice to anyone considering an arrangement like mine: Be a Buddhist. Don’t cling to the life you had before. I used to love mornings. In fact, it was my dad who taught me to savor good coffee and silence. Now I have to make eggs for me, my husband, and Sandra. We have to discuss whether Truvia is better than honey, whether sugar is better than Truvia. I give Martha a section of the paper, and she gives me the rundown on all the bizarre crime stories in the greater Houston area.

Then, with the efficiency of a five-star general, she gives me my to-do list: “Min, we’re out of latex gloves.” “Min, you need to reschedule your dad’s physical therapy because it conflicts with his podiatrist appointment.” She reminds me that my father wants to take a Caribbean cruise. “Soon,” I tell her. “Right after hurricane season ends.”

Despite feeling like the hurricane under my roof will never end, I’ve managed to experience some joy in all this chaos. I know the day is coming when my father won’t be with us anymore, and I know how much I’ll miss him. I watch as his caregivers kiss the top of his head and tuck him in, and I know I’ll miss them, too.

☐ Relocation, Relocation, Relocation

When her mother refused to move, JENNIFER WOLFF PERRINE *did what any sane person would do.*

ONLY AFTER the local police started charging $40 for answering each false alarm did this hard truth set in: Mom had to move. She was calling 911 at least once a week. Dutifully, the cops would rush in to investigate yet another burglary, only to find Mom’s “stolen” wallet between the seats of her silver Lexus or in the pachysandra in the backyard. Almost as often, fire trucks came roaring up her driveway, only to discover a hard-boiled egg scorched in an enamel pot on the stove, the smoke thick enough to set off the alarm my mother couldn’t hear from her disheveled bedroom.

Mom was in the middle stage of Alzheimer’s, a point where she had enough functioning gray matter to pretend that everything was fine. “You don’t know what you’re talking about!” she’d snap at the mere suggestion that she might want to move from her suburban house into the city 45 minutes away where my brother and I both lived. “I want to stay *here*.” For months, we argued, reasoned, and begged. Still she refused to pick an apartment.

So with the help of my brother and my mom’s sister, we hatched a plan that at the time felt incredibly clever: We’d move Mom out of her house without telling her. I rented her a two-bedroom apartment less than a mile from mine, close enough that I could check in on her often and big enough to accommodate the in-home caregiver she’d eventually require. My brother hired the movers who would empty out the house she had lived in for 47 years. My aunt lured her into spending a few nights at her place, while we rushed around making her new home appear identical to her old one, a challenging task given that we were swapping a French Tudor for a modern high-rise.

When the stained Persian rug we knew she couldn’t live without didn’t fit, we had the entire base of a stone fireplace chiseled away to make room. When the low marble shelf that had run along the back wall of her living room proved too long, we called a carpenter to shorten it, then arranged her knickknacks and photographs on top exactly as they had been at home. Japanese fishing floats filled the crystal bowl on her dining table, catching the sunlight through the window exactly as they had for the past four decades. In our bleary, deluded eyes, we had done it; in one expansive leap of magical thinking, I even thought Mom might be grateful.

Of course, Mom wasn’t grateful. Or happy. Or even for a moment fooled. She has Alzheimer’s, but she’s not stupid. Indeed, *I* was the fool for thinking she wouldn’t notice, or wouldn’t mind. This is where my caretaking had led me, to a place where I couldn’t tell the difference between what was genius and what was insane.

Of course, I could have just left her in her home, like she wanted. Maybe she would have wandered off into traffic or perished in a fire ignited by yet another forgotten meal on the stove. Or maybe she would have been fine.

Now, *there’s* some magical thinking.

The Email Ballad of the Caregiving Daughter

When one sister lives 18 minutes from Dad and the other's out of state, guess who's left holding the colostomy bag. A month's worth of real-life dispatches from the front lines…

✉
Sent: June 2, 2014, 3:55 P.M.
Subject: Dad

He's in the hospital with a urinary tract infection. They told me he's pretty lethargic, but his vitals are good. Yesterday he was talking about how he'd kill himself if he could. That scared the folks at Pinecrest, so they put him on suicide watch and called in a psychiatrist to evaluate. Aargh.

✉
Sent: June 5, 9:24 A.M.
Subject: Re: Dad

I visited today, and he seemed in good spirits, probably because his doctor was young and blonde. They're giving him antibiotics and trying to come up with ways to help him move his bowels. How was L.A.?

✉
Sent: June 8, 2:48 P.M.
Subject: Grrr

Dad's feeling better, judging from the marching orders he just gave me: get him more of "those barrel candies," which I guess means root beer barrels. He also said to order him some movies "on the ticktack," which I think means Netflix.

✉
Sent: June 17, 9:08 A.M.
Subject: Another UTI

Well, he's back in the hospital. They've got him on antibiotics, and they don't know how long he'll be there. He's hounding the doctor for his typewriter and "papers," whatever they are. Says he has something important to write. He also wants his copy of *One Hundred Years of Solitude,* which I'll pick up on the way out there. He misses you. Come when you can.

✉
Sent: June 20, 4:16 P.M.
Subject: Re: Another UTI

Dad just called. He says he wants me to come out to Pinecrest so we can discuss ending his life. Good times!

✉
Sent: June 24, 6:34 P.M.
Subject: Re: Another UTI

He gave me a copy of the obituary he wrote for himself. I lack the words.... Then he gave me his plan: "I'm going to stop eating. I'll have a light breakfast, and then I'll eat less throughout the day. It should take about five or six days, I figure."

✉
Sent: June 28, 1:18 P.M.
Subject: Phew...?

I saw Dad this morning. No mention of suicide. Just wanted to know how my work's going, how the girls are doing, and could I get him some more Nips. And a bourbon and a steak.

✉
Sent: July 3, 5:52 P.M.
Subject: Dad

They tuned the piano in the dining room at Pinecrest, so I wheeled Dad down to play it. It wasn't going well because his fingers are so stiff. I thought a duet might help, so we played "Heart and Soul." It was like a scene from a movie: I slid in on the bench next to him and draped my arm across his shoulders. We must have played the song six times. I cried. :)

All TOGETHER Now

When *Hannah Wallace*'s beloved aunt Holly fell ill, there was no immediate family to call on, but she had something just as good: a committee.

AS A GIRL PLAYING DRESS-UP, I always tried to channel my great-aunt Holly: fiery red lips, exotic silk scarves, gravity-defying coiffure. Holly's life was as outsize as her look. A journalist and playwright, she reported from Bangladesh and Burma on Christian relief efforts and wrote provocative musical revues; her swish apartment was always packed with thespians, writers, and theologians. When I visited her in New York City, she whisked me off to Serendipity 3 for frozen hot chocolate, then to Broadway for *Peter Pan*.

Holly was so delightfully eccentric that when she started answering the door in her underthings (she was 87 by then; I was 31 and working in Manhattan), I wasn't all that alarmed. Only after she began leaving her apartment late at night and subsisting on cheese puffs did my cousin Ed take her to a gerontologist, who confirmed she had Alzheimer's.

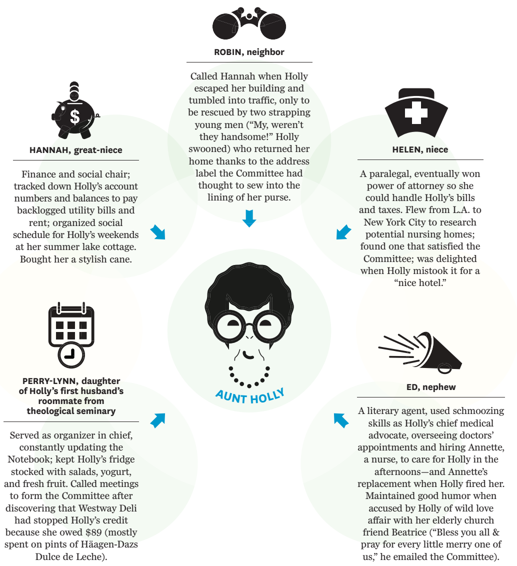
Holly never had children, but a group of younger friends and relatives quickly christened itself Holly's Committee. Together we compiled an exhaustive cache of information on her medical history, pills, account numbers, and contacts. "The Notebook" also included sections on food ("Likes grapefruit and melon. Bananas occasionally") and social life, with a reminder that she loved visiting the American Museum of Natural History.

For the Committee, caregiving was not an isolating burden, but a communal enterprise, with inside jokes ("She's inventing emergencies to keep me sequestered in her apartment") and commiseration ("She smacked the new nurse upside the head with a *Vanity Fair*"). For the most part, we kept Holly safe and happy—and each other sane.

A year later, when Holly's condition deteriorated, we transitioned her to an Alzheimer's facility, where nurses said she was once again "the life of the party."

As her committee's social chair, I wasn't surprised.

THE COMMITTEE



ROBIN, neighbor

Called Hannah when Holly escaped her building and tumbled into traffic, only to be rescued by two strapping young men ("My, weren't they handsome!" Holly swooned) who returned her home thanks to the address label the Committee had thought to sew into the lining of her purse.

HANNAH, great-niece

Finance and social chair; tracked down Holly's account numbers and balances to pay backlogged utility bills and rent; organized social schedule for Holly's weekends at her summer lake cottage. Bought her a stylish cane.

HELEN, niece

A paralegal, eventually won power of attorney so she could handle Holly's bills and taxes. Flew from L.A. to New York City to research potential nursing homes; found one that satisfied the Committee; was delighted when Holly mistook it for a "nice hotel."

PERRY-LYNN, daughter of Holly's first husband's roommate from theological seminary

Served as organizer in chief, constantly updating the Notebook; kept Holly's fridge stocked with salads, yogurt, and fresh fruit. Called meetings to form the Committee after discovering that Westway Deli had stopped Holly's credit because she owed $89 (mostly spent on pints of Häagen-Dazs Dulce de Leche).

ED, nephew

A literary agent, used schmoozing skills as Holly's chief medical advocate, overseeing doctors' appointments and hiring Annette, a nurse, to care for Holly in the afternoons—and Annette's replacement when Holly fired her. Maintained good humor when accused by Holly of wild love affair with her elderly church friend Beatrice ("Bless you all & pray for every little merry one of us," he emailed the Committee).

ICONS BY GERALDSON CHUA

NURSING HOME CARE AVERAGES $7,200 A MONTH.

Don't Let Medicaid Break You

It took *Jennifer Kaylin* 13 months, reams of paperwork, and untold hours on hold to get the Title 19 benefits—Medicaid funds for people with limited resources—her father needed to receive nursing home care. She shares her sanity-saving secrets.

STEP 1: Get started five years before you think you need to. Remember that paperwork we told you to have handy? Go grab it. Since Medicaid requires a five-year look back at all your parents' financial dealings, you'll be glad to have their banks' names and numbers right at your fingertips. "Regulators are looking for two things: if you're hiding any money and if you've given any away," says Donna Levine, an elder law attorney in Connecticut. And if one or both of your parents still live in the family homestead and you want to hang onto it, you'll need to transfer ownership (or establish a trust) at least five years before you even apply. There are a few exceptions, but generally, if you wait, you'll be forced to sell.

STEP 2: Make sure you get power of attorney. While you may not need power of attorney (POA) to obtain Medicaid approval for your parents, get it anyway. At every turn, people will simply say, "I'll need your POA to get that information for you." Even your parents' cable provider won't talk to you unless you have it, says Levine.

STEP 3: Prepare for the paperwork. Develop a filing system early. After you submit your initial application, you're going to need to answer a ton of questions, and each time you'll be asked for your case number. Write this number down, preferably on the cover of your Medicaid folder. Include dates of birth and Social Security numbers—you'll be asked for those often.

STEP 4: Make friends. You'll need allies—caseworkers, bank employees, eldercare counselors—to help you along the way. The tellers at your parents' bank can be lifesavers when your caseworker wants to know about a specific transaction, like that $1,200 check your dad wrote two years ago. Depending on a parent's mental state, that request could be manageable or maddening to figure out on your own.

STEP 5: Resume your life. When you get the letter saying your application has been approved, it's like a boulder has been lifted from your shoulders. There is a yearly "redetermination" process to prove your parents haven't won the lottery or otherwise seen an uptick in cash flow, but the pages and pages of paperwork are pretty much over. Hallelujah.

How to Care for PARENTS / IN-LAWS Who Did Not Even Go to Your Wedding

A step-by-step guide by *Jim and Karen Shepard.*

FIRST, TRY NOT TO hold it against them that they adamantly opposed your marriage, and in fact refused to meet their future daughter-in-law.

Then, once they're both incapacitated—once Ida is diagnosed with the kind of chronic obstructive pulmonary disease that would bring a charging rhino to its knees and Shep with the sort of dementia that causes him to ask 24 times over the course of a single lunch, "How long have I *lived* here, anyway?"—spend three to five years taking over their paperwork.

Track down 50 different bank accounts, some of which have balances of $127.32, at 18 different banks. Work your way through a six-inch stack of U.S. savings bonds in the safe-deposit box. Discover that Shep and Ida hold three shares of something for which they receive a check for 12 cents every quarter. Spend a year convincing two self-reliant children of the Depression to grant you power of attorney, and then on the big day, watch them refuse to go to the lawyer's office to sign the papers. Become the kind of son and daughter-in-law who threaten the elderly. Then answer ten calls a day from Shep about why he's no longer getting any paperwork in the mail.

Deal with the desolation of accompanying Shep to a dementia evaluation. Watch him fail to draw a clock face, bunching the numbers and hands together in the top left of the circle like corralled animals. Try to present a smile when he says apologetically, "I used to know how to do this."

Sell their Florida condo, despite their trepidation about the idea, and fudge for them the amount you receive. Tell them that the dealer who snorted at their "antiques" paid top dollar for the Dean Martin doll that croons "That's Amore."

Laugh when you can. Laugh when Shep looks into his lap at dinner and says, "Where'd I *get* these pants?" Or when he calls to tell you he can't reach his mother and brother in Connecticut, and you respond that's because they've both been dead for a while now, and he answers, "So who am I *talking* to down there, then?"

Figure out a way—imagine the logistics of the Normandy invasion or the Berlin airlift—to get them both to your house safely for Christmas Eve dinner. This will involve backup oxygen tanks, spare tables, and something called a cabulance, as well as hauling Ida's wheelchair (with her in it) up any number of steps and through a narrow doorway. It will involve cleaning and bandaging Shep's head wounds after he falls on the ice getting into the cabulance. It will involve wheeling Ida into the bathroom to wipe her. It will involve reminding her, once she's eaten too fast and started to choke, to breathe through her nose. This will seem beyond her. So it also will involve explaining that she should pretend she's smelling flowers. It will involve telling everyone else to keep eating while she gets the hang of that.

Strong-arm your children into a meal at their grandparents' house at least once or twice a month, even given the impossibility of coherent conversation around that dinner table, even given that the rooms smell stale and sad and the TV is at a volume that allows neighbors eight doors down to listen in. Remind your children that Shep and Ida are still their grandparents and will continue to be visited until they're not there to visit any longer.

Have your days hijacked by all the things—aides, pills, doctors' appointments—you have to organize and supervise, and, once Ida is hospitalized for ministrokes, stand by helplessly while she refuses any more diagnostic tests and checks herself out of the ER. Discover the despair you feel when, after you plead with her, "Do it for us," she refuses.

Do your best to grapple with the wedge that all this stress drives between the two of you. What daughter-in-law, previously forsaken, would want to subject herself to such a black hole of unhappiness? What son wouldn't be sad at his wife's refusal? What daughter-in-law wouldn't note that these are two people who, even when they were healthy, were expert at making themselves miserable? What son wouldn't feel as though he owed them at least his presence?

And when you're at your most self-pitying, try to remember that they were sometimes generous. Recall that Ida passed on her prized Persian lamb coat to you; that they gave you the down payment for your house; that they sent the kids motley care packages of toys grazed from Goodwill. Try to remember that you can never deliver happiness, but that you can help. Try to remember that all they're doing, finally, is all that they can. Try to remember that the same is true of you.

In Her Shoes

To keep her spirits up as she tends to her mother, EDWIDGE DANTICAT *looks down.*

BECOMING A PARENT'S caregiver is a lot like becoming a parent. No one hands you a manual, just a life to love and protect in new, uncharted ways. Except with parents, you have to negotiate that very sensitive space between being helpful and making them feel helpless—between your humility and their humiliation.

One of the things I do to "look after" my mother and myself during her doctors' appointments is take cell phone pictures of her feet—in sandals, in socks, barefoot. I take pictures of her feet with my feet lying in bed next to her, with doctors' feet, with lab technicians' feet. I do this sometimes to keep my head down so she can't see my tears as the nurses draw her blood for the thousandth time or as she is being slid through another diagnostic machine that looks like a coffin. But I also take these pictures to remind myself what it's like not just to be my mother's caregiver, but to be my mother.

There's a Haitian Creole expression, *pye poudre,* which is used to talk about people who have traveled long and far. My mother's feet have walked the circumference of my entire world, from Haiti, where we were born, to the United States, where she came when I was 4, leaving my brother and me in the care of relatives until she could support us and until U.S. immigration officials finally cleared our reunion, when I was 12. I used to count my age in Mommy years, subtracting the eight she and I spent apart. In early adulthood, I was the one who was *pye poudre,* venturing away from my mother: going to graduate school, falling in love, having babies of my own. These days, though, my mother and I find ourselves constantly side by side, our four feet lined up, as if waiting to head out on yet another trip, this time together.

Caring for my mother has meant supporting her as she faces some very difficult moments, but it has also meant embarking on a communal journey through bad and good times, which neither of us will ever take for granted.

WHO KNEW?

"Liquefy the oatmeal and the corn flakes, and pour them in a plastic sippy cup. It makes life so much easier."

—Zoraida,
Sunny Isles Beach, Florida

THANKS, MOM

"I walked into my mom's bedroom, and she said, 'Who are you?' I replied, 'Mom, it's Lisa, your baby girl.' She said, 'Humph, the Lisa I know is much skinnier.'"

—Lisa,
Richmond, Texas

Bank On This

Mom and Dad may be entitled to more money or discounts than you think. We asked experts to let us in on a few resources most people overlook.

Survivor Benefits
If your mother or father has passed away, your surviving parent may be entitled to survivor benefits through Social Security, explains Grace Whiting of caregiving.org. A widow 65 or older could be missing out on nearly $15,000 a year if she doesn't take advantage. Learn more at socialsecurity.gov/survivorplan.

Life Insurance Settlement
Though liquidating a life insurance policy often yields less than the death benefit, it can still add up to a serious chunk of change, says Andy Cohen, CEO of Caring.com.

Prescription Discounts, Federal Food Programs, Tax Breaks
BenefitsCheckup.org, created by the National Council on Aging, walks you through a series of questions, then identifies what sources of assistance your parent may qualify for.

The Family House
Reverse mortgages allow those 62 and older to convert a portion of the equity in their home into cash without having to put the home up for sale. But make sure it's worth it; fees for an appraisal, a credit report, title insurance, and more could cost you thousands of dollars.

Veterans' Benefits
Most honorably discharged veterans are eligible for VA medical benefits, says Whiting. Register online at va.gov/healthbenefits/apply. One caveat: There's a financial cap; some veterans with a high income or net worth aren't eligible.

—BLAKE MILLER

You're Doing FINE

In a situation that demands (and demands, and demands) so much of you, it's easy to feel inadequate. You're not, says *Martha Beck*.

WHEN A FRIEND OF MINE was dying, she said something I'll never forget. "Guilt is useless," she began. "If you did something wrong, let it go. If there's something you're doing wrong now, do better. If you can't do better, forgive yourself. I want to die in peace. The last thing I need is for you to drag your guilt in here."

Being a caregiver is hard. Being a caregiver burdened by guilt is immeasurably harder. That burden affects the quality of care, which creates still more guilt, and so on, until everyone gets so miserable, they just sit around drinking.

Guilt may seem to be an uncontrollable force, the result of factors you can't change. But guilt originates with us, not our situation. It wells up from our own judgment that we've done something wrong. Guiding a loved one through the final chapter of his or her life is a task so hard it weakens your ability to see your behavior objectively. The result: lots of guilt.

To let go of the guilt you feel as a caregiver, you must be kind to yourself, and you must befriend three things many of us would prefer not to: death, our limitations, and the structures we depend upon for help.

The most crucial of these steps—acquainting yourself with death—flies in the face of our socialization. Our culture sees illness, decline, and death as evil opponents. We encourage one another to think this way. Fight cancer! Rage, rage against the dying of the light! We celebrate stories of people who remain vital, healthy, and sexy—yes, sexy!—long after most folks their age are pushing up daisies. Hooray!

Except then they die.

But only always.

By contrast, consider traditional Tibetan culture, in which children are encouraged to ponder their own demise, where the word for body can be translated as "something you leave behind," and where revered teachers like Gyalse Rinpoche advise, "If you have got to think about something, make it the uncertainty of the hour of your death." Does that upset you? Then you're at war with one of the few certainties in life.

You must also make friends with your limitations. Start by honestly assessing what you are capable of, and I don't mean in some ideal world where you're always rested and you have all the money and time you need and the sun shines upon you forever and ever. I mean be honest about what you can accomplish on a bad day, when you're tired and sad. Treat this most limited version of yourself with the kindness you'd show an overtaxed friend. Sit yourself down. Pour yourself a cup of tea. Cry.

Having a support system is also necessary. Nobody should even try to attempt this alone. So ask for help. Almost anyone can do *something*—bring food or flowers, stop by to visit. Be grateful for the help you receive. Be kind to the doctors, nurses, and administrators you meet. Dealing with systems that exist to support the elderly can be infuriating, so if you lose your temper, forgive yourself. But remember that it's as easy to say "Thank you" as it is to say "Screw you," and the effects are worlds apart.

Befriending what is unavoidable—mortality, your limitations—and availing yourself of whatever aid you can find may require a hefty shift in perspective. But supplanting fear with friendship can, at the very least, allow us to tolerate what we once thought intolerable. And at best, it can transform despair into peace.

The Happy Ending

After her mother took to bed, LILY TUCK *read her a novel by Henry James—and righted one of literature's great wrongs.*

MY MOTHER was blonde and very beautiful—her looks were often compared to Greta Garbo's—and she spoke with a charming middle-European accent. Although she never graduated from high school, she was very wise and had good instincts. She was also warm and vivacious, and people liked her immediately. Indeed, many people loved her.

We were very different. I was studious and quiet. Although slightly mystified by my accomplishments as a writer, my mother was always proud of me. (After her death, I found a scrapbook she had kept with all my book reviews—good and bad.) Despite our differences, we were very close.

My mother died after a long and painful illness, though fortunately, and according to her wishes, she died at home. I, her only daughter, lived nearby. After she became sick, I visited her nearly every day. At some point during her illness, I suggested that I read out loud to her.

"All right," my mother said without much enthusiasm. "But what will you read?" She sounded wary. She was not interested in literature, had never read—nor probably heard of—James Joyce, Dostoevsky, or Beckett.

I thought long and hard before choosing a book from among my favorites: *To the Lighthouse*? No, too sad; Mrs. Ramsey dies. Joan Didion's *Democracy*? No, too disjunctive. Finally I decided on *The Portrait of a Lady*. I began:

"Under certain circumstances there are few hours in life more agreeable than the hour dedicated to the ceremony known as afternoon tea..."

Pausing, I looked over at my mother. Was she listening?

Sitting up in bed, dressed in her pretty pink robe and matching nightgown—until almost the last, appearances were very important to her—she was smiling. "I've always liked a cup of tea in the afternoon," she said.

I nodded and continued, reading the description of Lord Warburton: "a noticeably handsome face, fresh-coloured, fair and frank, with firm, straight features, a lively grey eye..." I felt my mother's interest growing.

Isabel Archer makes her appearance in the second chapter and is described as lovely and confident. After a week or two of listening, my mother, her voice still firm, said, "Isabel should change her mind and marry Lord Warburton. He's so good-looking, and he owns a house with a moat."

All of a sudden, I realized that the novel I picked was a big mistake. How would I explain Isabel's disastrous choice—Gilbert Osmond? This was not a novel with a happy ending. *Au contraire*. Nevertheless, I read on.

My mother complained that Caspar Goodwood was a bore; nor did she like pushy, noisy Henrietta Stackpole, and as for untrustworthy Madame Merle, my mother said, "She's a real social climber."

The description of Gilbert Osmond is ambiguous: his face, his head, was sensitive, he was not handsome, but he was fine... My mother was immediately suspicious. "He reminds me of your father's friend who married a woman twice his age because she had a lot of money."

By the time I was halfway through *The Portrait of a Lady*, my mother was too weak to sit up. She was sedated, and most of the time her eyes were closed, but when I stopped reading, she would open them again.

"Go on," she said softly.

In Rome, Isabel Archer meets Gilbert Osmond; Ralph Touchett, her cousin who is also in love with her; and Lord Warburton, whose offers of marriage she has repeatedly and perversely refused. It soon becomes clear that she will choose Gilbert Osmond. "Do you mean will she accept him?" Ralph Touchett asks Lord Warburton.

For my mother's sake, I decided that this could not be. My voice quavered a little as I altered Henry James's elegant words:

"'No, she will not accept him,' Lord Warburton answers Ralph Touchett. 'I am going to marry Isabel Archer.'"

"I knew it," my mother whispered.

THE BEST THING I DID

"In the last week of my mom's life, we had Champagne with breakfast every day. She had been a smoker; my dad thought she shouldn't smoke anymore. But her oncologist, knowing she was terminal, said, 'Go ahead; whatever you want.' So we sat on the porch in the morning sipping Champagne while she had a cigarette. It was a small, easy way to put a bit of pleasure into the day."

—Siofra, Louisville, Kentucky

I'll Do It MY WAY

After years of caring for her father, *Laura Pritchett* made a solemn vow: Her children will never go through what she has.

Your Survival Kit

O's list of essential sanity preservers.

WINE. Red, white, good, cheap. Sometimes self-medication is just what the doctor ordered.

A FRIEND ON SPEED DIAL. Somebody who can listen to you during dark nights of the soul and laugh with you at moments of total absurdity.

DISTRACTING MOVIES. Science has proved that it's impossible to feel worried or sad while watching *My Cousin Vinny, Singin' in the Rain,* or *The Princess Bride.* Okay, maybe not, but it can't hurt. Also, avoid all films with tragic parents (*Bambi, Amour*...).

MEMENTOS OF BETTER TIMES. If carrying around a seashell, a half-spent matchbook, or a tiny porcelain goat makes you smile, by all means do that.

A PILLOW. Once in a while, you'll want to punch something.

SOMETHING THAT'S PLEASURABLE, MINDLESS, AND YOURS. Tell everyone to leave you alone for an hour, then go weed your garden. Or dance the hully gully, or do something else that makes you happy. You need to carve out time for joy, and you need time to yourself.

OLD PHOTOS OF YOUR PARENTS. These folks in your care whose prescriptions need filling again, whose anecdotes take eons to relate? Here they are wearing bobby socks to a school dance, looking scrubbed and buoyant at their wedding, gripping your hand at Yellowstone. Look at these pictures and remember how singular their lives were, and are. Enjoy, even in this small way, the people who were there for you, and see if that doesn't make things just a tiny bit easier.

—KATIE ARNOLD-RATLIFF

MY TWO TEENAGERS are under strict instructions to honor their short, sweet time on this planet. This is no request—it's one of my few nonnegotiable orders. After all the work I've done to nudge them toward the world, I want them to charge forth unencumbered. I want them to embrace the fullest path available to them. And I'm quite sure that does not involve caring for anyone out of obligation, including me.

Minding my father these last 13 years as he succumbs to Alzheimer's disease has made me fierce about our ethical duty when it comes to end-of-life decisions. About 15 years ago, in his late 60s, my father had heart trouble. The operation, care, and pacemaker that prevented the problem from being fatal—well, they bring up some hard questions. Should he have died then? While so young and still healthy? The answer, in my mind, perhaps unbelievably, is yes. My father was a humble and gracious man, but long diseases, particularly Alzheimer's, make a tyrant out of anyone: He cannot be left alone, even for a moment, and there is no give-and-take, only constant taking. That's the way of things, and it certainly isn't his fault, but it doesn't make the situation any more pleasant. He does not remember how to buckle a seat belt, how to hold a sandwich, or that I am his daughter. I'm certain that if he'd been able to see the future, he would've wanted to die naturally, too, because caring for him has come at great cost to many. If I'm honest, I'd admit that rarely, if ever, are the few moments of connection we share worth the hours taken from my own children, from my own dreams, health, life.

Our time together has largely been spent wandering his Colorado ranch, where we spoke of his disease when he was able, lapsed into silence once he was not. Bald eagles and horses and happiness and bitterness. Now all of this has dissolved into acceptance. Our walks have made me mindful of the brevity of time—and how we ask others to use theirs.

Before my children get much older, I hope this country's conversation drastically changes. That we increasingly use phrases like *natural death, refusal of medical procedures,* and *assisted suicide,* that we say no to some life-prolonging measures and say yes to the art of dying. This is the final lesson I've learned from my father.

It's fall now, so the geese will fly over, the last hay will be cut, the horses will gallop in the cooler weather. It's been years of such cycles. I will continue to pave my way toward a good death. If it's in my power, I will do practical things: check into long-term care before I need it, make discerning decisions about lifesaving treatments, fill out forms both legal and personal. I hope to heed the prompting of my body, to go gracefully, to go young if need be, to set a good example, to set limits on my longevity.

Will I get what I want? Hard to say. One thing I know is that when I lose my resolve, I will close my eyes and think of my daughter's sparkling blue eyes and her hopes for the world; of the tilt of my son's head as he discusses philosophy and the elements of a life well lived. There, I am quite sure, I will find the necessary courage.

THE LITTLE THINGS

"My mother had a crystal bell that she could ring when she was ready to go to the bathroom, or when she wanted something to eat. Sometimes I hated that bell, but it gave her a piece of authority over her life when everything else had disappeared. I ring it once in a while just to remember the sound."

—Linda Spalla, Huntsville, Alabama

Still Here!

THOMAS MALLON *on the very long goodbye.*

I COULD ALWAYS tell which nursing home staffers had a gift for eldercare when they remarked to me on how pretty my mother was. Now ravaged by Parkinson's, she had often, in her 20s, been taken for Ingrid Bergman. So I felt reassured when one of the underpaid people attending to her displayed the imagination to peel away the years, and the disease, and see my mother the way she'd been before losing the ability to walk, to dress or feed herself, to speak above a whisper.

She remained remarkably cheerful in the nursing home—free from the rage that beset a number of the other residents. But for all her adaptive goodwill, she was beleaguered, and I began to wish that the ordeal would come to a peaceful end. I also, however guiltily, wanted it to be over for me. I was tired of witnessing her decrepitude, of seeing my own future decline prefigured, weary of smelling disinfectant and single-serve pudding cups, no longer amused by the genial male nurse's holiday reindeer antlers. I'd even had it with the weekly pet visits called "Touch and Cuddle," a phrase that I, horrified, took to mean something else entirely when I first saw it on the activities schedule in the lobby.

One night, a friend told a story of how her sister, trying to ease their dying and hard-of-hearing father toward death, had wound up shouting at him: "IT'S OKAY TO LET GO, DADDY!" My partner suggested that on my next trip to the nursing home I try the same approach, albeit at a lower decibel level.

During that next visit I sat beside my mother, silently telling myself that surely—after years of immobility, dementia, and hallucinations, with her weight hovering around 80 pounds—she would welcome my benign suggestion. But as I got ready to make it, I noticed her attempting, with a certain urgency, to tell me something. I leaned in to listen while she gathered the muscle strength to form the complete sentence she wanted me to hear: "I don't want to miss a thing!"

She wasn't kidding. I would go home and keep on visiting. She would go on living, at some mysterious level, on her own terms. The average nursing home stay for women is 31 months; hers lasted eight-and-a-half years.

This Magic Moment

Years into her mother's long battle with dementia, CARLA POWER *succumbed to a fleeting hope.*

I HAD NEVER been to the third floor before that afternoon, though my mind had wandered there many times. Just a floor below, residents still clung to normalcy, greeting visitors, raising frayed voices for "This Land Is Your Land" sing-alongs. But the third floor had an air of resignation. The third floor was for patients who, while there in body, were usually gone in spirit.

The head of the facility had called to tell me it was time. Now, walking to my mother's room, I passed a row of wheelchaired women, their heads nodding against their chests. From one bedroom, I heard a muffled cry.

My mother's head snapped up as I walked in. "With whom did you consult before consenting to have me moved here?" she said, her voice cutting.

"Shhh, Mom," I whispered. My chest tightened; I felt wretched and guilty, but also a distinct sense of hope.

"This is absolutely ludicrous, being put up here with these…people."

Since my mother had developed dementia at age 70, there'd been occasional glimmers of the sharp-witted, warmhearted woman who had taught literature in Afghanistan and Iran, chaired a university women's studies program, and revered what she rather quaintly called "the life of the mind." But her own mind had become clogged with tiny protein deposits that unsteadied her sense of reality. She hadn't been entirely present in years.

"Oh, honestly, Carla," she said. "This is just…humiliating." I was speechless. Could she be getting better? "Bingo and potpourri!" she crowed. "Is this the promised end?"

On the second floor she'd baby-talked through reruns of '70s sitcoms. Now she was quoting *King Lear*, Shakespeare's exploration of senility and daughterly loyalty. Her eyes weren't filmy; they sparkled. Her words weren't slurred, but crisp. I stroked her head. *Mom was back.*

"I'm so sorry," I said. I'd failed her. "I'll ask. I'll see if we can turn this around."

I wheeled her to the TV room and switched on a Rita Hayworth movie, remarking on the cut of the dresses, the dialogue's double entendres—details she once would have caught before me. "Your father loved this scene," she said, as Hayworth vamped in a black strapless number. But by the commercial break, her eyes were glazing over. She said, "Do you know where Daddy is? I haven't heard from him for months." My father died in 1993.

I turned away to hide my distress. She soon forgot her question. By the time a staffer took her to dinner, she was pliant and distant. Silent through her meal, she pushed her veal Parmesan and cherry pie around her plate.

"How are you?" I asked gently.

"I fine!" she said, oblivious to the fat splodge of cherry filling on her chest.

Leaving later, I met her former caregiver Carsanders. "I thought she might be getting better," I stuttered. Change can temporarily fire up the brain synapses, Carsanders explained. For a time, a person can seem like her old self.

But she'd never seen it last.

Everything Is ILLUMINATED

In her darkest hour, *Naomi Barr* found a peace she didn't think possible.

MY MOTHER NEVER WANTED anyone to have to take care of her. "Just send me out on an ice floe," she'd say. In the five years she had non-Hodgkin's lymphoma, she went to chemo, shopped for wigs, managed her insurance bills, and still made herb-stuffed chicken nearly every week for her and my dad. Then, abruptly, her oncologist said there was nothing more they could do. Two, maybe three months, he said.

Yet within a week, she no longer had the energy to shop or cook. She would sit in a chair, holding her head, staring and thinking.

It was a Sunday when she collapsed while walking upstairs. Hospice set up a bed in the den, where a wall of windows looked onto the snow-covered yard. On Tuesday, an aide taught me how to roll her from one side to the other to change the sheets. On Wednesday, a nurse showed me how to place a syringe between her cheek and molars so the bitter-tasting morphine could drip down her throat.

I'd shared nearly everything with my mom—probably too much. She could turn the knife, but she was usually right, and she loved me no matter what. She was the person I called when I broke up with a boyfriend ("He was wet behind the ears," she said) and when my first article got published ("Mazel tov! Now keep writing"). Sometimes I called simply to hear her voice.

And now I couldn't make her better the way she'd made me better. I read her Shakespeare and Robert Burns, but she struggled to stay awake. I made ice pops out of grape juice, crushed them, and spoon-fed her the pieces, but by Friday she could no longer swallow. No matter what I did, my mother was going to die.

When I was little, after my mom had tucked me in, I'd close my eyes, hold my breath, and try to imagine death. The thought scared me so badly, I'd scream, "I don't want to die!" and run to her.

As I watched her sleep, I wondered whether I could bear being in the room when it happened. One week after her initial collapse, she slipped into unconsciousness. My sisters and I stayed up through the night, watching for the signs that the end was near: Her breathing became shallow. Her skin cold. Her extremities had gone purple. The room was silent, save the hum of the oxygen machine; early morning light filled the space. My mother was still. There was no more attempting to move her, no more coming and going. Nothing needed to be done.

"We should say the Sh'ma for her," my oldest sister said. The Sh'ma is a Hebrew prayer that is supposed to be the last thing a Jew utters before dying. Because my mom could no longer speak, we spoke it for her.

Then my sister whispered, "You're also supposed to open a window to allow the spirit to leave." My mom didn't believe in an afterlife, but we cracked open a window just in case, then repeated the Sh'ma on the off chance she'd heard us talking.

I held her hand. Her breathing became slower, like a mechanical toy whose mechanism has begun to wind down. I watched as delicate breaths caught in her mouth—an inhale, a pause, an exhale, an inhale, a longer pause, an exhale. Then nothing. I stared for several seconds before I understood that I'd just witnessed my mother's last moment on earth.

I had imagined she would say a final word. But her passing was no less profound for its silence. As I watched the woman who gave birth to me die, the unknown became known. I had the answer I'd wanted since I was a little girl: *Death is a part of life*.

I thought the mother I'd relied upon had left us earlier that week. I thought she'd offered all the wisdom, all the comfort, she could. But I was wrong. Even with her last breath, she still had more to give.